THE SOCIAL SUPPORT NETWORKS OF UNIVERSITY STUDENTS WITH SOCIAL COMMUNICATION DIFFICULTIES: THE ROLE OF EDUCATIONAL SUPPORT WORKERS AND THE IMPLICATIONS FOR RETENTION AND PROGRESSION

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Copyright Statement

No man is an island, entire unto itself; every man is a
piece of the continent, a part of the main

John Donne, 1622: Devotions, XVII Meditation

Acknowledgements

Abstract

This study has utilised multiple methods that incorporate the use of 'innovative' communicative technology to provide an extensive exploration of students with social communication difficulties' (SCD) social support networks whilst attending university. Ten semi-structured online interviews were carried out with educational support workers (ESWs). Their analysis provides original and valuable insights into student disability support and the views of ESWs are further pursued in a series of seven web-based diaries with university students with SCD. Information gained here furnishes a critical account of student disability support. Critical points in the accounts of both ESWs and students are presented and evaluated in detail. Findings illustrate that informal personal support, such as peer networking, is vital for students' educational competence, social confidence and a sense of belonging at university, but is currently not taken into account in a system that promotes formal academic support alone. Lack of informal personal support could impact negatively on student personal adjustment and relationships, thus hindering access to the learning community. Universities have a key role in facilitating student social support networks that promote collaborative social networking. The dominant conceptual framework, based around the social model of disability and situated in a morality of 'rights', is considered in practice to atomise the person and overlook wider social aspects of disability. This study proposes to move the disability agenda away from one based on individualism to one based on social connection and located within a morality of care. This approach re-conceptualises students with a disability as interdependent, both in their capacity for personal autonomy, and their social need through relationships. This may go some way in improving university disability policy and practice by encouraging professionals to work in negotiation with students. Thus, appropriate plans can be put in place to meet students' wider academic, personal and social needs.

Abbreviations

ASD   Autistic Spectrum Disorder

D/HI   Deafness/Hearing Impairment

DDA   Disability Discrimination Act

DED   Disability Equality Duty

DSA   Disabled Students Allowance

ESW   Educational Support Worker

FE   Further Education

HE   Higher Education

HEFCE   Higher Education Funding Council for England

IM   Instant Messenger

LEA   Local Education Authority

PDA   Personal Digital Assistant

PGCE   Post Graduate Certificate of Education

SCD   Social Communication Difficulties

Table of Contents

Word Count: 86,105

List of Tables and Figures

Tables

Figures

List of Papers, Presentations and Other Accolades

Journal Papers

Hinchcliffe, V. (2009). Internet Mediated Research: The Viability of Synchronous Online Interviewing and Web-based Diaries for Data Collection with Participants with Social Communication Difficulties. *The International Journal of Interdisciplinary Social Sciences.* Vol. 4, (1), pp.181-198. [Online].
Available: <http://iji.cg.publisher.com/product/pub.88/prod.725>

Hinchcliffe, V., Gavin H. (2008). Internet Mediated Research: A Critical Reflection upon the Practice of Using Instant Messenger for Higher Educational Research Interviewing. *Psychology and Society.* Vol. 1, (1), pp.91-104. [Online].
Available:<http://www.psychologyandsociety.sps.cam.ac.uk/previousissues/?id=11>

Hinchcliffe, V., Gavin H. (2009). Social and Virtual Networks: Evaluating Synchronous Online Interviewing using Instant Messenger. *The Qualitative Report.* Vol. 14, (2). [Online]. Available: <http://www.nova.edu/ssss/QR/QR14-2/hinchcliffe.pdf>

Conference Presentations

Internet Mediated Research: A Critical Reflection upon the Practice of Using Instant Messenger for Higher Educational Research Interviewing. Paper presented at the 9th Inter-University Graduate Conference - Challenging the Boundaries in the Social Sciences, Cambridge, UK, 17 May 2008.

Internet Mediated Research, Synchronous Online Interviewing and Web-based Diaries: Widening Opportunities for Data Collection with Participants with Disabilities. Paper presented at the 2nd University of Huddersfield Research Festival, the School of Human and Health Sciences, Huddersfield, UK, 27 March 2009.

Who's Really Supporting Us? The Disabled Student Experience. Paper presented at the 1st Degrees of Independence Conference, University of Huddersfield, UK, 17 April 2009.

Internet Mediated Research, Synchronous Online Interviewing and Web-based Diaries: Widening Opportunities for Data Collection with Participants with Disabilities. Paper presented at the 4th International Conference on Interdisciplinary Social Sciences, Athens, Greece, 8-11 July 2009.

Internet Mediated Research, Synchronous Online Interviewing and Web-based Diaries: Widening Opportunities for Data Collection with Participants with Disabilities. Paper and workshop presentation at the Psychology Graduate Affairs Group (PsyPAG) Workshops - Exploring New, Innovative and Emerging Methods in Qualitative Research, University of Salford, UK, 26 November 2009.

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Associate Editor for: *The International Journal of Interdisciplinary Social Sciences*. May 2009, Vol. 4.

The Weekly Qualitative Report Article of the Week, 22 June 2009. [Online]. Available: <http://www.nova.edu/ssss/QR/WQR/wqr2_25.html>

Preface

Reflective Account: How the Study Came into Being

This study came into being because of a long and complex chain of events, many of which I had little control over. During my early socialisation process, children with disabilities were not children to be friends with. Whenever they happened to be around they were targets of jokes, objects of pity and provokers of fear and concern, an indication of how unfortunate life can be. Disability was an unfortunate condition – better to remain hidden because it was associated with feelings of guilt and embarrassment. Inclusive education was not the type of pedagogy I encountered in my schooling experience as a child. The belief of the educational system that I had experienced was based on competitiveness, in which in order to succeed, students had to strive for excellence. Excellence was perceived as an individual triumph. Boasting how well one had achieved academically bolstered egos that had arisen from notions of meritocracy. In such a system there was no place for students with a disability.

It was not a surprise, then, that I had a cultural, ideological and educational shock some years later, following the birth of my second child and her diagnosis two years later of severe learning, physical and emotional difficulties. Already having a young child who was meeting all the milestones, I knew that my two year old daughter had

developmental delay, but nothing could prepare me for the moment a geneticist broke the news that she had a rare syndrome. The geneticist's words still ring in my ears as if it were yesterday, "don't be a hero, no one will think badly of you if you decide not to raise her". My initial reaction was disbelief; how could anyone suggest that I would give my daughter away because she was less than perfect?

I wept buckets that day for three main reasons, firstly due to relief that they had finally diagnosed her condition; at this time the label Rubinstein–Taybi syndrome was welcoming because it ended two years of confusion as to why my daughter had learning, physical, and emotional difficulties, and my own self-blame. Secondly, I cried for my daughter, at the realisation that her life was going to be unbearably difficult at times – numerous medical and therapeutic procedures ensued until mutual agreement by the consultant paediatrician and myself that all had been done that could be. However, incongruity was evident between our motives for these procedures; I felt specialists were trying to make my daughter more aesthetically 'normal', whereas I was trying to ensure my daughter was more comfortable physiologically and experienced less pain. Finally, I grieved for the daughter I had lost, the daughter without disabilities that I thought I had carried for nine months; what was to become of us, how would we cope? The doctors were suggesting institutional care. But, with hindsight, we did cope.

Family and friends' initial good-will intentions of supporting me in raising my family were short lived, particularly due to their own family commitments. I soon realised that I was on my own; a solitary and difficult journey lay ahead. However, life has a strange way of ticking along regardless and I became a very independent 'parent-carer' - a label that I dislike to this day (I prefer 'parent') but find useful to enable others' understanding. When asked over the years by family, friends and the consultant paediatrician how I coped bringing up a child with severe difficulties, I would answer that it just became who we were as a family; we grew together and had our ups and downs just like 'normal' families.

In retrospect, I did not realise how socially isolated we had become, partly due to protecting my daughter from the cruel treatment she received from others; both young and old would stare or make fun of her, and partly to protect my own feelings – the pain was unbearable. It hurt terribly to witness such inhumane treatment on a daily basis and, as such, it became easier not to venture out. For example, a simple trip to the supermarket would become a floor show, or crossing the road a perilous journey because my daughter had behavioural difficulties, finding social situations difficult to manage – when situations became too much for her to cope with she would lie down on the floor and be physically violent toward anyone trying to get her to stand up. People who did not understand her difficulties would take every opportunity to criticise my parenting skills, when I was just trying my best to get through the day. The effect of social

criticism made me aware of how ignorant and un-accepting society is of difference. One thing I have always been immensely grateful for is that my daughter is unaware of her differences; I could not bear to see her hurt by ignorant people in need of educating on the benefits of being different.

Until the age of 11 years, my daughter's schooling took place in severe and then moderate 'special' educational establishments – I felt this contributed to her segregation from society alongside my isolation practices at home. I realised that hiding away was not helpful because it prevented her from accessing 'real' life experiences, such as everyday trials, tribulations and pleasures, essential for secondary socialisation. My displeasure with the quality of education she was receiving was further fuelled because 'special education' curricula focused on physical need and low expectations. Changing legislation toward integration and inclusive education prompted me to take the initiative and gain her a place in an inclusive high school. Questions over the five-year period concerning my daughter's placement in an inclusive educational setting came into my mind often. Was this the right decision to have made regarding her educational attainment, was she benefiting from the experience on a personal and social level, and was she being fully included?

The aforementioned questions fuelled my undergraduate studies as a mature student and now single parent with 3 children with various health difficulties and disabilities[1]. I took immense pleasure embarking on extensive research into inclusive education, with the writing of my undergraduate dissertation becoming yet another stage in a personal quest for answers.

Since graduating with a BSc (First Class Hons) in Social Psychology, my journey through inclusive education took giant steps forward, with my thirst for knowledge and research in this area remaining insatiable. My daughter completed high school, fulfilling her potential and in my opinion, educating those without disabilities. Myths were dispelled by banishing ignorance and fostering acceptance of students with difficulties and disabilities by exposing the 'non-disabled' to the 'reality' of living with severe learning difficulties. As French (1996: 159) suggests:

> Contact with disabled people is an important ingredient in bringing about positive attitude change. Most people do not get to know about disability at first hand and may avoid disabled people because of feelings of fear and inadequacy

Yet, I found it soul destroying that her further education was to be in a segregated unit within a local college. I had fought so hard to get my daughter into inclusive education, pitting myself against educational psychologists adamant for her to remain in 'special'

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[1] Alongside my daughter's diagnosis of Rubinstein-Taybi syndrome, my eldest son was diagnosed with Attention Deficit Hyperactivity Disorder, and my youngest son was diagnosed with severe asthma, eczema and various related allergies.

educational institutions. I believed inclusive education enabled her to have experiences that I felt she did not have access to in the social vacuum of 'special' education settings. Experiences that the 'non-disabled' take for granted, such as following academic timetables, deciding what to eat for lunch and having the opportunity to witness the formation, maintenance, dissipation and fragility of adolescent relationships. After all, my daughter was experiencing puberty and having thoughts and feelings just like any other adolescent.

I subsequently took a year out of my studies to reflect on my achievements and take time to consider my future career. At this time, I mentored higher educational (HE) students with a disability for a year. Although mentoring was both stressful and rewarding, this was a period in my life where I thought my academic and life skills were utilised to their best. In particular, I mentored students with social communication difficulties (deafness/hearing impairment and autistic spectrum disorder) at a very intensive level; I took their lecture notes, facilitated their group work sessions, aided their academic and research skills, proof read their work and was an exam amanuensis. This allowed me to gain beneficial insight into university life from their perspective, by experiencing what university life was like for students with social communication difficulties.

I found, to my dismay, that the ignorance and self absorption expressed by a large number of HE teaching staff was at best eye-opening, at worst atrocious; many academic staff felt that it was out

of the question that they should adapt their teaching style to accommodate students with difficulties and disabilities. One academic member of staff stated that it was unreasonable that they were expected to look at a student all the time, misunderstanding generic good teaching practice that necessitates facing all students when talking and ensuring the mouth area is not obstructed to enable audibility. In this case, the student with social communication difficulties was viewed as a nuisance when they dropped out of group work sessions, asking to undertake an alternative module because they felt it was mutually stressful for themselves and other students due to communication barriers. I also witnessed how socially isolated students with communication difficulties were, sitting alone at break times, not being invited to take part in group work and extracurricular activities.

To my benefit, I discovered I had an affinity with other educational support workers. Support workers choose this type of career mainly because they have also been parent-carers, siblings or children of people with difficulties and disabilities. Consequently, they have witnessed disability discrimination, disempowerment and social inequality. This has provided me with a wealth of knowledge useful to my research interests. The affinity I shared with other support workers was also a turning point for me; for the first time, I realised it was acceptable to have a hearing impairment; it did not have to remain a hidden condition. It is 'hidden' because most people are unaware that I have a severe hearing impairment - I do not wear the

visible hearing aids that signify this impairment. It now felt safe to ask people to repeat what they had said if I could not hear or had misheard them; it felt safe to be open about having a hearing impairment. With this increased confidence I realised that social communication was ultimately a shared interaction; responsibility for understanding lay with both the communicator and the receiver. It was not my sole responsibility to manage social situations; in order for people to communicate successfully with me, they also had to ensure that I could hear and understand them.

Through my educational and mentoring experiences I realised the power of education and decided to become a teacher. However, before I could embark on my chosen career I felt that I needed to understand my feelings towards being hearing impaired. This I did through academic reading. Learning about the social model of disability – that attitudes and oppressive practices of society can disable people, rather than impairments (Oliver, 1996) - facilitated my understanding of why my sympathies lay with this perspective. I came to realise how societal attitudes and practices had negatively impacted on my life experience.

Through reading academic literature I discovered that I was one of the many congenitally hearing impaired whose parents had been influenced by an international commitment to oralism – the rejection of sign language for the deaf/hearing impaired in favour of speech and lip reading so that the child is able to communicate in the hearing

world (Branson, 2002). This oral method of communication was, and still is, argued to offer enhanced educational and employment opportunities.

However, oralism limited my life experiences. I was not allowed to learn sign-language - my parent's wishes were that I should appear 'normal' and 'fit in' with the 'hearing world'. Adamant that I would not be part of the Deaf community, which forty years ago was stigmatised (and arguably still is), I was to communicate only through oral means. Self-taught lip reading became the norm for me but it was not until very recently that I realised how much this had been so ineffective. It was a shock to discover that throughout my life I had been getting things wrong by misinterpreting verbal communication. Everyone, including me, should have access to all the opportunities available to them to realise their full potential. As Ladd (2002: 35) points out:

> By learning both spoken and sign languages, you
> can learn to navigate your life path in, and around
> two cultures and two communities, selecting
> whatever you wish for from either in order to build
> your own lives

Feeling more comfortable in my perception of who I was and how I came to be me, I enrolled on the Post Graduate Certificate of Education (PGCE). Studying for a PGCE, specialising in learning difficulties and disabilities, maintained and enhanced my knowledge of inclusive education and disabilities and I again found I had an affinity with other trainee teachers in my specialism (parent-carers,

siblings, children of parents with difficulties and disabilities). However, I found other specialist trainee teachers' negative attitudes toward students with difficulties and disabilities highly problematic, particularly because they did not value lower level, non-vocational attainment as it did not reflect their teaching expertise. The voices of a small but significant number of teacher trainees from other specialisms disheartened me; I often heard them openly complaining: "I don't see why we should have to teach students with disabilities, they should be in remedial classes". The negative attitudes of these trainee teachers greatly saddened me, but also drove my desire to educate them about people with disabilities.

Whilst undertaking the PGCE, I took every opportunity to raise awareness of disability and the impact others can have with their negative and often ignorant practices. I often found myself challenging other teacher trainees' attitudes; I would ask, for example: "Have you thought why a particular student may be displaying disruptive behaviour in class – have you looked at underlying issues"?

However, my newfound enthusiasm and drive to educate others was soon to be overshadowed by family problems. I was about to encounter a family crisis that would affect me emotionally, physically and threaten to unbalance me psychologically. During this time, my now 18 year old daughter was finishing her two years of 'segregated' further education; with this, home life took a turn for the worse. My

daughter became severely depressed at the realisation that college was ending, with no prospect of another course due to further education funding being redirected by the Learning and Skills Council (Russell, 2005). Further educational establishments were being funded to focus on providing opportunities and incentives for teenagers who had not achieved Level 2 (GCSE equivalent) by age 16 to do so post-16 (Department for Education and Skills, 2005). Prioritising funding for 14-19 year olds, in effect, neglected learners in the 19-25 age bracket because funding was not guaranteed. Funding cutbacks meant course closure for students with difficulties and disabilities. This undoubtedly resulted in students, including my daughter, becoming more socially isolated because college is often the only place where students with difficulties and disabilities can meet with peers and form friendships.

As a result of this educational upheaval, which was affecting the entire family's psychological health, my daughter moved into residential care – she currently lives with other young adults with severe difficulties and disabilities. At this point, I felt a complete failure - failure as a parent and a carer. Yet, with hindsight, I am proud that she manages her 24 hour care well, has a very active social life - discos, dance classes, holidays abroad - and we frequently see each other and converse on the telephone. I am humbled to have had the opportunity to have experienced to date twenty two years in my daughter's company, knowing that she is in physical pain on a daily basis and the hurdles she overcomes to

achieve in her life, such as learning to read, trivialising my difficulties. This has left me with a zest to achieve my own goals and make her proud of me too – she delights in telling others that her mum is a teacher. If only the rest of the world could be more like her and smile in the face of adversity, making the most of what we have.

Following my daughter's departure, I decided to re-focus my life and find myself again after spending most of my adult life as a full-time parent-carer. I now had to adjust to having lots of spare time on my hands and felt I needed to fill the huge scary void left behind. With this, I found myself stepping out of the cocoon of 'parent-carer social isolation', becoming 'me', whoever that was, because I no longer recognised myself; 'me' had become lost somewhere throughout the years. With hindsight, it had been exhausting trying to ensure that I divided my time as equally as I could between my children – not an easy feat when one child needed 24 hour care and supervision. At times I felt stretched beyond my limits, trying to ensure my other two children got the attention they deserved. Shrouded in guilt at my newfound freedom, life itself beckoned; for the first time in two decades I had the time to undertake leisure activities! I began to cycle, walk, went out for meals, and listened to music again; having my hair done felt like a luxury. I was re-socialising and flourishing in my new teaching role too.

Yet despite the upheaval, the PGCE course tutors highly praised my coursework, attitude and enthusiasm for the specialism (learning difficulties and disabilities) - an external marker asked to meet me, shook my hand and expressed their delight at reading my work throughout the year. One week after qualifying on the pre-service PGCE course I found myself teaching the in-service trainee teachers at Summer School! I have currently taught a second year at Summer School and thoroughly enjoyed it. Not only does this teaching specialism keep my theory and research up-to-date, it sustains my conceptual beliefs. Again, I am with like-minded people with similar attitudes as myself toward disability – an inspirational drive toward supporting everyone, regardless of ability, to achieve their full academic potential. I live in hope of a more diverse, accepting and understanding society that values everyone for their positive contribution.

Toward the end of my PGCE I applied for, and was accepted, to undertake a PhD in the area of student social support networks and social communication difficulties, which comprised a one year full-time Masters in Social Research and Evaluation (Social Work) and three years PhD by research. By the time I embarked on my Masters course I was already equipped with armfuls of academic knowledge, personal and professional experience in the area of inclusive education; for me, the Masters course was a time to practise empirical research, develop my writing style and try out a pioneering

method for future data collection (discussed in more depth in Ch.4, p.180).

The above brief autobiographical account is highly relevant to this PhD study, in which the main interest is to explore social support networks of students with social communication difficulties. It constitutes an essential part of my cultural, historical baggage – including tensions, conflicts and enlightenment throughout the writing of this current thesis. Reflecting in this way facilitated my understanding of my conflicting thoughts concerning my conceptual stance. I sympathise greatly with the social model of disability, particularly on others' behalf - negative attitudes and practices of society can disable people (Oliver, 1996). However, I have personally experienced some of the benefits of medical model practice - impairment, being the disabling factor, requires medical intervention and treatment (Longmore, 2003), such as the relief treatment can bring from physical discomfort and how diagnostic labels can secure services and disability benefits (the conceptual debate surrounding disability is critically analysed in Ch.2, p.77).

Before I embark on my next quest for knowledge as a researcher in disability studies, I feel it is valuable to address the following tasks adapted from Barton (1996: 4):

- *What places me well to undertake this research?*

As a person with severe hearing impairment and a former parent-carer I am aware of disability issues. This will afford good rapport with research participants

- *What responsibilities arise from the privileges I have because of my social position?*

I have responsibilities to participants in this research study in that I uphold ethical principles relating to veracity (truthfulness), non-malevolence (do no harm), fidelity (don't make promises you cannot keep) and benevolence (doing good) – (see Economic and Social Research Council, 2006: Section 3.2.1 and Melia, 1989)

- *How can I use my knowledge and skills to challenge the forms of oppression people with disabilities experience and thereby help to empower them?*

I have a responsibility that I contribute through my research to the ending of oppression by enhancing empowerment of people with disabilities within both higher education (HE) and society. This may be actualised through influencing HE disability policy and practice

- *Does my writing and speaking reproduce a system of power or challenge that system?*

My role as a researcher involves more opportunities of public speaking and writing about disability issues in HE. In doing so, I will avoid unnecessary intrusions into privacy and sensitivities of participants, and refrain from using language that labels, stereotypes and stigmatises people with disabilities

- *Do I show respect to people with disabilities, during and as a result of, my research?*

I am mindful that my research is conducted in ways that people with disabilities perceive as appropriate and acceptable.

Chapter One - Introduction

1.1 Preamble

Most students entering HE adapt well to the academic, social and personal demands of university life (Rickinson and Rutherford, 1995; 1996). However, the majority of students with disabilities will need support in this new environment (Goode, 2007).

Generally, 'support' describes various acts of assistance. By support, I refer to a range of relationships within the HE context. This specifically includes formal academic support[2] for students with disabilities, such as the work of educational support workers, as well as the informal personal support[3] of family, friends and peers, each of which forms a part of a student's social support network. What is not covered here is medical support. I am most interested in the particular kinds of disability support which are encountered in the HE context, in particular for students with social communication difficulties (SCD). Specific definitions are set out below.

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[2] Formal academic support may range hierarchically according to level of expertise, from teaching for the Deaf, interpretation, BSL communication, mentoring, note-taking, campus and library support.

[3] Informal Personal support is defined here as helping students to build supportive relationships, giving relationship advice, peer mediation and/or facilitating integration into the wider learning environment.

1.2 Defining Impairment and Disability

Currently, definitions of impairment and disability are disparate. The Disability Discrimination Act (DDA, 1995a) defines disability as:

> …a person has a disability if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities

In contrast to the DDA's (1995a) individualistic view of disability, where the locus for disability is at a personal level, Albrecht's (1992: 35) definition of disability is far more socio-political:

> …the locus of disability is not solely within individuals who have impairments but also in the social, economic, and political environment. By this argument, people are impaired but the environment is disabling

For the purpose of the present study, I view impairment and disability as two separate phenomena that can pose difficulties both intra- and inter-personally. Impairment of bodily function or structure, whether biological or acquired, can affect individual activity, whereas disability can arise from both limitations in individual activity and restriction in social participation (see World Health Organisation, 2002).

1.3 Defining Social Communication Difficulties

This thesis focuses on students with SCD; in this case, specifically deafness/hearing impairment (D/HI) and autistic spectrum disorder (ASD). Operational definitions of D/HI and ASD are provided below to facilitate combining them as a single group with social communication difficulties and to provide rationale for subsequent sampling procedures (see also Ch.4, p.173 and Ch.6, p.253). The focus here is upon social communication difficulties (SCD), rather than the attributes of impairment and disability *per se*.

D/HI is defined as a permanent or fluctuating condition of profound or severe hearing loss without the use of hearing aids and, as such, a person's social communication and understanding is adversely affected by the impaired processing of linguistic information (National Dissemination Centre for Children with Disabilities, NICHCY, 2004). ASD is defined as a neuro-developmental disorder affecting the person's linguistic ability to communicate socially and relate to others. Diagnosis is based on Wing's (1988) 'triad of impairment'; consisting of impairments in social communication, interaction and understanding/imagination. Linguistic skills range from those with correct speech to those who have none (National Autistic Society, 2007).

Communication is not synonymous with speech, or face-to-face interactions; it is the ability to express oneself and to receive messages through whatever means (O'Neil, 2008). Thus, for the purpose of the present study, students with SCD include people with D/HI and/or ASD. Of course, there are recognisable differences between people with SCD. For example, the difficulties these students face in HE may vary from person to person, overlap, influence each other and change over time. Some students may need more or different types of support, while others perhaps need to be encouraged to interact socially. However, whilst I am sensitive to these differences, there are also significant connections which justify grouping these together.

In particular, these students share common difficulties with social communication and understanding, often relying on third-person mediation such as interpretation of communication for effective social interaction. In addition to whatever problems they may experience because of SCD, they are often subjected to social processes of exclusion (Blamires and Gee, 2002). People who regularly receive support may be viewed in ways which reinforce their isolation and dependency (Murray, 2001). Within the current HE climate, the focus is on broader issues around funding and planning disability support provision. Thus, these students may not have a 'voice' concerning their support needs (O'Neil, 2008). As such, there is a tendency for them to be ignored.

Within the present study, I discuss the providers (educational support workers [ESWs]) and recipients (students with SCD) of support, and the ways in which support is experienced. Receiving or not receiving support can and does impact on educational achievement, but can also often lead to isolation through exclusion (Kurth and Mellard, 2006). However, this is not a straightforward outcome of impairment and disability, but of the type of support and the context in which support is provided (Blamires and Gee, 2002).

I draw on arguments from various theories and research examples which offer insight into aspects of support for students with SCD in the HE context. The topic which links the chapters is the idea of students in social relationships; this is argued to be paramount to students achieving their full potential.

1.4 Overview of Forthcoming Chapters

This thesis comprises eight further chapters. As detailed below, chapters two and three present the background to the study and the literature review. Chapter four presents the theoretical and methodological framework, and phase one methods and procedures, with phase two methods and procedures in chapter six. The data presented and analysed in chapters five and seven are accompanied by a full discussion of the findings in chapter eight. The final concluding chapter address the implication of the findings for HE

disability policy and practice, and makes suggestions for future research in the area of student disability support.

Chapter two provides the background to the present thesis, looking at educational policy, practice and provision through an historical lens. The historical and cultural context is organised as a timeline of educational policy, practice and provision for students with a disability, with a specific focus upon the implications for students with SCD. Documentary sources relevant to the development of legislation and regulation pertaining to the educational rights of people with a disability were readily available. Analysis of such documentation proved itself to be crucial as background information for a thorough appreciation of the development and implementation of legislation and regulation. Towards the latter part of this chapter, conceptual debate concerning impairment and disability is productive in setting the scene and providing justification for my conceptual standpoint on these issues.

Chapter three provides an in-depth critical review of literature (educational psychology, psychology, sociology, social policy, and communication theory) pertinent to the present study. It covers social support networks and transition to university, social support networks and 'new' communicative technology, formal academic and informal personal support. As such, a critical analysis of multi-disciplinary theoretical literature and empirical research findings is undertaken here concerning the importance of social support networks for the

academic success of HE students. The research aims and intended outcomes are set out here. The literature review highlighted the need for work to be undertaken that would encompass the broader academic, personal and social needs of students with SCD.

Chapter four details the overarching theoretical perspective informing the present study and provides a rationale for the research process. Social constructionism proved itself to be an engrossing and productive platform upon which to build a consistent analysis that underpinned the research activity within the present study. Discussion of the methodology is set out in respective sections that detail the research strategy, study design, quality indicators, context and access to the area of study. Laying out the research strategy, study design, quality indicators, context and access to the area of study allowed insight into the study area before the empirical research was undertaken.

Chapter four also provides insight into ESW sampling and recruitment, ethical issues and the rationale for the data collection method – online interviewing. The task of designing an interview schedule for interviewing ESWs online using the Internet as the communication platform was facilitated by personal knowledge gained from previous experience of using the technique, experience of working as a former ESW and considerations of documentary sources. To this point, the use of a semi-structured design facilitated a reliable system for data gathering. The conduct of these innovative

interviews is also addressed here, with specific reference to the relative merits of online interviewing.

Chapter five presents the rationale for the chosen analytical technique and analysis of the findings from the ESW interviews. The analysis of ESW online interviews entailed use of the thematic technique 'template analysis' (see King, 2006), which proved useful for organising and managing the raw data and subsequent recognition of how prior knowledge and experience ultimately had an effect on the research process. Documentary sources relevant to student support issues reviewed in the literature (educational psychology, psychology, sociology, social policy, and communication theory) proved particularly valuable here. Consequently, findings from ESW interviews informed those themes that were to be pursued in subsequent student research diaries.

Chapter six provides sampling and recruitment procedures, followed by rationale for the data collection method; its design, materials and procedures are addressed in relation to students with SCDs' diaries. A number of issues relating to sampling, recruitment and data collection need to be considered when undertaking disability related research. For example, definition and classification of impairment and disability and the suitability of the data collection method need to be considered, not only epistemologically but its appropriateness with the sample. The task of designing a web-based diary schedule for gaining access to the daily support experiences of students with SCD

was influenced by the themes generated from the ESW interviews and considerations of documentary sources. Again, the use of a semi-structured design facilitated a reliable system for data gathering.

Chapter seven provides the rationale for the chosen analytical technique, which entailed a qualitative content analysis of the diary data. This proved useful in making recommendations for ways of supporting students with SCD with a view to providing access to the full range of social opportunities available within the HE environment. Qualitative analysis of student diaries deepened understandings gained from ESW interviews. Completion of the analysis marks a turning point in the present study and the merging and discussion of the key findings from both ESW interviews and student diaries.

Key contributions to knowledge, methods and concepts are discussed in chapter eight. Discussion of the findings with the existing literature brought to the fore not only similarities but tensions. The union of empirical data, method of analysis and theory was again a turning point. Recommendations for change quickly came together as I moved toward a conclusion.

Chapter nine concludes by addressing the significance of the research to disability policy and practice and outlining further areas for future scholarship.

1.4.1 A Brief Note about Style and Terminology

As a previous ESW, parent-carer and a postgraduate student with D/HI, I feel that writing this thesis from a first person perspective would place this study in danger of becoming another personal endeavour. This is because the issues addressed here are so close to home emotionally and not about objectivity; I believe I cannot stand wholly outside of my research as I have a central role to play in its construction. To be able to emphasise my personal commitment to a relational perspective without it being wholly about me, I thus needed a coping device to prevent this emotion overwhelming the research. Henceforth, writing the thesis in the third person 'voice' proved particularly helpful in allowing me to stand back enough to be able to see the issues more clearly.

Unless directly quoting from the literature, the term 'person or people with a disability' will be used. In this respect, the person is given priority over the disability; first and foremost they are people, only secondarily do they have a disabling condition.

Chapter Two – Background to the Study

2.1 Preamble

This chapter provides the background to the present study by mapping educational policy, practice and provision for students with a disability across time and through elementary, secondary and more latterly tertiary sectors (see Dawson and Wall, 1969). Tracing the antecedents to present conditions can facilitate understanding of current educational issues in their historical context (see Cregan, 2006):

> An understanding of history is vital if we are to engage with the present and influence the future. But all too often we have little or no knowledge of the concerns and insights of those who went before
>
> (Barnes, 2008: no page number)

By considering this history, it is possible to identify three significant periods in the formation of educational policy, practice and provision for students with a disability, each of which is differently constructed by the social, political and cultural influences of the time[4]:

1. Social and educational segregation (1764-1943)
2. Social and educational integration (1944-1996)
3. The current move toward social and educational inclusion (1997- 2010 the present)

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[4] It should be noted here that this is the researcher's version of 'key' events. It is not a definitive description of the past but a way of constructing what occurred to provide meaningful insight into the various and complex social forces that have influenced, and continue to influence, educational policy, practice and provision for students with a disability. When events are viewed in this way through an historical lens, 'influences' come to light that may not have been seen at the time.

An account of periods 1 and 2 above provides description of both segregative and integrative practices. These form the underpinnings of the current move toward inclusion, which will be treated to more critical scrutiny, as this is the period in which this research is situated and, as such, is still very much 'under construction'.

Tracing the progression of British educational policy, practice and provision for students with a disability (for a definition of disability see Ch.1, p.28), allows specific links to be made with the implications of educational events for the present study's sample, students with SCD (for a definition of SCD see Ch.1, p.29). However, it is important to note here that in the early part of the 20th century people would not have been recognised as having SCD; it is a current construction of these difficulties that did not exist at the time and is therefore limited in the literature.

Thus, this chapter is framed around generic educational policy, practice and provision for students with a disability and firstly explores social and educational segregation. Wherever the literature allows, those referred to in the period 1764-1943 are primarily people with D/HI as this was a recognisable condition at the time. In the mid 20th century, 1944 onwards, ASD was recognised and subsequent literature became available. Henceforth, people with ASD are included alongside people with D/HI. Social and educational integration is explored before a more critical review of the move toward social and educational inclusion. The latter part of the chapter

provides more context for the present study by considering conceptual frameworks currently surrounding disability and the researcher's conceptual stance. Finally, a chapter summary integrates the above and offers direction for understanding current educational issues for students with SCD.

2.2 Social and Educational Segregation (1764-1943)

Although not all schools for those with D/HI were residential institutions, Borsay (2005) claims: "they did function as 'dividing practices' that exerted formative influence on life experiences" (p.94). One of the earliest examples of segregation for people with D/HI came in 1764 when Thomas Braidwood started the first British 'school' for the 'Deaf and Dumb' in Edinburgh, moving to London in 1783, where 'fee paying' students of all ages were taught to speak and read. Thomas Braidwood promoted the oral method, using a small silver rod to position the tongue for the correct pronunciation of vowels and consonants. In contemporary society, segregation has negative connotations. However, at this time Braidwood would have been seen as a reformer.

In 1792, the first English Asylum opened for the 'Support and Education of the Deaf and Dumb Children of the Poor', with subsequent branches opening in 1809 (Margate), 1812 (Birmingham) and the 1820s (Liverpool, Manchester, Exeter, Doncaster). These

asylums provided minimal education and employment skills. Due to a lack of skills, those who were allowed to leave these institutions often had to resort to begging for survival (Warnock Report, 1978). However, they did present some opportunity for improvement:

> With education, 'helpless and possibly dangerous members of society' were rescued 'from their almost uncivilised state', offered religious salvation, and taught 'the means of maintaining themselves by their own industry'
>
> (Report for the Year 1865: Fortieth Report of the West of England Institution for the Instruction of Deaf and Dumb Children, Pollard, 1866: 8., quoted in Borsay, 2005: 95)

In this period, people began moving out of small villages into larger cities to find employment in the new industries. The rise of industrialisation and urbanisation was important because it meant a demand for a literate and skilled workforce. Finkelstein (1980) contends there was no place in the new heavy industries for people with disabilities, who were perceived as illiterate and physically incapable of carrying out semi-skilled, let alone skilled, labour.

In addition, parliamentary legislation has a very important influence on educational policy and practice for people with impairment and disability. The 1870 Elementary Education Act (The Forster Act), for example, initiated compulsory schooling for mainstream children aged 5-13 in Britain. School Boards were introduced and given the power to construct 'new' schools and pay the fees of the poorest children; these schools were built on notions of educational equality.

The introduction of voluntary maintained schools through public funding allowed independence from Church maintained schools, bringing choice of educational setting and access to a wider curriculum. However, this Act cemented segregation for the vast majority of people with SCD as they would not have received education in these mainstream schools (Dawson and Wall, 1969).

Compulsory schooling required the effective categorisation of educators in terms of what and who they taught, and the need for standardised curricula and tests in order to stream students into graded classes. Language abilities and communication skills were central to effective test performances. Those who "could not develop full speech" were thereby classified as "idiots", the word "dumb" being associated with stupidity (Gould 1984: 158). Branson (2002) argues that, at this time, people with D/HI were deemed 'idiots' because they lacked language skills, rather than being impaired, and as 'idiots' they were ineducable because education was equated with language ability. Thus, the majority of people with D/HI were segregated from society in institutions for the 'mentally defective' or asylums for the 'moral management' of the defective.

A decade later in 1880, the requirement of spoken language became government policy, with the triumph of 'oralism' taking place at the International Congress of Teachers of the Deaf in Milan. Declarations were passed by large majorities, including the British delegation, for the global implementation of pure oralism and the rejection of

'manualism', the use of sign language[5], in favour of speech and lip-reading in schools. Many students segregated into oral institutions experienced what Foster (2001) equates with cultural genocide, being denied access to both sign language and hearing schools. However, sign language continued to be used in segregated manual institutions for the 'Deaf and Dumb' (Branson, 2002), and within these institutions, when not being taught, students were engaged in "domestic tasks or physical exercise, and even more enjoyable excursions organised on an occasional basis were compulsory" (Borsay, 2005: 114).

The growth of segregation continued for people with D/HI. The 1889 Royal Commission on 'The Blind, the Deaf and Dumb and Others of the United Kingdom' was originally appointed to consider only the educational needs of the blind (Pritchard, 1963 cited in Warnock, 1978: 10). Subsequently, this was extended to the education of the 'Deaf and Dumb' and such other cases of 'special circumstances' requiring 'special' methods of education (Her Majesty's Stationery Office [HMSO], 1910 cited in Warnock Report, 1978: 14). However, people with D/HI did not receive educational equality or integration here; instead, the Royal Commission dealt them a heavy blow delaying their education by two years:

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[5] A visual-gestural language that combines finger spelling, hand/arm signals, facial expression, body language and gestures (Temple and Young, 2004).

> Since deaf children were generally less forward than hearing children they would not be ready to start school until the age of seven. Moreover, they would need to be taught not in ordinary classes but in separate schools or classes

> (Warnock Report, 1978: Ch.2.13: 11)

The 1902 Education Act (The Balfour Act) was significant because it abolished School Boards, creating Local Educational Authorities (LEAs) to organise funding, employ teachers and allocate school places. This Act established a two-tier system that distinguished between elementary and secondary education, but not for students with D/HI (Warnock Report, 1978).

Five years later the 1907 Education (Administrative Provisions) Act made medical examination of students compulsory in elementary schools (extended to secondary education in the 1918 Education Act [The Fisher Act]), along with the power to arrange medical treatment (Warnock Report, 1978). This saw the onset of the classification of D/HI as an inherent medical condition. Therefore, medical intervention and treatment of the student became the dominant conceptual framework in the "cultural construction of the deaf as 'disabled'" (Branson, 2002: 189). Four years later in 1911, Swiss psychiatrist Eugen Bleuler pioneered the term 'autism'. However, at this time it was applied to what is now known as the mental health condition schizophrenia (Frith, 2003). The term autism was subsequently re-characterised as a developmental disorder in the

Diagnostic and Statistical Manual of Mental Disorders DSM-IV (see American Psychiatric Association, 1994).

The onset of medical classification of disabilities was apparent in the 1913 Mental Deficiency Act, which brought about two legislative categories. People were defined in one of two ways, as either 'mentally defective' under the terms idiot, imbecile, feeble minded; or 'morally defective' in terms of vicious, criminal tendencies on which punishment had no effect (see Wormald and Wormald, 1914). With respect to education, LEAs were given the responsibility for identifying school age 'defectives', organising medical examinations and notifying the mental deficiency committee accordingly (Jones, 1998). This regulatory system was intended to provide the legal means to protect both the individual and society through institutional segregation (Goodman, 2003).

However, during the passage of the 1913 Mental Deficiency Act, parliamentary debate arose concerning the legal loss of liberty for those considered as 'mentally or morally defective'. Yet, the liberty from which they required most protection was, in the view of eugenicists, the liberty to procreate and increase the numbers of the 'degenerate and wastrel classes', which could have disastrous consequences for society (Wormald and Wormald, 1914). Winston Churchill MP, prominent in the list of Vice-Presidents at the 1912 International Eugenics Congress held in London (Mackenzie, 1976) and Home Secretary when the 1913 Mental Deficiency Act became

law, circulated amongst the parliamentary cabinet an article titled 'The Feeble-Minded: A Social Danger', published by the Eugenics Education Society in 'The Eugenics Review, 1911' (Searle, 1976). According to Searle (1976: 108), this article explicitly endorsed eugenicist ideals:

> The unnatural and increasingly rapid growth of the feebleminded classes, coupled with a steady restriction among all the thrifty, energetic and superior stocks constituted a race danger. I feel that the source from which the stream of madness is fed should be cut off and sealed up before another year has passed

The eugenic view of British society saw social failure as resulting from biological unfitness; thus, social progress came with the repression of the unfit. The Eugenics Education Society came into prominence in 1913-14 with over 1,000 members. One prominent and self-identified eugenicist, Cyril Burt, who pioneered the introduction of intelligence testing (Mackenzie, 1976), was appointed by the London County Council as a psychologist to examine, among other things, individual 'defectives' referred by teachers and school doctors (Warnock Report, 1978). The Eugenics Education Society claimed responsibility for the formulation and passing of the 1913 Mental Deficiency Act through its parliamentary influence:

> What they wanted was to improve the discipline, physique and intelligence of the working class by eradicating the 'lowest' elements of it… A pliable and fit working class could be bred by isolating the residuum in institutions where parenthood would be made impossible
>
> (Mackenzie, 1976: 517)

Legislative categorisation of people with D/HI was extensive within the 1913 Mental Deficiency Act. However, the 1914 Elementary Education (Defective and Epileptic Children) Act brought about 'special' education in segregated schools, as opposed to segregated medical institutions, to provide "character training for the backward [*behaviour modification; if the surrounding environment and stimuli are altered, the unacceptable behaviour will change*], but not for the ineducable defective student [*with D/HI*]", who at this time remained the responsibility of the Health Service (Jones, 1998: 72, *author insertions*):

> …the obvious fear was that doctors ignorant of the effects of deafness on behaviour would certify as defective deaf children who were merely neglected…the worst thought was that such wrongful certification would save a local authority the expense of educating the child
>
> (Hodgson, 1953: 293-294)

Hence, at this time, some people with D/HI, due to difficulties in understanding and processing language, were probably destined by the Health Service to lifelong care and control. Viewed as 'mentally defective', they remained segregated from society in medical, rather than educational institutions, destined for medical treatment or moral management. Intervention and therapy would enrich the 'defective', both spiritually and morally, to enable them to become 'normal' members of society (Branson, 2002). Despite this, the Health Service's medical influence did promote and action the virtues of fresh air and physical exercise:

In the 1920s, many disabled children were not attending a school of any description. For those who were, photographic images portrayed a happy, carefree existence with education interspersed with outings to the seaside

(Borsay, 2005: 112-113)

Following a study of 11 children, Dr. Leo Kanner in 1943 described autism for the first time and Hans Asperger in 1944 independently differentiated a group of children as 'autistic psychopaths', subsequently diagnosed with Aspergers syndrome (see Wing, 1988). This point in time also saw Bruno Bettelheim, director of the Chicago-based Ortho-genic School for children with emotional problems, placing emphasis on the treatment of autism. Bettelheim considered un-stimulating environments during the first few years of life and maternal unresponsiveness as underlying causes of autistic behaviour, initiating the now much contested term 'refrigerator mother' (Wing, 1988).

To summarise briefly, in the early nineteenth century the eugenic emphasis on the hereditary nature of impairment and the inception of intelligence testing had a major influence in the institutionalisation of disabled people, including those with D/HI (Mackenzie, 1976; Searle, 1976). Segregated, institutional living was positively experienced by some. Those that were impoverished were provided with a relatively safe place to live, medical care, food and clothing, religious instruction, encouraged to partake of physical exercise, outings and develop self-help skills (Goodman, 2003; Borsay, 2005). Although limited, some educational skills were gained with which to possibly

seek employment. However, an arguably negative consequence of segregation was that for many years some people with D/HI were 'socially managed', passive and spoken for, rather than having an independent 'voice' (Branson, 2002). Their self-esteem was arguably impeded by this segregation, which conveyed dependency and impeded their association with the non-disabled population (Warnock Report, 1978).

Nevertheless, concepts of impairment and disability were about to undergo more change. Through the social movement, people with a disability were about to find their 'voice' and begin to 'socially manage' themselves through engagement with political influence.

2.3 Social and Educational Integration (1944-1996)

Armitage et al. (2003) situate HE practice within its current political context, providing an understanding of the emergence of issues that are to be considered in the present study. Historically, views regarding education changed considerably. For example, there were three 'ways' – each 'way' contained different policies of governmental commitments and programmes to address particular social values of the time, such as education, employment and social exclusion. The 'first' (professional autonomy, post-war 1944-1979) and 'second' ways (de-professionalisation and market-oriented managerialism, Thatcherism 1979-1997) saw the introduction of policies that are argued here to have constituted minimal interventions in HE practice for students with SCD. These relate to period 2 identified here as social and educational integration (1944-1996) and are addressed below.

However, under New Labour (1997 – present), political intervention in HE became commonplace. By widening opportunity and choice, the 'third way' (self-regulation) currently encourages a consumerist society in which students have better access to 'cherry pick' HE courses to their advantage. Self-governing citizens, through volition, actively and responsibly shape their own lives and employability status in pursuit of becoming part of a civil society (Rose, 1999; Davies et al., 2000). The third way will be addressed in period 3, 'Towards Social and Educational Inclusion (1997 – Present).

In the post-war period 1944-1979, education entered the era of welfare consensus and professional independence, the 'first way'. In this 'first way', educators were valued for their expertise in teaching and learning and became a powerful group with professional status, accorded relatively high salaries and a significant amount of professional autonomy (Hayes, 2003).

The 1944 Education Act (The Butler Act) was an attempt to create the structure for the post-war British education system by raising the compulsory school-leaving age to 15 and introducing the tripartite system with three different types of schooling to cater for different academic levels and aptitudes; grammar, secondary modern and technical. Entry to these schools was based on the eleven plus examination (Dawson and Wall, 1969). People with D/HI and ASD, under a new framework of categories of disabilities, were now re-categorised through school medical examination as 'seriously disabled'. This meant that they were educable and for the first time became the responsibility of the LEAs, rather than the Health Service. Subsequently, people with D/HI and ASD were removed from segregated medical institutions and placed into more appropriate 'special' segregated education, with the lower age of compulsory school attendance uniformly reduced to 5 years. Although this Act was integrative in intention, Borsay (2005) suggests claims to professional expertise underwrote the expansion of segregated education from which students emerged with below-average qualifications.

Special provisions to assist students with a disability were made available under the 1945 Handicapped Pupils and Medical Services Act such as aids, equipment and tuition in lip-reading for students with D/HI. Moreover, this Act replaced the derogatory term 'mental deficiency' with 'educational sub-normality' and 'maladjustment' because they "were claimed to be less insulting" (Borsay, 2005: 111).

A decade later in 1955, the number of students attending 'special' segregated education in England rose by nearly 20,000 from 38,499 to 58,034 (Tomlinson, 1982). This, claim Barnes et al. (1999), was for two main reasons. Firstly, these institutions had specialist teachers who could deliver curricula according to circumstance of impairment and access resources to assist them in doing so. For example, D/HI students attending such schools could learn sign language, which was important for their identity construction in relation to personal acceptance of their difference (Shapiro, 1994) and their place within the Deaf community[6] (for a broader discussion of these issues see this chapter, pp.82-83). Secondly, the environment was positive in the sense that students could acquire interpersonal skills necessary for association with the non-disabled population.

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[6] The use of uppercase 'D' in the spelling of Deaf is used when referring to people who are members of the Deaf community, lowercase 'd' is used in the spelling of deaf when referring to the inability to hear. The Deaf community in Britain is made up of people who share a common language and common experiences. These serve to bind them together and give them a group identity. At the heart of any community is the language which carries the thoughts, memories and hopes of the members (Baker and Padden, 1978).

In terms of educational policy, practice and provision for students with SCD, the 1960s were relatively poor (Borsay, 2005). However, those categorised as 'uneducable' did remain the responsibility of the Health Service until 1971 (Warnock Report, 1978), when following the 1970 Education (Handicapped Children) Act, LEAs took responsibility and saw fit to integrate them into 'special' education (Jones, 1998). Although legislative provision was to be made in 'special' segregated schools, within the 1970 Education (Chronically Sick and Disabled Persons) Act, the move was distinctly toward integration in mainstream educational establishments "the intention was clear that provision should, except for good reason, be made in ordinary schools" (Warnock Report, 1978: Ch.83).

Subsequently, the 1976 Education Act promoted greater educational integration in mainstream schools:

> …except where this was impracticable, incompatible with the efficient instruction in the schools or involved unreasonable public expenditure, in which case it could be given in special schools
>
> (Warnock Report, 1978: Ch.2.84)

Nelson and Berens (1997) explain that it was at this point that people with D/HI were finally considered educable and integration became more appropriate. The term 'deaf', for example, began to have two meanings, one biological (pathological difference) and the other social (communication difference). Branson (2002: 218) asserts that the transitional period of integration was a political response to social

movements that challenged the whole basis of 'special' segregated education:

> In line with the radical educational movements of the 1960s and 1970s, the social movements, and the international battles for human rights, integration highlighted the need to recognise equality and the rights of students with disabilities

The Warnock Report (1978) - the first national Committee of Enquiries into the Education of Handicapped Children and Young People - followed a major review of existing provision and practice for students with a disability "...of the body or mind" (p.1). This report advocated the closure of 'special' segregated schools, with integrative education for all. Students, regardless of (dis)ability, should be educated wherever possible in mainstream educational establishments. Following recommendations from the report, legislation replaced the term 'educationally sub-normal' with 'students with disabilities' and initiated preparation for the transition to adulthood, which included educational provision for students with a disability in integrated further and higher education settings:

> Wherever possible young people with special needs should be given the necessary support to enable them to attend ordinary courses of further education…All universities and polytechnics as well as other establishments of higher education should formulate and publicise a policy on the admission of students with disabilities or significant difficulties and should make systematic arrangements to meet their welfare and special needs
>
> (Warnock Report, 1978: Ch.10.37: 10.49)

Widening participation in tertiary education followed the Warnock Report (1978), particularly with the 1985 Education Act, which established a national curriculum for all (see HMSO, 1985). However, the Conservative term (1979-1997) saw the beginnings of managerialist and bureaucratic practices in education - the 'second way' of Thatcherism (Hayes, 2003). Managerialism was about to present more challenges for students with a disability. The introduction of control through 'market' mechanisms, imposed on all public sectors, including educational institutions, characterised the decline of professional autonomy and the rise of social individuation and social disconnection; the 'death of society':

> The Thatcherite 'second way' set out to destroy what she called 'socialism', that is, trade unions and the communities of the period of welfare consensus, or the 'first way'. However, Thatcherism left nothing in their place, only the illusory 'market mechanisms' imposed on all public sector institutions, including schools, colleges and universities. The legacy of the second way is not just a morass of managerialist and bureaucratic practices. Mrs Thatcher's claim in the popular magazine *Women's Own* that 'There is no such thing as Society. There are individual men and women, and there are families' (*Women's Own, 31 October 1987*) is a statement that characterizes both the consequences of the second way and contemporary context of social individuation and atomization
>
> (Hayes, 2003: 90)

Within this 'second way' managerialist climate, the issue of appropriate education for students with a disability had little impact upon further and higher education (FE/HE); many disabilities were at best unrecognised, at worst, stigmatised. Consequently, generations of educable people with D/HI and ASD were denied opportunities in

FE and HE, both in terms of access and attainment. Over the years, attitudes and more latterly educational activities changed, albeit slowly and unevenly in the FE and HE sectors, with primary and secondary education often taking the lead (Hayes, 2003). With this came the inception of the Disabled Students Allowance (DSA). This was established in 1990 and, at this time, it was means-tested and only payable to students qualifying for a local authority award. Following an initial assessment, DSA was paid directly to the student to cover costs incurred as a result of disability, such as special equipment and non-medical support with study (Riddell et al., 2005).

Major change for tertiary education was driven by the 1992 Further and Higher Education Act, with the inception of national funding councils that would focus on meeting the needs of students with learning difficulties:

> A person is not to be taken as having a learning difficulty solely because the language (or form of the language) in which he is, or will be, taught is different from a language (or form of a language) which has at any time been spoken in his home
>
> (Further and Higher Education Act, 1992, Ch.13: Part 1, Sect.4, Paragraph 7)

The distinction between students with learning difficulties and students with different forms of communication, albeit equated with spoken language, was beneficial for students with SCD (D/HI and ASD) because it brought to the fore that different forms of language use should not be equated with the (in)ability to learn.

However, minimal educational interventions were apparent not only for students with SCD (D/HI and ASD) but for students with a disability *per se* – legislation, through the Disability Discrimination Act (DDA, 1995b), addressed discrimination against people with a disability in employment and in the provision of goods and services but not in education. However, following a mandatory requirement driven by HEFCE, amendments were made to Chapter 13 of the 1992 Further and Higher Education Act (DDA, 1995c: Part 4). All HE establishments were now required to produce a 'disability statement', outlining policies and practices relevant to the needs of students with a disability, to be reviewed and updated triennially (see HEFCE, 1996).

The 1995 Tomlinson Committee Report 'Inclusive Learning' (see Centre for Studies on Inclusive Education, 1996) brought major change, particularly within FE policy and practice. Widening participation concepts endeavoured to address students with a disability and the disadvantaged through equitable access, choice, reasonable adjustments and encouragement for those who may otherwise find the FE experience problematic, whether it be cultural [class, age, gender, ethnicity], structural [financial, time, resources] and/or personal [self-esteem/belief, motivation, peer pressure] (Maxted, 1999).

The introduction of Direct Payments through the 1996 Community Care (Direct Payments) Act also brought about major change in terms of choice and control over disabled adult's personal assistance. This Act enabled local authorities responsible for community care services "to make payments to persons in respect of their securing the provision of such services" (Community Care [Direct Payments] Act 1996, Ch.30: Sect.3, see Office of Public Sector Information, 1996). Implemented in April 1997, those adults up to the age of 65 assessed as needing community care, and at the discretion of the local authority, if they so wished, were provided with a budget rather than services, to buy in and tailor support to suit their daily needs, such as housing, personal care and domestic assistance provided by private companies and the voluntary sector (Carmichael and Brown, 2002). However, this service was not extended to educational support until the broadening of Direct Payments under the 2001 Health and Social Care Act (see this chapter, p.67). For some disabled people, Direct Payments are paramount to independent living – not self-sufficiency but choice of where and how they live, control over who supplies personal assistance and the circumstances in which it is provided:

> Although not satisfying the demands of disabled people in terms of their scope or value, direct payments do represent a significant step along the road to that goal: they offer disabled people some measure of greater choice, control and flexibility regarding the circumstances in which they live and how they are supported

> (Carmichael and Brown, 2002: 798)

However, according to Carmichael and Brown (2002: 804):

> …there was an 'absolutely huge fear factor' with regard to direct payments. There was a lack of confidence and a high level of anxiety regarding the complexity of the system

The time it takes to advertise and recruit good quality staff with appropriate skills and attitudes (respect, dignity, equality, trust, reliability) and the complexities involved in the administration of direct payments, opening a dedicated bank account and submitting monthly statements, coupled with employer responsibility, acted as deterrents. As such, many people with a disability continued to opt for directly provided services.

To summarise briefly, educational provision for students with SCD (D/HI and ASD) no longer had to comprise segregation in 'special' educational institutions. Education had evolved from a segregation paradigm to integration. In its broadest sense, integration demanded reforms in rights to local schooling and education for students with a disability but had a limited focus on inclusive teaching, learning and classroom processes. Inclusion, however, deals more with the quality of educational provision for the student with a disability in an integrated setting (Vislie, 2003). The move toward inclusion was now imminent.

2.4 Toward Social and Educational Inclusion (1997- 2010 the Present)

The move toward inclusion became apparent with the change in government in 1997 where under New Labour education had again entered a new political sphere. In this period, a new-managerialist approach is identifiable:

> Today, when we talk of 'managerialism' or the 'new managerialism' [*the 'third way'*] in further and higher education, or in any other context, this should not be confused with, or seen as a continuation of, the market-oriented managerialism of the Thatcherite 1980's [*the 'second way'*]...In the late 1990's and the early part of the twenty-first century, managerialism has to be seen in the context of the politics of TINA (There Is No Alternative!). The crucial point about TINA, and the difference between the two political periods, is that there is no longer any serious belief in an alternative to liberal democracy and its economic form (capitalism). In this new political context, running the state, a business, a college or a university is seen as a purely technical matter

> (Hayes, 2003: 89)

New-managerialism can thus be defined as an approach to reduce social exclusion through policy and practice that encourages self-regulating, responsible citizens to take charge of their learning to improve employment opportunities - the 'third way'[7] (see Davies et al., 2000).

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[7] There were three 'ways' – each 'way' contained different policies of governmental commitments and programmes to address particular social values of the time such as, education, employment, social exclusion (for a fuller discussion see Armitage et al., 2003).

The 'third way' came as a political response to 'second way' problems of societal 'disconnection' - social individuation having weakened social and community networks (Hayes, 2003). Educators were no longer viewed as 'all seeing', 'all knowing' experts, but professionals seeking to be congruent with current government 'inclusive' policy of achieving social justice. Societal 'reconnection' was seen as achievable by reducing exclusion through education and subsequent employment. Self-governing citizens actively shape their lives and employability status through education (Rose, 1999; Davies et al., 2000). The needs and demands of the student (consumer) are paramount, rather than the educator (provider). Currently, evaluation of teaching is imposed, through self-assessment, transparency reviews and accountability that enforces personal responsibility for teaching and learning (Mahony and Hextall, 2000). At the administrative level, financial monitoring, quality audit and performance measurement is based on new-managerial assumptions that:

> …all human behaviour can and should be measured and, in order to achieve efficiency, effectiveness and value for money in the public sector, all activity should be measured against agreeable targets. The higher education sector exemplifies this approach, where targets are set by HEFCE in relation to, for example, student retention and completion rates which feature in league tables
>
> (Riddell et al., 2007: 616)

This new-managerialism consists of a complex mix of rational choice theory (see for example, Coleman, 1990), agency theory (in this context, the capacity of individuals to act independently and to make their own free choices, see Berger, 2008), and social exchange theory (see Thibaut and Kelley, 1959) using cost and benefits analyses (rewards and costs in interpersonal relationships, see Homans, 1974). Thus, students are responsible for their own self-determination through autonomy, competence and relatedness. Students take responsibility for their education [autonomy], academic progression and subsequent employment [competence] and are thus able to participate with others in society [relatedness] (Patrick et al., 2007). The rational student has a capacity for self-determination by assuming a competent course of action that most effectively, with minimal cost and maximum benefit, fulfils their need for academic achievement and increases their employability status.

Williams (2001) argues that this powerful employment ethic has weakened social and community networks for vulnerable individuals and those already at a disadvantage, such as asylum seekers, lone parents, carers and people with disabilities and/or mental health problems. Rather than strengthening communities, this may exacerbate social divisions and increase exclusion:

> ...in terms of the casualties, rejects, dropouts and failures of these measures, and those deemed incapable of participation in them

<p style="text-align:right">(Jordan, 2001: 536)</p>

Following New Labour 'third way' incentives, a major review of HE was undertaken by the National Committee of Inquiry into Higher Education (NCIHE, 1997a, the Dearing Committee Report). The under-representation of students with a disability in HE was recognised by the Dearing Committee in the report. However, it was noted that the data on which under-representation was based was unreliable because it depended on whether or not students identified themselves as having a disability. Moreover, the Dearing Committee was unable to evaluate the extent to which students with disabilities needed formal academic support because of a lack of available data:

> More significantly the data does not appear to record those who need assistance in order to study as a result of a disability, rather than those who have a disability irrespective of its impact on their studies

> (NCIHE, 1997a: 7.14)

The Dearing Committee appeared to take a step toward a more social model of disability (for an overview see this chapter, p.79) with its recognition of oppressive practice and institutional barriers. The 'normalisation' of disability implies that universities should be encouraged to generate a culture and environment where disability is not regarded as a problem. Students with a disability rarely need special or exceptional treatment but they do need considerate and fair treatment. Institutions should therefore work towards:

> *Disability awareness* – a recognition of the structural, organisational, relational and financial consequences of establishing barrier-free access, where 'barrier-free' should take the meaning adopted by the Open University of providing a learning environment which is open to students regardless of disability and circumstance
>
> *Disability sensitivity* – a recognition that 'disability' as a concept covers a multitude of different cases and special needs; that students with disabilities have already demonstrated fitness to achieve in higher education; and that students with disabilities, despite their ability to negotiate the world in which they find themselves, will from time to time need intervention and support
>
> (NCIHE, 1997b: 5.1)

The Dearing Committee (NCIHE, 1997b: 5.13) abolished means-testing of the DSA and it was extended to all students. They recommended a "fixed rate to the student by disability" in the form of Disabled Students Allowance (5.12) for full and part-time HE students (5.10). However, in these recommendations the Dearing Committee did not take into account individual experience of disability. For example, students with SCD were then, as now, categorised into groups by disability and assessed as requiring formal academic support according to a pre-set list of categorical need. This 'one-size-fits-all' approach was, and remains, contradictory because it conflicted with some of the Dearing Committee's own recommendations that were made earlier in the same section of the report, for example, that social aspects of disability and individual experience *should* be taken into account. This point is brought out very clearly in recommendations that encouraged universities to distinguish between environmental

(appropriateness of the physical environment), experiential (quality of learning and learning support experience), and personal dimensions of disability:

> …personal factors concern the extent to which students with disabilities require support and interventions in negotiating relationships within the university, with family and friends, with peers and with external agencies where necessary
>
> (NCIHE, 1997b: 5.9)

Arguably this contradiction, albeit confusing, was more than a return to 'personal' welfare and care as argued by Hurst (1999); it was more congruent with the move toward new-managerialist 'impersonal' outcome measures based on rationality, bureaucracy and economic efficiency. These outcome-based measures require administrative audit and assessment through group categorisation, counting and accountability (for an overview of new-managerialism principles, see Reed and Deem, 2002). Riddell et al. (2007) illustrate how new-managerialism has a guiding influence on university academic administration with regard to students with a disability. If universities opt out, their premium funding (paid to universities on the basis of students claiming DSA) diminishes. If they opt in, they cannot retain a critical agenda because the process classifies student into groups by disability. The Higher Education Statistics Agency (2010) annually counts the number of students with a disability on HE programmes and provides funding to universities based on these numbers. Individual universities conduct financial analyses based on the most cost-effective way to spend this funding. As such, outcome targets

for universities are to increase recruitment and retention of students with a disability.

Following publication of the Dearing Committee Report and in consultation with the HE sector, the Quality Assurance Agency published a *Code of Practice* in 1999 for the assurance of the quality of learning opportunities and educational provision for HE students with a disability. At an institutional level, the Quality Assurance Agency for HE general principles (1999: 6) urged inclusive practice for the student with a disability:

> Institutions should ensure that in all their policies, procedures and activities, including strategic planning and resource allocation, consideration is given to the means of enabling disabled students' participation in all aspects of the academic and social life of the institution

However, these steps were not enforceable by law and the way in which institutions responded to these principles remained ultimately the choice of the individual institution. Thus, in practice, procedures were poorly operationalised. The means to anticipate and meet specific, often highly individual, need remained unclear (see Open University, 2003).

It is now more widely accepted that everyone can be educated regardless of (dis)abilities and there is no need to segregate students with a disability from mainstream educational establishments (Graves and Tracy, 1998). Supportive legislation such as the DDA (1995d) amended by the Special Educational Needs Disability Act (SENDA,

2001: Part 4) aimed to ensure that students with a disability had the right to access education in an establishment of their choice with reasonable adjustments that ensured current and prospective students were not placed at a substantial disadvantage in comparison with their non-disabled peers. The amendment provided, for the first time, legislative protection for students with a disability. However, there was no provision for a Commission to enforce it, in contrast with arrangements on sex and race (Disability Rights Commission, 2007a).

The enforcement of SENDA (2001) should have led to educational improvements for students with a disability. However, the National Opinion Poll 2002 (Disability Rights Commission, 2002) surveyed 305 people with a disability aged 16 – 24 who perceived that this was not the case. Many disabled people were discouraged from taking GCSEs and 27% surveyed did not go on to further or higher education; of those at college or university, 17% reported personal experience of discrimination because of their disability. Similarly, figures from the Labour Force Survey 2005 (see Disability Rights Commission, 2007a) demonstrated that disabled people aged 16 - 24 were almost twice as likely as their non-disabled peers to have no qualifications (23% compared to 13%). Further to this, at age 16, young people with a disability were still almost twice as likely as their non-disabled peers not to be in any form of education, employment or training (15% compared to 7%). In part, this may have been a new-managerial response to the lack of status of pre-Entry life skills

programmes and awards that promote personal, social and health development rather than vocational courses (Qualifications and Curriculum Authority [QCA], 2004):

> …they are not part of the National Qualifications Framework [NQF] and do not contribute to performance indicators; and a more complex funding model (funding is not guaranteed in the same way as for a qualification in the NQF) is needed

> (QCA, 2004: 23)

A small but significant number of educators suggested that colleagues in FE colleges did not value these qualifications. Similarly, senior managers did not value such qualifications because they did not attract performance points (QCA, 2004). This is hardly surprising in view of the current new-managerialist climate that enforces evidenced-based accountability for teaching and learning (Mahony and Hextall, 2000).

The 2001 Health and Social Care Act, Chapter 15, Part 4 extended the 1996 Community Care (Direct Payments) Act. Direct Payments were made mandatory, not at the discretion of local authorities [sect. 57], and extended to children with a disability aged 16 and 17 and to parents, guardians and carers of children with a disability [sect. 58] (Office of Public Sector Information, 2008; Department of Health, 2000). Priestly et al. (2006: 1190) argue that the introduction of mandatory duties for local authorities, targets and performance indicators can be viewed within the wider context of new managerialism under New Labour:

> In April 2003 it became mandatory for local authorities to offer direct payments at the time of assessment or review of community care packages, and to publicise direct payments to eligible social service users

This enabled students with a disability, if they so wished, to utilise Direct Payments for personal support to access education and training (it should be noted here that at the University in which the present study was undertaken only one student with SCD has currently opted for Direct Payments). However, problems with Direct Payments abound "difficulties in recruitment, potential confusion in roles, unreasonable expectations, quick turnover of staff, and problems of confidentiality" (Shakespeare, 2006: 142). Thus, Carmichael and Brown (2002: 806) caution:

> …if such an approach is to deliver for all people with personal support needs, it must recognise the diversity among service users, taking into account age, gender, sexual orientation, race and ethnicity, and social background. There will also remain a degree of need for directly provided services, both to accommodate individual preference and for specific situations like short-term support to cover significant life events. It is important, therefore, that these services are not neglected in favour of direct payments

Nevertheless, Barnes and Mercer (2006) argue that choice is paramount to the concept of independent living and this can be argued to be related to self-determination (see Patrick et al., 2007). Appropriate academic support allows for self-determination through student autonomy, competence and relatedness. Autonomy should be respected regardless of (dis)ability by allowing students, for example, to participate in decision-making regarding their academic

support. Allocation of support, fair distribution of support resources and respect for students' rights allows equal access to, and choices within, student support. Priestley (1999) contends that having control over support and assistance can facilitate student participation, equality and enhanced inclusion. Currently, students with a disability who opt to use directly provided services are not included in the appointment process for support workers.

Provision of auxiliary aids and services were made mandatory in 2003, as were adjustments to physical features of premises to overcome barriers to access in 2004 (DDA, 1995b: Part 3). However, changes to the built environment can be argued to have had little impact for students with SCD (Parr et al., 2003).

Another plausible explanation for the minimal educational improvements for students with a disability came twenty-seven years after the Warnock Report (1978). The now Baroness Warnock (2005), in a guidance pamphlet, suggested that inclusive provision of 'special' educational needs within mainstream schools had a damaging impact on students with a disability. Baroness Warnock conceded that policy resulting from the 1978 Report had backfired, leaving a "disastrous legacy". She now called "for a radical review" of the closure of 'special' schools, arguing that pressure to include students with a disability had led to "confusion, of which children were the casualties" (p.12):

> Governments must come to recognise that even if inclusion is an ideal for society in general; it may not always be an ideal for school

> (Warnock, 2005: 43)

Despite the potential damage to inclusive education following Baroness Warnock's 'u-turn', a growing and influential disability rights movement in the UK, and legislation aimed at promoting equality of 'rights' for students with a disability was viewed by many as long overdue. The impact of the DDA (1995a) and its subsequent amendments should not be underestimated. As a result of the European Union Employment Directive on Equal Treatment, Part 2 of the DDA was amended in 2004 to strengthen the rights of people with a disability in employment and vocational training. This included work-based placement (see Disability Rights Commission, 2006). Key amendments to Part 4 of the DDA (1995c) means there are currently four types of discrimination:

1) Direct discrimination
2) Failure to make a reasonable adjustment
3) Disability-related discrimination
4) Victimisation

Amendments to the DDA (1995a) introduced wide ranging measures that, together with higher attainment due to changes in FE sectors, means an increasing number of students with a disability will be entering the HE sector expecting to see their potential fulfilled. The most recent figures available from the UK Higher Education Statistics Agency (2010) show the UK number of HE students with D/HI increased by 400 students over the 3 academic years 2006/07

(3,010), 2007/08 (3,030) and 2008/09 (3,425). Students with ASD increased annually by 200 students in those 3 academic years, 2006/07 (465), 2007/08 (665) and 2008/09 (855). Combined, there was an annual increase of 585 HE students with SCD in the academic year 2008/09 alone. Whether students with SCDs' aspirations can be achieved depends on many factors, but HE establishments have their part to play. Key to this is accommodation of academic need.

A plethora of research, influencing HE policy and practice, has ensured that for many students with a disability a range of accommodations may offer real benefits; HE establishments now seek to support students with a variety of diagnosed disabilities through provision of academic support (Gorard et al., 2006). Students with SCD, in particular, now have access to mentors, note takers, exam amanuensis, educators for the Deaf, British Sign Language communicators, dyslexia tutors and library/campus support. Despite this introduction of guidance and support for students with SCD, issues of retention and progression remain intractable (Sellers and van der Velden, 2003). These issues are central to the present study and require an in-depth critical review of the literature; as such, they are discussed in more detail in chapter three.

The final phases of amendments to the DDA (1995a) were made in the Disability Equality Duty (DED, 2006, see Disability Rights Commission, 2007b – renamed Equality and Human Rights Commission in October 2007). As well as protecting individuals from discrimination, this new legislation emphasises promotion of disability equality and opportunity. This approach reflects the social model of disability (see this chapter, p.79) by perceiving negative attitudes and oppressive practices within society as disabling factors, rather than impairment (see Oliver, 1996). The DED (2006) has charged public bodies (including HE institutions) with the statutory responsibility of demonstrating anticipatory measures to eliminate disability discrimination and promote equality through annual reviews and the publication of a Disability Equality Scheme [reviewed triennially]. General duties include the need to:

- Eliminate discrimination
- Eliminate harassment
- Promote equality of opportunity between a disabled person and other people
- Encourage participation by disabled persons in public life
- Promote positive attitudes towards disabled people

Specific duties undertaken by HE institutions, through the development and implementation of a Disability Equality Scheme, will need to reflect the following priorities:

- Active engagement of disabled people
- Institutional strategic targets
- Annual progression, which measures and reports achievement in attaining set targets

(Adapted from the Disability Rights Commission, 2007b)

Thus to be fully inclusive, meeting DED (2006) legislation arguably requires HE institutions, in consultation and participation with those directly affected, to be anticipatory of all student need, both academic (formal) and social (informal). This was recommended a decade ago in the Dearing Report (NCIHE, 1997b) into widening HE participation for students with a disability and was the general principle at the forefront of QAA (1999) assurances of academic quality and standards in HE for students with a disability (see this chapter, pp.64-65). These student-centred recommendations and general principles appear to have been sidelined by new-managerialist outcome-based policies and practices that provoke the meeting of formal academic need, to allow quantifiable measures to evidence accountability of HE practice.

The next section addresses conceptions of disability because they too influence HE policies, practice and provision that are made manifest in the experiences of HE students with SCD (Riddell et al., 2005). As such, the next section places more emphasis on the context of this thesis by moving principally into current British literature, which broadly describes two conceptual models of disability: the 'medical/individual' and the 'social'.

2.5 Conceptual Debate Surrounding Disability

The traditional British view of disability saw people with impairments as victims of disease and deficit. Disability was defined in individual and medical terms by scientists and medical professionals, and the priority is given to prevent and mitigate disability through therapies, cures, antenatal diagnosis and selective termination – the medical/individual model. This approach "has dominated modern policy making, professional practice and societal arrangements regarding people with disabilities" (Longmore and Umansky, 2001: 7). However, the term medical/individual model of disability is not one that was created by those who practice it; instead it arose from the:

> …many disability scholars rejection of medicalisation, defined as the dominance of medical approaches and of medical experts… [*However*] no authors have ever explicitly affiliated themselves to this medical or individual model perspective
>
> (Shakespeare, 2006: 15)

The British disability movement comprises disability activists and scholars who promote a new view of people with impairments as disabled by society – the social model of disability. In this view, disability is defined as the oppressive relationship between people with impairment and disabling societies. The priority is to use law and policy to remove the barriers that exclude people (Swain et al., 2004):

> The social model was first devised in the 1970s. It was developed in academic form in the publications of Vic Finkelstein (1980) and Michael Oliver (1990). It was prompted through the work of Colin Barnes (1991) and successive waves of disability studies scholars

> (Shakespeare, 2006: 33)

It would be naïve to claim that disability scholars strictly adhere to one model or the other; this is not the case, as many are eclectic in approach (for an overview of authors who have spanned the continuum, see Shakespeare, 2006: Ch.2). However, these models do dominate British disability studies:

> It is also important to understand the ways in which the social model has been counterposed to the 'medical model'. To activists, the power of the latter has made the need for the former more urgent…British disability studies has distinguished the right way – defined in terms of a social model perspective – from the wrong way represented by the medical [*individual*] model

> (Shakespeare, 2006: 10)

Currently, the medical/individual and social models can be argued to be the principal conceptual frameworks that delineate impairment and disability. These conceptions and the differences between them serve to inform not only the way in which people with impairment are perceived, but more significantly, how they *should* be treated, both medically and within society more generally. The next section will begin by setting out the basic tenets of the medical and social models of disability within a historical and cultural framework. Each model will then be subject to further critical scrutiny before the researcher positions herself within the debate (see this chapter, p.98).

2.5.1 The Medical/Individual Model of Disability

Prior to the seventeenth century, in Judean and Christian religious beliefs, impairment and disability were un-Godly consequences of wrongdoing, such as witchcraft and sorcery, or possession by demons; living proof of Satan (Barnes, 1997). However, the rise of the scientific revolution brought about fundamental changes in worldview thinking and progress "associated with rationality, science, technological advancement and the accumulation of knowledge" (Potter, 2000: 240).

As a part of this scientific revolution, the conceptualisation and measurement of health and well-being fed into subsequent medical conceptions of disability. A person's health is good when there is an absence of illness or an ability to function 'normally', with well-being as a health outcome which includes physical, psychological and social functioning. Thus, health and well-being became measures of 'normality'. This focus on pathology largely arose from the view that the health problem facing society, and medicine in particular, has been to overcome disease and impairment (Breslow, 1972). Subsequently, disability was perceived as treatable, with impairment a medical anomaly in need of remedial intervention. This led to the emergence of the medical/individual model of disability (Longmore, 2003).

The medical/individual model of disability operates in terms of the World Health Organisation International Classification of Impairment, Disability and Handicap (developed by Wood, 1981). Within the context of health experience:

- Impairment is any loss or abnormality of psychological, physiological, or anatomical structure or function
- Disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being
- Handicap is a disadvantage for a given individual, resulting from impairment or a disability that limits or prevents the fulfilment of a role that is normal (depending on the age, sex, social and cultural factors) for that individual

The medical/individual model conceptualises impairment as a "societal disease"; largely due to some inherent physical or developmental defect (Longmore, 2003: 218). As such, the disability that follows impairment is undesirable both for the individual and society in its entirety (Harris, 2000). It is to be expected that, without treatment, the impaired individual will inevitably suffer disabling consequences, such as an inability to perform everyday activities; through this they will experience disadvantage and a reduced 'quality of life':

Quality of life is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationships to salient features in their environment

(World Health Organisation Quality of Life Group, 1993: 30)

The focus for intervention and treatment is therefore directly upon the individual's impairment, their health and well-being. Management or treatment of impairment is thus predicated on more general clinical practices; classifying impairment, understanding its etiology and developing treatments that best achieve soundness, particularly of the body or mind and freedom from abnormality and subsequent disability. Resources are allocated to healthcare and related services that align the impaired individual as closely as possible to 'normality' (Stone, 1985).

Interventions and treatments from within this conceptual framework are argued to have had many positive outcomes for people in light of alleviating or preventing disability:

> The moral motive to intervene in the natural lottery of life is for the sake of the good that it will bring about. Saving lives, removing or preventing disability or disease, or enhancing human functioning are examples of this good
>
> (Harris, 2005: 17)

Successful treatment of impairment can offer personal and societal benefits, such as a longer, more independent, pain free existence, access to education and employment opportunity, all of which enhances an individual's self-concept and enables them to 'fit' in with 'normal' society.

2.5.2 The Social Model of Disability

In the mid twentieth century, society again underwent fundamental changes, such as "the recognition of difference between groups and the shifting nature of our multiple identities" (Potter, 2000: 151) and with this came the rise of the disability movement. The social model of disability was constructed by a social movement of people with physical disabilities who were in direct opposition to much of the medical/individual model assumptions (Longmore, 2003).

The social model of disability operates in terms of the declaration of Union of the Physically Impaired Against Segregation (1976: 3-4), which defines disability as:

> …the disadvantage or restriction of activity caused by contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities

Proponents of the social model of disability recognise that impairment and chronic illnesses exist and often pose real difficulties for people. However, within this perspective assumptions are challenged that individuals are disabled exclusively by their impairments. The social model of disability seeks to reduce prejudice, fear and discrimination towards people with a disability, brought about through centuries of negative attitudes and practices. Social model activists argue that the practice of finding medically-based cures detracts from looking at social causes of disability.

Instead, social model activists explore how people are disabled by socially constructed barriers, such as environmental structures and hostile social attitudes (Barnes and Mercer, 1997).

2.5.3 The Medical (Individual)/Social Model Debate

The medical/individual model, as set out above, offers real benefits for people with impairment. However, it also brings with it the potential to generate inequality and disadvantage. It may mask unequal power relations and important social aspects of disability. The social model of disability thus holds forth at least five key criticisms of the medical/individual model. The medical/individual model perpetuates negative attitudes; maintains negative social values; disempowers people; masks environmental features that constitute barriers; propagates educational inequality (amalgamated from Oliver, 1996; Barnes, 1997; Finkelstein, 1980; Hahn, 2001; Rieser, 2001). Each will be examined below.

Advocates of the social model argue that medical/individual model practices perpetuate disability through negative attitudes of impairment that instil dependency, pity and fear (Barnes, 1997). Those who are seen to achieve, regardless of their disability, are perceived as 'super-cripples' or considered to 'triumph over personal tragedy' (Hunt, 1996; Finkelstein, 1980). Physicist Professor Stephen Hawking is a good example here, perceived to have triumphed over

severe physical disablement (Larsen, 2005) because of the view that people with impairment usually cannot or should not be doing ordinary everyday activities, let alone achieving something extraordinary.

The importance and desirability of bodily and intellectual perfection is endemic in Western society. Harris (2000), a bioethicist, suggests impairment has no place here; it is an undesirable condition from which a person wishes to escape. These cultural representations of impairment derive from ancient Greece and Rome, which is manifest in Greek Gods/Goddesses' ideal representations of perfected humanity. Barnes (1997) explains that following their conquest of Greece, the Romans maintained these cultural representations and transmitted them globally. Middleton (1996) argues that power lies within the medical and associated professions to enhance bodily physique and functioning. Intervention and treatment practices relate to cures and normalisation, which serve negative social values based on superficial appearance and bodily functioning. This leads to the oppression of people with impairment. This is a reasonable criticism of the medical/individual model of disability because it raises important issues for, among others, people with SCD, as set out in the following example.

One example pertinent to this research because it relates to people with SCD is cochlear implantation for those with D/HI. This procedure has lead to ethical tension surrounding who benefits from this medical procedure and the possible threat it poses to the Deaf community (see below).

Cochlear implantation is a surgical procedure lasting about three and a half hours and performed under general anaesthetic. It is claimed to cure deafness in the profoundly deaf/hearing impaired "to make deaf people hear. It is the 'bionic ear'" (Branson, 2002: 224). Ladd (2002), from a social model perspective, argues that advocates of the medical model proclaim cochlear implantation as a miraculous procedure, a beneficial educational and therapeutic process that will adapt the person with D/HI to fit the wider 'normal' society. In this view, being able to hear and speak is vital for society's communication as a whole; oralism (verbal communication) should be the only 'natural' form of communication. In this respect, the medical/individual model conceptualisation of disability is grounded in the values of normalisation "personal behaviours and characteristics which are as culturally normal as possible" (Wolfensberger, 1972: 28). In comparison to what the so called 'normal' person can do, this emphasises what a person with D/HI cannot do, and needs to do, in order to function properly according to their medical impairment (Hahn, 2001).

Conversely, proponents of the social model contend that cochlear implantation is an unnecessary and dangerous procedure. Lane (1992) reports that "damage to facial nerves caused disfigurement for as many as one child in six" that had undergone this surgical procedure in America (p.217). Furthermore, cochlear implantation, argues Branson (2002: 155), threatens the eradication of sign language, which, in turn, may adversely impact on personal experience, culture and identity construction:

> By removing signing they sought to normalise the deaf individual. They sought to destroy deaf people's difference, to destroy the cultural aspects of their deafness. In the process, they would destroy those aspects of deaf people's identity associated with the recognition that deaf people were an acceptable albeit devalued part of nature's diversity

In this view, deaf/hearing impaired people's identity construction, their perceptions, values, norms and beliefs are situated in, and mediated through, their use of sign language. This distinguishes them as a linguistic minority group, who use the term 'Deaf' with a capital D to indicate that they belong to a Deaf community (Ladd, 2002):

> …who share a common language, common experiences and values, and a common way of interacting with each other, and with hearing people

> (Baker and Padden, 1978: 4)

The view taken here is that the medical/individual model remains the framework through which discrimination can be legitimised and 'normality' actualised.

Middleton (1996: 36) goes further, arguing that scientists and assessors not only determine welfare, type of education, housing and access to work, but whether or not people with impairments are born, or are allowed to procreate:

> As a society we do not want to include disabled people. We do our best to prevent their birth. If this fails we seek to normalise them. If this fails we render them invisible by an elaborate system of segregation

Medical/individual model practices position people with impairment within prevailing discourses of dependency; in need of specialist medical care and procedures. This, in turn, positions medical and associated professionals as better placed to make decisions in the person with impairment's best interests because they are assumed to lack the competence to exercise responsibility for their own lives (Riddell, 1998). Although this critique raises important concerns, it still needs to be recognised here that medical intervention and treatment can have 'life changing' benefits for people with disabilities.

Advocates of the social model argue marginalisation and disempowerment is exercised through the design of the physical environment, which is built for, and by, able bodied people. The built environment presents many barriers, making it difficult to access work, school, leisure and entertainment facilities, transport, training, higher education and housing (Oliver, 1996). Although it is important to recognise that mandatory legislation (see DDA, 1995b: Part III), actioned in 2004 to remove physical barriers in the built environment,

has opened up access for people with physical disabilities, the dominant view remains that impairments are barriers to 'normal' interaction with society and medical solutions are still fervently sought (Harris, 2005).

Educational inequality is a central theme in this thesis, therefore the influence of the medical/individual and social models of disability are paramount in this context. Medical/individual model concepts prevail in education too. In this view, the student with a disability is viewed as faulty, needing to be assessed in order to be made as 'normal' as possible through imposed programmes of therapy:

> Diagnosis is necessary, labelling is unavoidable, and impairment becomes the focus of attention. Imposed assessment, monitoring, programmes of therapy lead to segregation and alternative services, ordinary needs are put on hold and re-entry into the standard educational system is only possible if students are assessed as 'normal'. Society remains unchanged
>
> (Rieser, 2001: 139)

Armstrong and Barton (1999: 223) provide reasonable criticism of this view and argue that medical/individual model practices in education cause inequality by denying students their educational rights:

> …attachment of resources to particular named impairments obscures the socially constructed nature of disability and the social and educational interests of students

Alternatively, social model practice is argued to enhance the educational experience of people with disabilities by placing responsibility for equality and inclusion in the hands of all its members. For example, Avramidis and Norwich (2002) carried out an extensive international review of the literature to explore educator attitudes concerning students with a disability, and suggested that where educators have active experience of educational inclusion their attitudes are positive. Salend (1999: 10) proposes through promotion of positive attitudes toward students with a disability:

> Educators can promote an acceptance of individual differences and friendships among their students by serving as role models to show that all students are valued, respected and accepted

Within this view, students with a disability must be fully included in all aspects of their education. They should be valued for their contribution, their strengths should be focused on rather than their weaknesses, and resources and the educational environment should be made accessible. Above all, diversity should be welcomed:

> Strengths and needs are defined by self and others through identification of barriers and development of solutions…Resources are made available; training for parents and professionals. Diversity is welcomed. Society evolves
>
> (Rieser, 2001: 139)

Increasingly, proponents of the social model of disability have influenced educational policy, practice and provision for students with a disability. Currently, legislation such as the DED (2006 see Disability Rights Commission, 2007b) is re-constructing disabled

people as agents alongside the non-disabled – recognising them as capable of rational thinking and forming their own interpretations and views on how they should be treated, medically and socially. Prioritising the voices of people with disabilities may enable them to have some agency in their lives and shed images of dependency and passivity. This may prevent them positioning themselves as solely subject to medical and associated professional decisions.

The social model of disability has enabled socially constructed barriers to be perceived as obstacles to accessing the environment, education, work and social activities. Burr (2003) suggests this widens participation by taking responsibility for change "off the shoulders of the disabled person and places it in the realm of social practices, organisations and the law" (p.50). Thus, the welcome re-construction of Western society's oppressive attitudes toward disability has begun. A new socio-political discourse surrounds disability that includes terminology such as rights, acknowledgement, equality, accommodation, acceptance, diversity, which is aimed at promoting celebration of difference, whatever its cause (Disability Rights Commission, 2006). Impairment and disability are being recast into more positive aspects of social understanding of difference, albeit slowly.

Critique from advocates of the social model of disability is primarily directed at the medical/individual model and has raised some important issues concerning the perpetuation of negative attitudes and social values, disempowerment and inequalities toward disabled people. However, at least four key overlapping criticisms of the social model are recognised by some of its advocates who argue for development of the model. As set out below, the social model approach neglects the implications of impairment and the body; it presents a limited approach to understanding identity; fails to recognise differentiated experiences of impairment; and propagates a reluctance to discuss the social relations of disability.

Although the social model aims to ease social oppression and environmental barriers, from within the disability movement (Shakespeare, 2006) and notably from a feminist perspective Morris (1991), French (1993), Crow (1996) and Thomas (1999) have each challenged it for neglecting the implications of impairment and the body, and the interaction between impairment and disability. For example, Morris (1991: 10) discusses what she feels has been neglected by the social model approach:

> While environmental barriers and social attitudes are a crucial part of our experience of disability – and do indeed disable us – to suggest that this is all there is to it is to deny the personal experiences of physical and intellectual restrictions, of illness, of the fear of dying

The concern here is that concepts of disability need to take the lived experience of having impairments into account, something that the social model is argued to have neglected:

> …preventing people becoming impaired is as important, on a global scale, as preventing people from becoming disabled. For those who already have impairments, or those whose impairments cannot easily be cured, the priority may be removal of social barriers and promotion of inclusion and equal respect. But for the vast population of individuals vulnerable to impairment, measures to forestall impairment are vital

> (Shakespeare, 2005: 89-90)

There is an emerging view that even after social restrictions have been removed, impairment effects remain. The neglect of the implications of impairment such as aches, pain, infection and distress can be argued to separate impairment from the body, treating the body as a "pre-social, inert, physical object, as discrete, palpable and separate from the self" (Hughes and Paterson, 1997: 329). Thomas (1999) argues it is not simply a matter of social oppression; many people with a disability experience bodily discomfort from disease and impairment effects, which manifest in their daily experience. This is a reasonable criticism of the social model of disability because it raises important issues as to how impairment can limit experiences and opportunities for people with disabilities, as set out in the following example.

A pertinent example to this thesis is provided by Shakespeare (2006) who draws attention to a central issue for people with SCD, who may experience "…frustrations and difficulties with communication, which cannot simply be attributed to oppression, but also arises from the very real problems in understanding people" (p.173).

Shakespeare (2006: 63), in his controversial publication 'Disability Rights and Wrongs', calls for a more holistic approach, and explains the difficulties which impairment may present, viewing it as a predicament – "an unpleasant, trying or dangerous situation":

> They [impairments] make life harder, although this hardship can be overcome. The added burden of social oppression and social exclusion, which turn impairment into disadvantage, need to be removed

Counterargument is provided here from disability activist and scholar Oliver (2007: 232) who, stepping briefly out of retirement, defends his position on this issue:

> He [Shakespeare] freely admits that his own impairment is minor…I have always refused to parade the 'pains' of my impairment in public and I have no intention of doing so here, but in more than forty years since I acquired it I have been aware of it every waking moment and I have even trained myself to wake at night should a blocked catheter or awkward sleeping position put my health, and even my life at risk. I do not make this point as part of a macho 'my impairment's bigger than yours' contest, but rather to demonstrate that not understanding the critical reality of severe impairment leads to Shakespeare making dangerous comments about social and legal change

It is argued that the social model is largely unrepresentative of the diversity of people with disabilities. Having been created by, and for, people with physical impairments, it can be argued to have neglected those with alternative and often hidden difficulties, such as social communication (D/HI, ASD), sensory (visual impairments), mental health and learning difficulties. These groups, according to Shakespeare (2006: 75), tend not to be part of the mainstream of the disability movement and disability activism:

> For example, people with learning difficulties may have been excluded because their particular access and language issues have not been properly understood, or because they have not been welcomed, or because the social model theory has not effectively incorporated intellectual impairments. Some disabled people have sought to bolster their own status as people with physical impairments at the expense of those with intellectual impairments. Another example is the Deaf community, who have resisted identification with the mainstream disability movement. Often this is because Deaf people see themselves as a linguistic minority, not as people defined by a medical condition

The prevailing discourse of people with disabilities appears to contradict a social model approach by being narrowed to those with physical impairment. As recently as 2006, the British Social Attitudes Survey showed that "disability is still largely perceived in the narrow and outdated sense of visible physical disability" (Disability Rights Commission, 2007c: 7). This national consensus of disability as typically physical impairment can be argued to have been perpetuated by social model activists and political bodies through public policy interest aimed at overtly ending the oppression of

people with physical impairments. Shakespeare (2006: 13) illustrates this point:

> ...dominated by wheelchair users, perhaps because many had previously been able bodied, and had been involved with other political movements (Finkelstein, 2001: 4). Some activists remember it [*the social model of disability*] as being sexist (Campbell and Oliver, 1996: 52), and as dominated by a typically masculine form of politics, which was hard, ideological and combative (Campbell and Oliver, 1996: 67)

Concentration of funding to remove physical barriers in the environment can be argued to have negatively impacted on allocation of resources for people with difficulties other than physical. For example, people with specific learning difficulties such as dyslexia (difficulty with words) and dyspraxia (difficulty with fine motor skills) (see Holford, 2007). Disability Rights Commission (2007c: 8) go on to argue as a result:

> …employers and service providers would consider the 'job done' if they took action on physical access but would not invest time and thought, for example, in the types of adjustments that meant they could employ or retain someone with bi-polar disorder – 'the mental health equivalent of the ramp'

In addition, current funding and promotion of an educational campaign to raise public awareness of disability was wholly focused on physical impairment (see the 2008 national disability awareness campaign designed to change the way people think – available at the time of writing on television, billboard displays and also at www.ableize.com). These media advertisements used the voices of people with physical impairment. However, portrayal of people with

physical impairments as animated slugs, tortoises, dogs, hedgehogs and stick insects can be suggested to instil images of people with impairments as objects of ridicule. This advertising campaign can therefore be argued to merely emphasise disability as social tragedy and invoke feelings of pity rather than understanding, something of which advocates of the social model accuse medical/individual model proponents. This can be further argued to have negatively impacted on social perceptions of people with impairments other than physical.

The danger here is that other types of impairments, having no clear representation, may be publicly interpreted and personally internalised as being less important compared with physical disabilities, affecting a person's identity:

> …linked to this public perception of who 'disabled people' are, is the risk that very many people would not consider themselves to be 'disabled'

> (Disability Rights Commission, 2007c: 7)

The boundaries between impairment and disability may be unclear but the origins of disability are argued to be more important. As Shakespeare and Watson (2001: 12) explain:

> Congenital impairments have different implications for self-identity than acquired impairments. Some impairments are static, others are episodic or degenerative. Some mainly affect appearance, others restrict functioning. All these differences have salient impacts at both the individual and psychological level, and at the social and structural level

Neglecting the personal limitations of living with impairment and the ensuing psycho-emotional consequences, as the social model arguably does, may perpetuate a division between 'the private' (interpersonal relationships, sexuality and family life) and 'the public' (employment, education, leisure). From a social model perspective, Finkelstein (2001: 2) points out:

> The agreed UPIAS interpretation was that, although it may be a tragedy to have an impairment, it is oppression that characterises the way our society is organised so that we are prevented from functioning. In other words, at the personal level we may talk about acquiring an impairment as a personal tragedy, but at the social level we should talk about the restrictions we face

It is therefore reasonable to suggest that this arguably prevents engagement with both the self and others' personal experiences, which is essential to understanding the differentiated social world (Thomas, 1999). Thomas (2004: 10) goes on to illustrate this point, arguing that on the 'inside':

> It is about being made to feel of lesser value, worthless, unattractive, or disgusting…about 'outside' matters: being turned down for a job through prejudice, or not being able to get one's wheelchair on a bus

Therefore, Shakespeare and Watson (2001: 27, *original emphasis*) argue that whilst there are commonalities among people with impairments, an important advancement would be recognition of the different aspects disability experience can bring "*we are all impaired*. Impairment is not the core component of disability (as the medical model might suggest), it is the inherent nature of humanity". This is

not, however, to trivialise impairment or its impact but to raise awareness of the extent to which individuals are affected by different suffering and bodily restrictions (Shakespeare, 2006).

The World Health Organisation (2002) argues that people with disabilities should be enabled to be active citizens working in partnership with others because anyone, at any time, can become disabled, develop a physical or psychological impairment. As Coleridge (1993: 6) points out:

> Disability is an issue that touches us all and can affect anybody of any background, in any country, at any time. It is 'all our' problem, not 'just their' problem

Decades ago, Finkelstein (1981: 1) in his short essay '*Disability and the Helper/Helped Relationship. An Historical View*', drew attention to what he argued was a long neglected area of study:

> …the historical origins of the relationship between disabled people and those, professional or lay, who may work with them in a helping role. [*Albeit*] For convenience the discussion is centred around the disablement of those who have physical impairments (excluding those with partial sight or deafness, as well as mentally handicapped and mentally ill people)

However, Shakespeare (2006) argues advocates of the social model of disability in their research practice: "Campbell and Oliver, 1996; Barnes and Mercer, 2003; Swain et al., 2003; Swain et al., 2004; Barnes and Mercer, 2004; Barnes et al., 2002" (pp.182-183) present a limited perspective by "ignoring the positive aspects" of social relations of disabled and non-disabled people (p.197). The focus

here, he argues, is usually on oppression and less on solidarity, partnership and alliance:

> I am convinced that many non-disabled people, most of the time, are accepting and supporting of disabled people. Where they fail adequately to respond, the problem is as likely to be ignorance and even fear as active hostility…A more realistic appraisal of the role of non-disabled people…is long overdue

> (Shakespeare, 2006: 197)

Moreover, research into social relations – isolation and friendship, and intimate relationships - has been limited to participants with learning difficulties and mental health issues. This, Shakespeare (2006: 176) argues, neglects how:

> Some impairments make social relations more difficult. Deaf people may rely on sign language for communication, which many hearing people are unfamiliar with, or may have limited confidence with. Deafened or hard of hearing people may become isolated as a result of difficulties of communicating with others

Sheldon (2007) claims the aforementioned critique of the social model is largely theoretical: "Rather than being firmly rooted in empirical evidence, much here is unsubstantiated" (p.212). However, empirical research evidence that critiques the social model can be argued to be emerging. For example, Watson et al. (1999) and Skar's (2003) research findings suggest that isolation is a major issue for young people with an impairment who experience great difficulty, for a variety of reasons, in developing social and support networks.

More recently, van de Ven et al's. (2005) research considers factors influencing successful social integration from the perspective of 11 people with either physical, sensory or communication difficulties, and two significant others within their close social environment, such as a partner, relative, friend or colleague, 19 were non-disabled and three disabled. Findings suggest that the interplay between the individual (attitude toward integration, strategies, roles), society (culture, rights, restriction) and social support (support workers, assistive devices) were 'key' factors in the social integration of disabled people.

On this note, although it is important to acknowledge that some support workers are themselves people with a disability (Boxall, 2007), Shakespeare (2006: 193) raise the important issue that analysis of their role, motivations, views and experience is long overdue:

> The increasingly important role of non-disabled people committed to the empowerment and inclusion of disabled people seems not to have received the attention it deserves. This constituency includes advocates and supporters of people with learning difficulties, those who are paid as personal assistants for disabled individuals, and perhaps also those who act as sign language interpreters or facilitate communication and inclusion in other ways

As part of the contextual background, the researcher's conceptual stance on the aforementioned issues is provided below.

2.6 The Researcher's Conceptual Stance

Conceptual frameworks surrounding disability arguably remain in a state of flux; there appears to be little prospect of an immediate resolution. Rather than being constrained by one model of disability, important elements from both models are taken and presented below. At this point, it should be recognised that the researcher shares a particular affinity with Shakespeare (2006) who rejects:

> …the strong social model approach to disability and attempts to construct an alternative which neither reduces disability to an individual medical problem, nor neglects the predicament of bodily limitations and difference (p.2)…but combines the best of both (p.55)

Shakespeare (2006) provides the means by which to progress beyond the medical/individual and social model dichotomy, particularly when British disability scholars are seen to conform to the social model because it is seen as the "right way", as opposed to the medical model "wrong way" (p.10).

The importance of the British social model is acknowledged here. It provides a step in the right direction towards ending oppression, discrimination and prejudice for people with disabilities, through environmental and attitudinal change. The removal of attitudinal and environmental barriers can facilitate participation and inclusion but it does not abolish disability entirely. Disabling barriers create difficulties on top of impairment, but even in the absence of barriers and following their removal, there is an emerging view that factors

intrinsic to the individual (type and severity of impairment) also create difficulties. Impairment limits experience and opportunities: "People with hearing impairments may miss out on the sounds of birds, wind and waves. It is hard to blame the natural environment" (Shakespeare, 2006: 45).

Thus, although sympathies lie within the social model of disability, the researcher cannot wholly be bound by it. Instead, the researcher is a critical consumer of both models. Medical intervention and treatment can have 'life changing' benefits for people with disabilities and so too can the abolition of social oppression. Therefore, doctors should continue to seek medical solutions for those who want them, whilst everyone should attempt to make society less disabling, both through their attitudes and actions.

Claims to-date regarding impairment effects are largely theoretical, rather than empirically based, and, as such, unsubstantiated. However, they are recognised here as an emerging issue in disability studies. Educational policy, practice and provision can alleviate social restrictions and make accommodations for individual impairment effects, such as pain and discomfort. Nevertheless, the focus of this thesis is the contribution of social support networks of students with SCD to their retention and progression. Consideration of the social relations between people with and without SCD, and the part ESWs play, are neglected in medical/individual and social

models; these are important elements of integration and are argued to be paramount in this thesis (see Ch.3, p.132).

Conceptualisation of the 'reality' of impairment and disability is complex. The dichotomy between British medical/individual and social models of disability, rather than being helpful, create tension between disability studies scholars by dictating how they should think, act and feel. Arguably, energy would best be spent on striving for a mutual goal; successful integration and inclusion for people with disabilities by promoting acceptance in all areas of social life and providing the supportive means for this to be realised.

2.7 Chapter One Summary

Three significant periods have been identified in the current formation of educational policy, practice and provision for students with a disability; the move from social and educational segregation, through integration toward inclusion provided positive experiences for people with SCD. Segregated institutions provided a safe haven from poverty and discrimination alongside opportunities to improve health and general well-being, and acquire self-help and educational skills (Borsay, 2005). Integration policy demanded reforms in rights to access local educational establishments for students with impairments (Warnock Report, 1978), whereas inclusion policy now moves towards improving teaching, learning and classroom

experiences for students with a disability in the integrated educational setting (Vislie, 2003).

However, throughout these periods it can be argued that the shift of power from medical and associated professionals to managers over perception and treatment of people with impairments may have merely served to transfer inequality from remedy to bureaucracy and the pursuit of economic efficiency. Medical and educational funding is currently in the hands of politicians who are guided by political policy; currently who gets what is not entirely based on medical-ethical principles with an emphasis on life-saving and enhancing procedures but driven by managerial judgment with an emphasis on minimising cost and maximising benefit (Riddell et al., 2007). Robson (2002: 116) argues:

> In an age of accountability, the quest is for 'evidence-based' everything: medicine, health care, social services, education…While the motivation may be financial, there is an ethical dimension. It is difficult to justify doing things with, to or for people if we do not know what their effects are…

The current move toward economic new-managerialism has made it necessary to allocate pre-defined academic resources on a one-size-fits-all basis categorised by disability, rather than to accommodate student perceived need (Priestley, 1999; Barnes and Mercer, 2006). Meeting pre-set categorically defined academic need alone may exacerbate inequality for students with SCD, who rely on third-person

mediation (provided by support workers) as a resource for effective interpretation of social communication.

It is argued throughout this thesis that the politically driven focus within new-managerialist practice evokes formal academic accountability, creating a climate within which vital informal 'personal aspects' of HE teaching and learning experience are neglected. This narrow focus is both to the detriment of students with SCDs' experience and the HE sector.

A review of the theoretical literature and empirical research findings concerning the importance of social support for the retention and progression of HE students with SCD now follows in chapter three.

Chapter Three – Literature Review

3.1 Preamble

The previous chapter presented the background to the present study. Three significant periods were argued to mark out the move towards inclusive education for students with SCD – segregation, integration and inclusion. It also presented the conceptual debate concerning impairment and disability. This current chapter presents a critical review of multi-disciplinary theoretical literature and empirical research concerning the importance of social support for the retention and progression of HE students. Also presented here are the aims and intended outcomes of the present study. This chapter thus builds upon the previous chapter looking at the current HE climate. It will argue that inclusion will not be complete until all aspects of student support are considered by HE institutions.

As such, this current chapter focuses on social support, the transition to university and the importance of student membership of the learning community. It draws on substantial bodies of multidisciplinary literature, educational and social psychological evidence, and the sociology of transitions (see George, 1993) to illustrate personal and social consequences of HE transition. In terms of student support, it is argued that the experience of HE is no longer exclusively one of interpersonal communication in lectures, tutorials, and third-person mediation through support workers, but now

includes wider communities of practice via 'new' communicative technologies, such as Virtual Learning Environments and the Internet. In an age in which social networking is significantly mediated by 'new' communicative technologies, these may prove to be a 'best fit' to achieving parity between students with and without disabilities in the social networking realm.

Formal academic support is situated within the backdrop of new-managerialist incentives under New Labour and the influence of the dominant ideology underpinning disability policy, practice and research. The role of ESWs is sketched out here in terms of their provision of formal academic support, before the usefulness of such support is evaluated. Issues around informal personal support provide the major critique of the predominance of formal academic support. This critique allows insight into the benefits of providing informal support alongside formal academic support, and brings to the fore the negative impact that limited support networks may have on students. The paucity of empirical research that includes the perspectives of students with a disability is also addressed here. A chapter summary integrates the main findings from this critical review of social support literature to the central aim of the present study. Finally, the research aims are stated here.

3.2 Social Support and the Transition to University

Social support can be argued to comprise supportive behaviour and resources provided by a person's social ties. This operates at two levels: individual and community. At the individual level, it provides an opportunity to draw on available resources from social ties, such as student peers. At the community level, interconnectedness or social embeddedness with others gives more opportunity to exchange support and resources, such as knowledge and information. This can include practical and/or emotional support through intimacy and companionship (House, 1981). Conversely, the loss of such social support is a source of unhappiness, and distress (Bronfenbrenner, 1974).

University education may be regarded as a positive experience that provides opportunities for academic, personal and social development. However, transition to university can present students with personal difficulties that are, for some, resolvable and yet for others insurmountable (Heiman, 2006). Well-established social support provided by family and familiar friends may be disrupted by this transition, leaving some students struggling to adjust (Wilcox et al., 2005). Lowe and Cook's (2003) research was based on a survey with 2519 first year undergraduates at the University of Ulster and suggested most students successfully manage the transition to university without any academic problems (course-related), social

and personal problems (homesickness and family support), and practical difficulties (financial difficulties and other commitments). However, Lowe and Cook note that a considerable minority of 20-30% consistently experienced academic, social and personal difficulties during the transition period to university that were related to homesickness, the degree of family support and level of student confidence. This, they argue, can have a detrimental effect on academic performance, and student personal and social development, which can manifest in dropout and under-achievement.

Little empirical evidence is available about the experience of students with a disability in this transition period. One exception here is Goode (2007), who interviewed 20 students with various impairments and disabilities (visual/hearing impairments, cerebral palsy, dyslexia and physical impairments) to explore their early university experiences. Findings here suggest that: "Disabled students may have more complex sets of social relations to negotiate as part of this process than others" (p.41). Moreover, Goode's (2007) evidence suggests that students with a disability acknowledged problems relating to academic, personal and social issues within the university environment. These academic, personal and social issues included difficulties with disclosure of disability, in accessing learning and teaching, 'fitting in', feeling included and gaining independence from family.

However, not all students are able to gain independence from their family. Parker (1999) studied personal support through interviews with six university students with disabilities. Findings here suggest that these students were more likely than those without disabilities to rely on the support of family, rather than paid professionals, for personal care, assistance at university, travel and finance. Whilst it was argued that family members were often more "flexible, comforting, supportive, and cheaper" than professional assistance, this was considered [*by the students*] inappropriate as those providing this support may feel "obliged" to do so (p.493). Yet, the author did not establish the possible effects this could have on the students. Similar results were reported by Richmond and Ross (2008) from interviews with 26 individuals. These authors argue that although social ties can buffer against health problems and the bulk of evidence emphasises the health-enhancing effect of social support, "…certain aspects can have negative consequences for health (e.g. social obligations)" (p.1).

Reliance on family could have both a negative and positive impact on levels of student independence. Literature on positive social support often makes a distinction between types of support with little agreement on what aspects are most relevant. Nevertheless, social support can impact on students' sense of belongingness, peer relationships, and membership of the learning community. These three things are important to students' social support networks and, as such, are discussed in more detail below.

3.3 Students' Sense of Belongingness

Typically, students can and do construct new social support networks for themselves that provide practical help with academic tasks, appreciation of opinions (Hobfoll, 1998), emotional support and social companionship (Walker et al., 1994) that allow them to feel cared about and understood (McKinney, 2002). Those who provide social support are vital in this transition and beyond (Agneessens et al., 2006).

Strong social support networks "keep us emotionally stable and help us see where we stand *vis-à-vis* other people and whether we are doing OK" (Duck, 1991: 15) and are thus argued to have a direct and significant impact upon the academic experience and achievement of students:

> People exchange emotional and material aid, information and companionship. Although these forms sometimes flow in only one direction, exchanges can reciprocate between two persons or more indirectly through a larger network. Such exchanges are key to obtaining *network capital*: social capital that is embedded in interpersonal relations that can provide custom-tailored helpful resources that are flexible, efficient and effective
>
> (Plickert et al., 2007: 406, *original emphasis*)

There is a growing body of international evidence that shows how social support can have a positive impact upon student self-identity (Paulson and Everall, 2001), self-esteem (Lev-Wiesel et al., 2006), membership of the learning community (Antia et al., 2002; Dawson,

2006) and sense of belongingness, "the degree to which they feel secure, accepted, included, valued and respected by a defined group" (Levett-Jones and Lathlean, 2007: 2). A lack of a sense of belonging may diminish student self-esteem (Goodenow, 2006), increase stress, anxiety (Saenz et al., 1999) and depression (Sargent et al., 2002).

Levett-Jones and Lathlean (2007) report on findings from a mixed methods study that explored students' positive experience of belongingness. These authors argue that as a consequence of belongingness students feel more empowered and enabled to capitalise on the available learning opportunities when they have a legitimate place in the environment, and are often more self-directed and independent. Similarly, Martin and Dowson (2009), in their review of educational research, argue that when students' need for belonging is fulfilled, this fulfilment produces positive emotional responses. These emotions are said to raise student achievement, self-regulation and participation. A complimentary perspective is provided by self-determination theory (Patrick et al., 2007), which posits three basic psychological needs for optimal well-being; autonomy (feeling un-coerced in one's actions), competence (feeling capable) and relatedness (feeling connected and a sense of belonging with others).

Social support networks are thus argued here to be an asset that enhances student well-being by allowing individuals and groups to co-operate with other members of the HE community to achieve individual and collective goals (Kuehnast, 2004).

It is argued here that there is a good balance of approaches to research in this area; quantitative, qualitative, mixed methods and literature reviews. As demonstrated below, this provides a broad spectrum of understandings and allows synthesis of various issues of student social support. For example, quantitative studies, such as Lowe and Cook's (2003) survey techniques, measure the extent and significance of students' agreement regarding a range of issues related to social support, such as reasons for coming to university, opinions of the campus environment and teaching practice. Furthermore, an extensive body of research focuses on social network analysis (see Scott, 2000; Wasserman and Faust, 1994) to explore relational data from a range of sources including surveys, documents, interviews or participant observation, which utilises sociograms (visual maps in which nodes represent individuals or organisations and the connections between them) to reveal closeness, strengths, weaknesses and amount of social ties such as friendships, community and kinship (Granovetter, 1973).

Complimentary qualitative work reveals that strong social support networks are based on wider concerns imbued with personal meaning, such as establishing reciprocal trust and sharing, making compatible friends and having living arrangements, meeting spaces and campus locality conducive to their establishment and maintenance (Steele et al., 2005; Wilcox et al., 2005).

The existing literature shows that qualitative methods, notably semi-structured interviews, in the area of student social support networks have been particularly applied to nursing studies (Levett-Jones and Lathlean, 2007). Stanley (2003) used unstructured interviews and found that social support networks reduced student nurse anxiety and motivated students to continue when faced with academic difficulties. Similarly, Steele et al. (2005) revealed social support networks were based upon trust and sharing - and that there is a need for HE institutions to pay more attention to the social needs of students "to minimise problems and increase retention rates" (p.573).

The positive contribution of social support networks, however, goes beyond the personal and students' sense of belongingness, affecting academic performance. Korinek et al. (1999), Peat et al. (2000) and O'Connell (2005) have begun to explore the links between social support networks and academic performance. Their work suggests that strong social support networks are central in the transition to university, retention and progression, because of their potential to impact upon both formal and informal aspects of student academic

experience. Peat et al., (2000) for example, describe both qualitative and quantitative analyses of an annual student one-day workshop developed to facilitate academic and social peer networks during the transition period. The qualitative evaluation found that the workshop facilitated the establishment of strong peer relationships and increased students' sense of belongingness, and this, in turn, enhanced study, self-motivation and general enjoyment of university life. Quantitative analyses found that, in comparison to participants, non-attendees were significantly more likely to feel isolated or depressed, and had greater difficulty in adapting to university life.

More recently, in an extensive review of literature concerning the role of students' interpersonal relationships, Martin and Dowson (2009) conclude that "high-quality interpersonal relationships in students' lives contribute to their academic motivation, engagement, and achievement" (p.351). Students engaged in strong social support networks clearly benefit academically and socially from their experiences.

It appears that there is substantial evidence that inclusion for students with SCD demands support for both formal academic and informal personal aspects of HE, such as peer mediation.

3.3.1 The Importance of Peer Support

Positively supported students have strong (Putnam, 2000) and numerous (Elias, 2006) connections with others. Altman (1988) suggests that friendships can more than compensate for family separation. In a study that surveyed students' opinions of the effects of friendship networks on depressive symptoms, Ueno (2005) gave support for the argument that integration positively contributes to mental health by strengthening a sense of belonging.

Allan (2001), Pahl and Pevalin (2005), and Sullivan (1998) [*in the university context*], assert that peer relations become more important than family for students' sense of belongingness. Support provided within peer friendships, as voluntary relationships, encompasses values of choice and equality, which they argue may be more genuine and supportive than the obligatory nature of familial relationships. Taylor (1996) interviewed six students with D/HI to explore their experiences of university and suggested that generally, practical support from student peers was an everyday occurrence. However, it could be "patchy as collection of hand-outs, general classroom orientation, and informal note-taking were all offered to different degrees" (p.66). Nevertheless, peer support was argued to be beneficial because it encouraged friendships between students with and without disabilities, increased a sense of belongingness and raised student confidence.

Taylor and Palfreman-Kay's (2000) research findings from interviews with deaf and dyslexic students further support the argument that developing good relationships between disabled and non-disabled student peers are central to the sense of belonging whilst attending university. Moreover, the development of peer support networks (Garrison-Harrell and Kamps, 1997; Kamps et al., 1997) and peer support training (McGee et al., 1992; Morrison et al., 2001) have been identified as beneficial for the successful academic and social integration of students with ASD (see chapter one for definitions). Through peer support, students can capitalise on the empathy that is derived from shared experiences but it has its drawbacks; peers are limited in the extent of their support experience and training for students with disabilities (Chelser and Chelser, 2002; McCauley and Van Velsor, 2004). This highlights the need for ESWs to provide such support.

3.3.2 Membership of the Learning Community

Weiner and Wiener (1996) suggest that social support is an important advantage for students that provides "an opportunity to problem solve, learn more about the university environment, form relationships, and not feel so socially isolated" (p.6). In part, this addresses the notion of a 'community of practice' within which students are located:

> ...membership in a community of practice involves participation in an activity system in which participants share understandings concerning what they are doing and what this means in their lives and for their communities
>
> (Lave and Wenger, 1991: 98)

This is akin to the notions of dialogic engagement (conversation), which can seek to resolve contradictions by developing critical thinking skills (Fink, 2003) and the theory of collective intelligence, empowerment through development and pooling of intelligence to attain a common purpose (see Brown and Lauder, 2000). "This notion of dialogue and contradiction underpins understanding of critical intelligence and expansive learning" (Avis et al., 2002: 31); for example, the formation of a community of students who meet to resolve a shared assignment directive or attain a common goal. Students may plan essays, research a topic area together or share resources. Avis et al. (2002) further argue that "the importance of peer relations and dialogue anticipates the acquisition and formation of collective intelligence" (p.34).

Higher education is thus a community of learners, with a focus on the development of the intellectual and personal growth of community members (Zellers et al., 2008). Research focussing on educational communities of practice suggests that communication frequency (Wood and Smith, 2005) and learner-to-learner discussion (Palloff and Pratt, 1999) are necessary to create and sustain a learning community. Indeed, Habermas's (1984; 1987) theory of communicative action posits that although communication can be

constrained by the environment, such as physical distance between people, people actively adapt their communicative media in order to continue to develop both intellectually and personally.

To summarise briefly, in contrast to New Labour initiatives that encourage autonomy and independence (see Ch.2, p.59), people do learn in relation to others, interdependently, not as discrete units. Students cannot simultaneously be both individual learners and a community of learners as these are incompatible positions; individualism rests upon notions of social disconnection, community rests upon notions of social connection. Initiatives that encourage self-governance and competitiveness are thus argued here to send mixed messages to students, because they are expected to be both independent and work co-operatively, for example, in group work sessions and will readily adapt communication media to allow them to do so. As such, in contemporary society communication has now developed into the realm of 'new' technologies. Alternative forms of communication are argued to provide more opportunities for creating and sustaining social support networks, which now extend in-person interaction into the realm of 'virtual communities of practice', as set out below.

3.4 Social Support Networks and 'New' Communicative Technology

According to Germonprez and Zigurs (2009), communication is the "essence of organisations, and technology is part and parcel of that communication" (p.41). They argue that university students represent "the new generation of technology users who are likely to be adept at tailoring [*modifying computer applications during the context of use*], given that they have grown up with blogging, cell phones, and social networking" (p.43). Online technologies have thus evolved into a central and essential resource for HE (Dawson, 2006). Internationally, numerous authors have noted the general benefits of this use of 'new' communicative technologies for developing a sense of community in the learning environment (see for example, Palloff and Pratt, 1999 in the USA context; Brook and Oliver, 2003 in the Australasian context; Rafaeli et al., 2004 in the Israeli context). More contemporary sources specifically related to student social support networks are presented below.

3.4.1 Benefits and Opportunities of 'New' Communicative Technology for Membership in the Learning Community

With the current rise in the use of 'new' communicative technologies peer support is often provided via Internet-based social networking sites, such as Facebook (see Steinfield et al., 2008), mobile

telephone text messaging[8], email, online discussion forums through university Virtual Learning Environments (VLE) and Instant Messaging[9].

Churchill et al. (2009) conducted a study with students at the University of Hong Kong and argued that social networking technologies "have the capacity to engage enormous numbers of ordinary people in networking, sharing, and working with digital resources" (p.1). Results from this study indicate that online social networking features allow students to manage lists of student peers at the University with similar interests, communicate and share resources with these student peers about specific topics and track activities (both students and tutors) relative to course learning outcomes. Arguably, this allows students to engage in 'communities of practice' (Dawson, 2006; 2008; Gooding et al. 2007).

So and Brush (2008), in the USA context, claim that blending communicative technologies with face-to-face communication "may provide students with more opportunities to interact with learning contents, peers, and instructors" (p.332). However, in the United Kingdom (UK) context, privacy and data protection issues (providing names and email addresses), can and does deter HE students from

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[8] According to a study undertaken by Markett et al. (2006), 80% of HE students send a text message every day.
[9] Combines telephone and email facilities to provide instant textual communication (see Hinchcliffe and Gavin, 2008; 2009; Hinchcliffe, 2009).

partaking of online learning activities (Rosenblum, 2007), in comparison with personal social networking usage (Cole, 2009).

In the UK, Jones et al. (2009) explored experiences of online social networking at four universities through 76 student survey responses and 14 student follow-up interviews. Findings here suggest there are two primary benefits and opportunities brought about by social software; they create a community of inquiry that encourages co-operative learning and fosters independent learning for better employability prospects.

Harley et al. (2007) report from their analysis of 30 interviews undertaken with UK university students that mobile text messaging is the dominant mode of electronic communication amongst students and plays a central role in maintaining their social networks. Text messaging between students provides academic, social and emotional peer support; it provides:

> …an informal system of interdependent learning in relation to navigating unfamiliar academic and administrative systems…and aids students' social integration into university life
> (Harley et al., 2007: 229)

Further, contemporary research evidence from the UK suggests that communicative technologies can enhance existing peer support and facilitate additional support between students and university staff. For example, Stone's (2004) research findings from an email questionnaire indicate the usefulness of mobile telephone text

messaging to inform students of changes to timetabled lectures, seminars and workshops, remind them of imminent deadlines and advise them to visit the University's VLE for assignment help. More recently, Brett's (2008) evaluation project investigated mobile telephone text messaging to enhance learning and support activities at university. Participants included 27 staff and 938 students, with 11,522 texts sent. Conclusions suggest that although further investigation of usage is needed, universities and their students will benefit from institution-wide use of communication via mobile text messaging for learning and teaching activity - specifically, one-way staff–learner communication, formative assessment with feedback and as a collaborative learning discursive tool. Similarly, Jones and Edward's (2009) survey results indicate that mobile telephone text was useful for supporting student transition to university and facilitating improvements in their time management and engagement with academic activity.

According to Hinchcliffe and Gavin's (2008) interview findings, communicative technologies such as mobile telephone text and Instant Messenger provide university students with the possibility to stay in contact with peers and provide academic, social and emotional support, even though they are separated physically in time and space. However, these technologies are not simply a substitute to overcome or compensate for absence of face-to-face interaction, but constitute an additional resource of connected presence, which can help sustain social ties. In particular, Hinchcliffe and Gavin

(2009: 331) found research evidence that due to temporal-spatial separation associated with differing student timetables and increased heavy workloads:

> …final year students' use mediated technology as their preferred choice of communication to bridge time-space separations. IM [*Instant Messenger*] is an integral part of university life

Moreover, communicative technologies may be a 'best fit' to achieving parity between disabled and non-disabled peers in the social networking realm (see Ch.4, p.182 and Ch.6, p.267). They are a useful means for people with SCD to communicate as they "can thrive on the Internet and exchange much needed support without having to engage in the face-to-face contact that sometimes exhausts them" (O'Neil, 2008: 792).

To summarise, 'new' communicative technologies show promise as additional platforms for student social networking, not only for administrative purposes, but academic teaching and membership of the learning community through student social integration, sharing of resources and intelligence. These types of exchanges have been argued to increase network capital, "social capital that is embedded in interpersonal relations that can provide custom-tailored helpful resources" (Plickert et al., 2007: 406). As such, because of the large number of students utilising 'new' communicative technology (Markett et al., 2006; Harley, 2007; Churchill, 2009), it should at least be an avenue explored for its potential to widen research

participation generally, and specifically for those who find face-to-face interaction difficult, such as those individuals with SCD (O'Neil, 2008; Hinchcliffe, 2009, see also the present thesis, Ch.4, p.182 and Ch.6, p.267).

3.5 Formal Academic Support

For one group within the student population at university, the formation of social support networks may be problematic. Academic needs of students with a disability have become the focus of considerable research informing legislation, policy and practice (see Gorard et al., 2006). For example, the academic needs of students with dyslexia (see British Dyslexia Association, 2009) and learning difficulties (see Heiman, 2006) have been extensively researched.

Within the present new-managerialist climate, the New Labour government (1997 – present, as detailed in Ch.2, p.59 of the present study) currently asserts that social justice will be achieved by reducing exclusion through education and subsequent employment (Armitage et al., 2003). Thus, UK policy instituted a system of evidence-based accountability for the formal academic needs of students with a disability.

The present new-managerialist climate under New Labour encourages students to take responsibility for their academic needs as informed consumers who 'cherry pick' their way through educational opportunities (see Rose, 1999). The role of professionals in HE institutions is seen as empowering them to do so. This is based on a notion of empowerment as individualised. Students control their own learning; teachers provide useful experiences:

> Each adult learner will take away from any learning situation what they require; learning is unique to each learner and uncertain
>
> (Rogers, 2002: 97)

At first glance, this appears to constitute a positive step toward reducing social exclusion through access to education and thus increasing opportunities for labour market participation. This ideology suggests students are in control, but in practice this is not so, and especially for students with disabilities (see Archer, 1990).

A critical point here is the extent to which people with a disability feel that their 'voices' are heard and, in turn, how this may impact on their access to 'rights'. Increasingly, political influence through legislation such as the DED (2006 see Disability Rights Commission, 2007b), is reconstructing people with disabilities as agents alongside the non-disabled – recognising them as capable of rational thinking and forming their own interpretations and views on how they should be treated, medically and socially. Prioritising the voices of people with a disability may empower them to have some agency in their lives and

shed images of dependency and passivity. This may prevent them positioning themselves as solely subject to the influence of 'expert' knowledge through associated professional decisions.

Nevertheless, there is a legal requirement to provide resources and services and most HE institutions now have a disability service that liaises with academic Departments on appropriate formal academic support to meet the needs of student with a disability. Students must self-disclose impairments and disability, and provide medical documentation to be eligible for disability support. This approach to student disability services assumes that environments should be adapted and accommodations provided. Accommodations can include assignment/exam extensions and reasonable adjustments in the form of the provision of ESWs who can carry out various support duties, for example, note-taking, mentoring, campus support, British Sign Language interpretation and exam amanuensis.

Parker (1999) found evidence from six student interviews that the role of ESWs could influence the relationship between students with and without disabilities. Indeed, students without disabilities viewed the ESW and student with a disability as a 'pair' and not as individuals. Yet, there appears to be a distinct paucity of empirical research in the literature that gathers the views of ESWs about the support they provide and the impact on students. This scarcity may indicate something about the limits of ESW support, and, as such, suggests the need for further investigation.

Furthermore, Weiner and Wiener (1996: 3) stress caution on the subject of formal academic provision:

> Although some of these needs are common to disability groups in general (e.g., extensions on assignments, adaptations of modes of learning), each disability group may exhibit unique needs depending upon the nature and severity of the disability. Furthermore, within any given disability group there are individual differences among students with regards to their needs and concerns

To summarise, although there is a distinct paucity of research on ESW perspectives, a plethora of research has been dedicated to the formal academic needs of HE students in pursuit of improvements in achievement (McLean, 2001), retention and progression (Christie, 2004; Raab and Adam, 2005). Concerns about the formal academic needs of students with physical, sensory and learning disabilities such as dyslexia (see Skinner, 2006), expressed in mandatory legislation and HE institutional policy (HEFCE, 2006), has lead to routine needs assessment.

The new-managerialist climate (see Riddell et al., 2007) within contemporary HE has created an environment in which the focus is almost exclusively on formal academic need to the neglect of social need. This present climate is thus one that promotes individual empowerment yet institutions can constrain this. Support is based on formal academic need which, in turn, is based on New Labour notions of independence that underplay the importance of wider social networks.

Thus, universities make provision for accessible formal academic support through accommodations and guidance to meet the needs of students with a disability. In the HE context, research has provided evidence of the usefulness of formal academic support for 'levelling the academic playing field', as set below.

3.5.1 Levelling the Academic Playing Field

Cremer (1991) reported on a survey of 125 deaf/hearing impaired HE students. Findings suggested that 99% of respondents thought that formal academic support services were vital to their studies. Sixty-nine percent identified note-takers as most important to their academic achievement, followed closely by tutors (59%) and then interpreters (34%).

Similarly, Bertocci et al. (1992) surveyed a large number of students with a disability focusing on perceived barriers to learning, help-seeking behaviours and the use of disability support services. Evidence suggested that student anxieties, phobias and panic attacks were associated with academic-related concerns, such as needing to improve their concentration, assignment completion and time management skills.

More recently, Weiner and Wiener (1996) surveyed, then conducted follow-up interviews, with 24 students with a disability to gather their experiences of formal academic support and the usefulness of accommodations. Five areas of concern were identified: problems with focusing attention and organisation, low self-esteem, problems with trust, stigma and high levels of stress. However, reduction in course load, provision of skills workshops, academic related advice, and administrative assistance with admissions were seen as essential in the retention of students with a disability. Likewise, Stanley and Manthorpe (2002) provided research evidence for the effectiveness of formal academic support for course progression and completion of students with disabilities. Assignment extensions, exam re-sits, flexible credit requirements and supportive tutors were all beneficial. Most student participants had already graduated, or were expected to graduate.

Student formal academic support is clearly important. However, accommodations can lead to social isolation for some students with a disability. Using a mixed-methods approach, Kurth and Mellard (2006) studied perceptions of the accommodation process from students with a disability in HE institutions. Survey findings from 108 students suggested that 27% of student participants did not find their exam accommodations to be effective. In follow-up interviews with 104 participants, one student in particular explained one reason for this was because his sense of 'belonging' in the university community was disrupted due to his exams organised in a separate location

from his peers. Most importantly, students indicated that they wanted to feel accepted, to belong in the university setting. Therefore, although accommodations provided to students may meet the legislative requirements and 'level the academic playing field', they do not always provide an inclusive environment.

Moreover, Weiner (1999) found survey evidence that indicated barriers to course progression and completion for students with a disability were not merely associated with academic issues but also medical and social ones. Academic issues of task completion and pressures of deadlines were of major concern. However, students expressed that the unpredictable nature of disability greatly influenced academic attainment. Social issues, such as making friends, were related to how well students were able to integrate into the learning environment. Consequently, it was argued that there was a need for more flexibility from HE institutions in their policy, practice and provision of student disability support.

Stewart-Brown et al. (2000), Grant (2002) and Avramidis and Skidmore (2004) concur in their conclusions from survey results that HE institutions should take a more holistic approach to identify issues that could impact on student well-being. All students, regardless of (dis)ability, when adjusting to university life can experience difficulties other than academic ones; such as making friends, dealing with housing and finances, and in most cases, finding part-time employment, all of which can have a negative impact on student well-

being. Nevertheless, academic-related concerns of managing and completing coursework, overcoming exam fears and dealing with future career concerns were more frequently reported by students with, as opposed to those without, a disability.

The research noted above has offered valuable insight into the importance of formal academic support, demonstrating that students' with disabilities experiences were not isolated incidents. However, the aforementioned research has been predominantly quantitative, based on standardised self-report inventories (Lev-Wiesel et al., 2006) that measure perceived academic support from closed questions, fixed-choice answers and Likert-type scales (see Procidano and Heller, 1983).

Such highly structured quantitative designs leave little scope for unexpected issues that may arise, obscuring vital aspects of subjective understanding (Potter, 2000). Quantitative self-report measures can be restrictive, as the categories under investigation are defined and structured by a subsequently 'absent' researcher. Knox et al. (2006) along with Case and Marshall (2008) criticise the quantitative analysis of social support networks for their focus on individualistic attributes that appear to "erase all social connection", and reduce social support networks to nothing more than "mere representational tropes" (p.116), rather than recognising their embeddedness in a particular social, cultural, temporal and spatial context:

> Context does not determine experience or set the course of action, but it does identify the sets of conditions in which problems and/or situations arise and to which persons respond through some form of action/interaction and emotion (process), and in doing so it brings about consequences that in turn might go back to impact upon conditions

> (Corbin and Strauss, 2008: 208)

To remedy the relative paucity of qualitative analysis of student support in the literature, Wilcox et al. (2005) have begun the exploration of HE retention by investigating the processes through which student social support networks influenced decisions to remain at, or leave university. Analysis of interviews with first year undergraduate students revealed that making compatible friends is essential to retention, and that student living arrangements, meeting spaces and campus locality are central to this process. Positive student social support networks provide emotional support to facilitate the transition from home/college to university, and also 'level the academic playing field' through informative and evaluative support with academic course work, which raises personal confidence within the academic environment.

Wilcox et al. (2005) have made an important first step by providing insight into the crucial importance of wider HE student social support networks for university retention. However, their research is limited to first year non-disabled student experience undertaken through face-to-face and telephone interviews concerning transition to university (from home/college) rather than continuity from one academic year to

another. Hinchcliffe and Gavin (2009) extended this, using online interviewing techniques to explore students' social support throughout their time at university, both with students with and without disabilities. These important new understandings indicate that a qualitative approach to this area of study may enhance understandings (see the present study, Ch.4, p.153).

To summarise briefly, under new-managerialism, which encourages evidence-based accountability, much quantitative research and resource has been dedicated to the formal academic needs of university students, in search of improvements in achievement (McLean, 2001), retention and progression (Christie, 2004; Raab and Adam, 2005). This has created a climate in which the focus is almost exclusively on formal academic need, yet consideration of purely formal academic need alone may be insufficient to ensure that students fully benefit from their education. As such, it may be indicative of a system in danger of becoming increasingly unresponsive to 'real' student need. The forthcoming section, largely based upon qualitative research, suggests that HE institutions may not be retaining this group of students because of the under development of wider social support networks.

3.6 Informal Personal Support

The introduction of guidance and support for students with a disability has proven problematic. Indeed, some would argue that issues such as retention and progression remain intractable (Sellers and van der Velden, 2003) and "solutions few and far between" (Lang, 2002: 268). This raises the question of whether or not the root cause of this difficulty may be strictly academic. Instead, it may be that students with a disability face greater challenges than their non-disabled peers in establishing positive support networks (Pescosolido, 2001), and maintaining peer friendships (O'Connell, 2005). Indeed, Hirst and Baldwin's (1994) research evidence goes so far as to suggest that almost 30% of non-disabled, compared to 50% of people with a disability, felt anxious when meeting new people, which could affect their levels of self-confidence and feelings of self-worth.

One example of this issue is students with SCD, who for the purpose of the present study include students with D/HI and ASD who often rely on mediation for effective interpretation of social interaction in the wider university context. This distinctive group has much in common with those without SCD; they share basic human needs for education, friendship, self-identity, self-esteem and membership in a community (Gaustad, 1999). However, they often cannot access typical channels of communication and thus have limited opportunity to meet peers in the wider university context available to other students. Mollenhorst et al. (2008: 61) surveyed 1007 individuals to

examine the effect of social context on personal relationships. Evidence here suggests that meeting opportunities have a strong effect on the social composition of an individual's personal network:

> Social contexts, like meeting places and institutional arrangements, delimit 'the pool' from which people can choose their friends, a partner, and acquaintances

Instead, there is a growing body of literature, predominantly from qualitative research, that suggests students with SCD do not feel as much a part of the 'university family' as do their peers (Foster et al., 1999), with feelings of isolation, loneliness and resentment being critical in the first year of study (Kersting, 1997). University students with SCD are often prone to isolation because of difficulties with social communication.

Blamires and Gee (2002), through a HEFCE funded project over a two-year period, explored the support needs of HE students with SCD. They gathered information and best practice through workshops undertaken in universities and colleges across the UK and emphasised that for these students:

> The greatest difficulty was creating social networks. Many students use this to share difficulties and this might not be open to this group of students. There is a limit and staff did not want to intervene as it was seen as off limits
>
> (Blamires and Gee, 2002: 20)

Whilst these findings differ somewhat from the results reported by Walker et al. (2008), where buddy schemes in the Australian context were informal, characterised by poor preparation, short-term interaction and lack of professional recognition, they do suggest the most useful support was a 'buddy/mentor' scheme. This was identified by 92% of disability advisors.

The buddy/mentor scheme involved having someone as a contact point that the student could meet with on a regular basis to discuss difficulties that may be arising both academically and socially. One disability advisor in Blamires and Gee's (2002: 17) study commented:

> We found it most helpful for students to have "mentors" who assist them in understanding what is required academically as well as in other aspects of University life, as well as facilitating better communication with the student. For the two students we have very successfully supported, a pair of mentors was used. One mentor was a post graduate, within the students department who, liaised with members of teaching staff, personal tutor etc to ensure the student understood what was expected of him/her, stayed focused on the needed work and was aware of what action they needed to take. The other support worker supported the students on aspects of student life i.e. how to make friends, how to approach tutors or other academic staff for help

Ragins and Cotton (1999) in the American context recommend that institutions use "formal mentoring relationships as a springboard for the development of informal relationships" (p.546). However, more recently McGowan et al. (2009), like Blamires and Gee (2002) in the UK context, distinguish between formal academic and informal personal mentoring. They argue that whilst both formal academic and

informal personal mentoring approaches can provide skills and encouragement at points of specific need to empower the vulnerable and/or disadvantaged, it remains more problematic where there are deep-seated difficulties in social, communication and organisational skills such as negotiation. According to these authors, the challenge in formal institutional settings is to:

> …promote and preserve the person-centred quality of the attachment relationship by ensuring that it enhances the experience of the recipient and does not become subservient to and displaced by organisationally driven bureaucratic processes and agendas
>
> (McGowan et al., 2009: 628)

The notion of dual (formal academic and informal personal) mentoring can encourage individuals to draw upon a range of people, such as a network of mentors for specific reasons:

> One mentor is no longer adequate to meet the full complement of another's technical and personal needs in the context of modern society. Dynamic organisational change, increased specialisation, and innovation, and the acceleration of technological advances prescribe a new mentoring paradigm in which mentoring relationships are pluralistic and reciprocal
>
> (Zellers et al., 2008: 563)

Taken together, the aforementioned qualitative research provides a positive step towards understanding the support needs of university students with SCD because it broadens understandings of student support by embedding it within social, cultural and contextual meanings. However, these studies were largely conducted with non-

disabled university staff and/or parent-carers. There was very little input from students with a disability themselves:

> Instead of ignoring or silencing them it is time to lend them our ears. Who better to ask, after all, about what ASD really is than someone who lives with it every day

> (O'Neil, 2008: 787)

Therefore, it is argued here that to fully understand the informal support needs of students with SCD, priority should be given to the views of participants with disabilities because for too long their 'voices' have been ignored and silenced, their needs, wishes and desires denied.

O'Connell (2005), and more recently Müller et al. (2008), note the absence of 'voices' of people with disabilities in current research. They each sought to remedy this by interviewing participants with SCD to gain their views about their social experiences. Müller et al. (2008) for example, asked 18 participants to recommend effective social supports and strategies for improving social connectedness. These recommendations included external supports (activities based on shared interests, highly structured activities and small groups), communication supports (alternative modes of communication, such as Internet-based social networking sites), and self-initiated strategies for handling anxiety (physical activity, spiritual practice and time alone). Findings indicated that whilst these people experienced serious social challenges – isolation and problems with communication, they longed for intimacy, social connectedness and

had desires to make a contribution to the well-being of others (at both individual and community levels).

Moreover, Eby and Allen (2002) argue that the literature's almost exclusive focus on the positive aspects of mentoring overshadows the negative. The negative aspects may include distancing and manipulative behaviour through deceptiveness, neglect and abuse of power and incompatibility on interpersonal levels, such as clashes of personalities and likes/dislikes. Darwin (2000) goes further, asserting that mentoring is an autocratic system for handing down knowledge, bestowing power, maintaining the dominant culture, and protecting the status quo. Whereas, Murray (2001) argues that having a mentor implies helplessness and can thus create social stigma. Within the present new-managerialist climate that values independence and autonomy, exposing deficiencies or weaknesses in the context of a mentoring relationship could impede, rather than facilitate, social networks.

In addition, Lang (2002: 270) suggests other aspects, such as access, time and availability of published research documentation can also impact on the establishment of positive social support networks:

With access/support services comes, for some students, the stigma of being different and, in many colleges and universities, the need to expend valuable time and energy in arranging the appropriate logistics (scheduling of support, covering costs etc.). Despite the use of such services by thousands of students in higher education, there is sparse published research to guide those interested in providing such support

To summarise briefly, informal student support networks are at least equally important as formal and to date, along with the distinct absence of student 'voices', given little emphasis in HE research. It seems paradoxical, then, that formal academic support is reified in social support theory and research practice, but this has been suggested to be largely a consequence of new-managerialist incentives. These incentives have been argued to reinforce dependency on the power and administrations of 'expert' professionals who define the boundaries of student educational experience and support practice. Education is managed and packaged in such an individualised way; it is beginning to become apparent that for social networks to operate efficiently, formal academic and informal personal support cannot be disaggregated as this may contribute to limited support networks and the social isolation of students with a disability.

3.6.1 Counting the Costs of Limited Support Networks

Hirst and Baldwin (1994), and more recently Martin and Dowson (2009), argue that extracurricular activities outside of academic studies are an important part of student experience at university. The former's research evidence indicated that students with a disability were less likely to visit friends, go for a drink, go to a nightclub or take part in sport activities. Social events, such as people getting together for picnics, celebrations and dances to relax and have fun are important forms of positive social support that can prevent social isolation (Richmond and Ross, 2008), and can increase a sense of belonging in the academic community (Griffen, 1997; O'Connell, 2005). Research suggests that student participation with student peers increases the chance of academic success (Lang et al., 1998; Dowaliby and Lang, 1999). Tinto's (1987: 53) research findings into student attrition indicated that social aspects of university, particularly difficulties integrating into the HE environment, were a major factor in course withdrawal for students with SCD:

> Rather than mirroring academic difficulties, they reflect the character of the individual's social and intellectual experiences within the institution following entry. Specifically, they mirror the degree to which those experiences serve to integrate individuals into the social and intellectual life of the institution. Generally, the more integrative those experiences are, that is, the more they are seen as satisfying and leading to integration into the life of the college, the more likely are individuals to persists until degree completion. Conversely, the less integrative they are, the more likely are individuals to withdraw voluntarily prior to degree completion

In a literature review, Stinson and Walter (1992) conclude that social isolation is a major reason for non-completion of university courses for students with SCD, who often rely heavily on the mediation of communication and social interaction provided by ESWs. When ESWs provided mediation of communication and social interaction for extracurricular activities, students were more likely to participate (Stinson and Whitmore, 1992 in the UK context and Kluwin and Stinson, 1993; Stinson and Kluwin, 1996 in the USA context). Their role in the promotion of broader social support networks may have a direct impact upon academic experience and achievement of students with SCD (Larose et al., 2005; Mesibov et al., 2005). Establishing social support networks remains a critical factor in the retention and progression of university students with SCD (Dagel and Dowaliby, 1989; Mesibov et al., 2005), and this is encumbered by the exclusive focus upon meeting academic need.

A small but growing body of qualitative research (see for example, Putnam, 2000; Blamires and Gee, 2002; Elias, 2006) indicates that students' academic, social and personal issues feature significantly in student experience and their progression and retention. Overlooking all or some of these aspects, institutions may fail to capture the balance needed in HE that encourages students to learn, work and contribute to wider communities (Elias, 2006). Indeed, Osterman (2000) suggests that educational institutions may implement organisational practices that neglect and thus undermine student experience of a supportive 'community of practice',

representing a threat to their physical (Degenne and Forse, 1999; Granello, 1999) and psychological welfare (DiFilippo and Overholser, 2000). The relationship between these issues merits further investigation.

According to Blamires and Gee (2002), one way forward is to recognise that "the role of support workers may just begin when the lecture ends as the student with social communication difficulties may need support in unstructured time" (p.22).

In the present climate, the formation and maintenance of these vital social support networks in the university sector appears to be the responsibility of no one. There is an emerging view that this should be the responsibility of universities (Tweedal, 2000).

The Disability Equality Duty [DED] (2006) has charged public bodies with the statutory responsibility of demonstrating anticipatory measures through annual reviews and the publication of a Disability Equality Scheme [reviewed triennially] (see Disability Rights Commission, 2006). Meeting DED (2006) legislation requires educational establishments to be anticipatory of all student need. Significantly for students with SCD, this may include support in the establishment and maintenance of wider social support networks that include both formal academic and informal personal support. This issue, at least, merits further investigation.

3.7 Chapter Two Summary

On the basis of this review of the literature, it appears that for students with SCD entering university the ongoing focus on academic need creates a climate within which consideration of personal and social need, demonstrably so important to educational attainment, is neglected to the possible detriment of their educational experience, progression and retention. This may be indicative of a university system in danger of becoming increasingly less, not more, responsive to student need.

Student formal academic support is clearly important. However, informal student support networks are at least equally important and to date, given little emphasis in HE research. The central aim of the present study is therefore to explore both ESW and student experience of student social support networks, which actively seeks ways of supporting students with SCD that provide appropriate integration and access to the full range of opportunities provided within the learning environment. Consideration of both formal and informal social support may allow for beneficial outcomes that can influence student overall well-being, retention and progression.

Henceforth, the present study will have a specific focus upon the benefits of wider social support networks. These are defined here as a web of relationships through which physical, psychological, emotional support and companionship, trust and information are

transacted, and through which resource sharing activities directly enhance student experience at university.

3.8 Research Aims

The present study relates to others in that it seeks to broaden understanding of students with SCDs' social support networks. However, a number of shortcomings have been identified in the literature which merit further investigation:

1) Research that explores formal academic support is predominantly carried out using quantitative survey methods. This is argued to lead to a limited understanding of student support
2) Research that explores informal personal support is predominantly carried out using a variety of qualitative methods (interviews, workshops). This is argued to broaden understandings of student support because it embeds it within social, cultural and contextual meanings
3) Generally, there is a distinct paucity of ESW perspectives in the area of interest
4) Specifically, there is a distinct paucity in the 'voices of students with disabilities' in the area of interest
5) Suggestions in the literature that formal academic and informal personal support should be considered collectively to provide a more holistic approach to student disability support is, at present, largely theoretical with limited empirical research in this area

To redress these shortcomings, the present study will utilise qualitative methods to consider both formal academic and informal personal support from the perspectives of both ESWs and students with SCD. Thus, contribution to 'new' knowledge may be achieved by exploring the part ESWs play in both formal and informal support and

students with SCDs' experiences of these and other types of support,

and their suggestions for improvements. The research will:

> 1. Explore how the current role of ESWs contributes to the establishment and maintenance of social support networks of students with SCD

> 2. Assess the contribution of formal academic support to students with SCDs' retention and progression

> 3. Make recommendations for effective ways of supporting students with SCD with a view to providing access to the full range of social opportunities available within the HE environment.

Chapter four will now consider the methodology and phase one

method and procedure. In particular, it will present the theoretical

stance underpinning the present study, the research strategy, design,

ethics and quality assurance, and the research context.

Chapter Four – Methodology

4.1 Preamble

The previous chapter provided a critical review of extant literature, both theory and research, concerning students with SCDs' formal academic and informal personal support networks. The research aims were also set out here. This chapter begins by detailing the overarching theoretical perspective informing the present study and provides a rationale for the research (see Crotty, 1998). Discussion of the methodology is set out in respective sections that detail the research strategy, study design, quality indicators, context and access to the area of study. Phase one method and procedure are detailed toward the latter part of this chapter.

4.2 Theoretical Perspective

Theoretical perspectives offer different, but valuable insights into knowledge acquisition, ways of 'knowing', through descriptive and explanatory epistemological and ontological principles – ways of theorising, conducting and disseminating research (Potter, 2000). Indeed, the purpose of this section is not to critique or exceed existing perspectives *per se*; rather, the intention lies with the need to ground this research within an appropriate theoretical perspective (Cheek, 2007). The theoretical stance adopted for the present study is social constructionism; this is described below.

Social constructionism has a multidisciplinary background (see Gergen, 1994), drawing its ideas from a variety of disciplines such as philosophy (Wittgenstein, 1963; Kuhn, 1970; Feyerabend, 1976; Barnes, 1977); cultural studies (Mannheim, 1951); anthropology and history (Aries, 1962; Heelas and Lock, 1981); sociology of knowledge (Berger and Luckmann, 1966); ethnomethodology (Garfinkel, 1967); Austin's (1962) speech act theory; semiology (Barthes, 1972) and post-structuralism (Derrida, 1976).

Social constructionism is anti-essentialist. Anti-essentialism arose out of discontent with the essentialism manifest in behaviourist and cognitivist approaches to knowledge production and understanding (Gergen, 1994). Crucially, Gergen (1985) articulates the point that social constructionism "invites one to challenge the objective basis of conventional knowledge" (p.267) and "the concept of knowledge as mental representation" (p.270). Knowledge is not a stable internal state "something people possess somewhere in their heads, but rather something people do together" (p.270). This shifts focus onto the role of language in constructing knowledge and the person as a relational being:

> The terms in which the world is understood are social artefacts, products of historically situated interchanges among people…the process of understanding is not automatically driven by the forces of nature, but is the result of an active cooperative enterprise of persons in relationship
>
> (Gergen, 1985: 267)

Thus, social constructionism is underpinned by the argument that its predecessors, the behaviourists and the cognitivists, neglected to properly address the central role of language in knowledge construction (Gergen, 1985). Absent are communal constructions and the role of language in knowledge construction (Gergen, 1994). The view taken here is that knowledge is a:

> ...by-product not of individual minds but of communal relationships...*all meaningful propositions about the real and the good have their origins in relationships.* This is to bring into sharp focus the site of knowledge generation: the ongoing process of coordinating action among persons. It is to foreground the moment-to-moment interchange between and among interlocutors, and locate meaning within patterns of interdependency
>
> (Gergen, 2001: 119, *original emphasis*)

There are various forms of social constructionism, some of which are more widely known and revolve around language, and some of which are lesser known and revolve around social interaction (Burr, 2003). By their insistence upon language as the medium of interaction, some social constructionists (see Bruner, 1990; Wetherell and Potter, 1992; Riessman, 1993; Billig, 1995; Mishler, 1995) move away from a realist ontological base, relocating levels of explanation within the linguistic space people share with others and have a focus on the construction of accounts, what Burr (2003) terms as "micro social constructionism" (p.21). To this end, the analysis of discourse has been undertaken by researchers from a discursive psychology perspective (see for example, Wetherell and Potter, 1992), which has its roots in ethnomethodology (see Garfinkel, 1967) and

conversational analysis (see Sacks, 1992). These discourse analysts have a particular concern with the performative functions of language, how people use language for their own means, how they construct accounts for a purpose. Discursive psychology, which emphasises the constructive work of people, can be contrasted with de-constructionism - the critical analysis of text – (see Derrida, 1976) and the research application of Foucauldian discourse analysis (Foucault, 1972), what Burr (2003) terms as "macro social constructionism" (p.22). Foucauldian discourse analysts, analyse text (printed, visual, oral, auditory) to reveal the constructive power of language and the discourses operating within them, paying particular attention to subject positioning and power relations, how people become constructed through the structures of language.

With a focus upon relationships, some social constructionists (Gergen, 2009; Shotter, 1995) also move away from a realist ontological base, relocating levels of explanation in the social realm. This lesser known relational approach to social research has a principle belief that phenomena (people, objects, social situations) are constructed within social interactions. That is, knowing comes into existence only through social participation. Acts of research only become intelligible and worth doing through a relationship that precedes the acts themselves. In effect: "I speak with others, and therefore I can know" (Gergen, 2009: 229). The concept of 'joint action' provides a way of understanding people as interlinked (Shotter, 1993). People coordinate their actions with the actions of

others in a responsive way (like a dance, moving together and responding to each other); what the individual desires and the outcome of these exchanges is often different:

> ...a crucial feature of joint action is that within it, in our moment by moment negotiations and struggles with the others with whom we are involved, we continue to interact with them until we shape or construct between us an outcome to an extent satisfactory to us all...we must address them [*other people*] not just as isolated, atomic human beings, but as occupying with us a shared 'situation'...this gives rise to outcomes independent of the wishes or interests of the individuals involved in it
>
> (Shotter, 1995: 166)

To this end, Shotter (1995) suggests that methodology attending to the constructive activities that occur between people can allow for comparisons to be made between people's accounts in order to draw attention to the ways people co-construct actions and negotiate different ways of being. The feminist understanding of self-in-relationship is especially pertinent in this respect, for example, Wolgast (1987) and Sevenhuijsen (2000) argue that people are what they are only by virtue of relationships. Yet, feminists who take this stance are not necessarily social constructionists.

Thus, among other things such as the turn to language, at the heart of social constructionism is the central role of relationships. The focus on the self as a co-construction rather than the constructed nature of disability support is especially relevant to the study of students' social support networks. The present study is interested in how people locate themselves in relationships, what it means when a

person tells their experience, not how they build accounts, although power is an issue for people with a disability. This relational approach may provide some index of 'real' expression and access to subjective experience; what is 'real' for the person can reflect their experience embedded in context. Students' social support networks are reliant upon relationships, negotiations and interactions with others – people are products of social processes:

> From this standpoint there is no isolated self or fully private experience. Rather we exist in a world of co-constitution. We are already emerging from relationship; we cannot step out of relationship; even in our most private moments we are never alone
>
> (Gergen, 2009: xv)

From a relational standpoint, the practice of disability support, for example, can be located in terms of the interactive processes that take place between people; it is something that people do together[10]. What constitutes disability support is therefore created and negotiated by people in relationships. Disability support thus gains meaning within particular contexts of usage and functions as a means of coordinating action within these contexts. Knowledge of disability serves to unite those in a student's social support network (student peers, family, disability support staff, teaching staff, disability assessors, the LEA), and serves to define and bestow worthiness to particular resources.

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[10] See Bury (1996) who also argues for a 'relational' view of disability.

Disability support and its meaning are thus created in human social interactions and as such are open to change. There is no access to 'truth', just current versions of disability support. It is these basic tenets, the shift from a focus on the individual to a focus on relationships, and the negotiation of factors within the process of disability support that are consistent with the needs of this research, which similarly locates disability in these terms. The present study focuses upon the possible contribution of students with SCDs' social support networks to their retention and progression. Consideration of the social relations between people with and without SCD, and the part ESWs play (the majority in the present study did not disclose impairment), are neglected in medical/individual and social models (Shakespeare, 2006).

The present study demanded an approach that could include the concerns of those involved (students with SCD and ESWs) in the particular educational context that is currently student disability support. As proposed here, ideas encompassed within social constructionism can be drawn upon to develop understanding of these concerns along with variations in experiences and meanings of support activities. Thus, research grounded within this theoretical framework can capture the social construction of the unique phenomenon that is student disability support. This will be the approach in the present study and, as such, is now discussed in context.

In light of the needs of this research – considering the social construction of student support rather than cause and effect - the aforementioned basic tenets (self-in-relationship) of social constructionism were a sufficient framework to allow the researcher to attend to the social and support factors that shape and re-shape students with SCDs' disability support. Collectively as a 'society', and constantly through connectivity, meaning becomes possible. Social constructionism can thus reveal how definitions of the concept of disability are shifting, especially historically (see chapter two of this thesis). Possible applications of a social constructionist relational approach to the present study are set out below:

- Review the literature to gain understanding of events that have led to current disability support practice. History, culture, political influence and the impact on student HE experience (achieved in chapters 1 and 2)
- Investigate disability support practice through direct communication with key participants (see forthcoming chapters 4 and 6)
- Follow participants' lead and analyse accounts. Identify and investigate relationships in terms of communication, power, resources and influence (see forthcoming chapters 5 and 7)
- Identify people in the disability support network that can influence as well as be influenced by current policies and practices (see forthcoming chapter 8)

Social constructionism is compatible with a broad range of research methods. Researchers taking a social constructionist stance (see for example, Shotter, 1993; Gergen, 1994; 2009) are mainly concerned with explaining participant's accounts of the world; having preference for, although not exclusively "qualitative research methods of enquiry

since these are often ideal for gathering linguistic and textual data and are viewed as less likely to decontextualise the experience and accounts of respondents" (Burr, 2003:149). In practice, this has often been the analysis of interview transcripts and other textual material. Analysing the ways in which participants make sense of student social support networks will provide understandings of how they locate themselves in relationships, what it means when they tell their experience. The view maintained here is that one participant's account is as credible as any other. Even so, methodological choices should be appropriate to both the object of study (see the research strategy below) and the research aims (see Ch.3, p.144). The specific methodological approach used in the present study is set out below.

4.3 Research Strategy

This section outlines the specific methodological approach used in the present study in the context of existing alternatives in the area of interest.

Quantitative approaches to research posit the notion that only scientific methodology can provide 'expert' knowledge (Guba and Lincoln, 1989). Typically, the testing of hypotheses is conducted through empirical experiments, observations and surveys, which provide the researcher direct access to measure; in this case, the strengths, weaknesses and density of the ties that bind social

support networks (see Procidano and Heller, 1983; Lev-Wiesel et al., 2006). This is conducted to produce results that can be both replicated and generalised to the broader population.

In contrast, qualitative approaches are typically concerned with capturing the meanings and interpretations that people subjectively assign to; in this case, social support networks, in order to describe and explain their accounts of supportive events by exploring how they experience and share these social phenomena with others (see Denzin and Lincoln 2003; Patton, 1990).

It is argued here that people and their practices, their thoughts and feelings do not fit neatly into prescribed categories that can be measured. Previous quantitative studies have been argued to dominate social support network research (see Ch.3, p.129) and neglect social connection by concentrating upon individual attributes of social support for students with SCD (Knox et al., 2006), giving relatively little attention to social, cultural aspects and situational contexts (Levett-Jones and Lathlean, 2007). This level of explanation is incommensurate with the overall aims of the present study (see Ch.3, p.144).

A major influence upon the present study's methodological approach was the commitment to the theoretical perspective of social constructionism (see this chapter, p.146). This commitment entailed assumptions about the nature of 'truth', human behaviour, representation and 'reality'.

Qualitative research is consistent with a social constructionist stance because they both can assume "a naturalistic [*in the natural world as opposed to a laboratory or other de-contextualised setting*] set of methodological procedures" (Denzin and Lincoln, 2003: 35) to correspond with the purpose of study; in this case, disability support. These procedures can seek to explore phenomena by entering into the world of participants to gather their experiences and the meanings they attach to those experiences, rather than 'expert' knowledge determining 'truth'. Thus, qualitative research can be assimilated with social constructionism because:

> Qualitative research is an interdisciplinary, transdisciplinary, and sometimes counterdisciplinary field…Its practioners are sensitive to the value of the multimethod approach. They are committed to the naturalistic perspective and to the interpretative understanding of human experience. At the same time, the field is inherently political and shaped by multiple ethical and political positions
>
> (Nelson et al., 1992: 4)

Findings from qualitative research are transient, modifiable and open to change as 'new' knowledge is accrued. The qualitative research process is thus:

> …fluid, evolving, and dynamic in nature, in contrast to the more rigid and structured format of quantitative methods…it is the endless possibilities to learn more about people that qualitative researchers resonate to. It is not the distance the qualitative researchers want between themselves and their participants, but the opportunity to connect with them at a human level…a challenge that brings the whole self into the process

> (Corbin and Strauss, 2008: 13)

A brief examination of a number of desirable aspects of a qualitative approach to data collection and analysis is set out below to illustrate how such an approach may facilitate further exploration of issues highlighted in the present study.

Qualitative methods would also facilitate a continuation and enhancement of the researcher's immersion in the research setting. Meeting and conversing with Disability Support management, School Disability co-ordinators, ESWs and students with SCD and experiencing the current support environment can extend immersion in the present study. Enhanced immersion would boost the researcher's grounding within the context from which participants draw their understanding and interpretation of events. Thus, the researcher is positioned as an informed and active participant in the research process (Lincoln and Guba, 1985).

Qualitative methods provide opportunity for 'thick description' (Geertz, 1973). Such data is a consequence of contextualisation through immersion, and through theoretical and analytical description to provide "…detail, context, emotion and webs of social relationships" (Denzin, 1989: 83). This approach should therefore facilitate a deeper and broader understanding of disability support practices and the experiences of ESWs and students with SCD.

Within the qualitative paradigm, there are varieties of research designs for data collection (see Cassell and Symon, 2004). The rationale for the design chosen for the present study is presented below.

4.4 Research Design

Flick (1998) states that qualitative research is "inherently multimethod in focus" (p.229). The use of multiple methods or triangulation reflects an attempt to secure an in-depth understanding of the phenomena in question, rather than an objective 'out there' reality. It offers an alternative to validity through strategies that add "rigor, breadth, complexity, richness and depth to any inquiry" (p.231).

The integration of two or more research methods (triangulation, see Brewer and Hunter, 2006) can provide a compatible alternative to using a single quantitative or qualitative method. The use of an eclectic approach can avoid/minimise limitations by revealing the different dimensions of a phenomenon, which can "enrich understandings of the multi-faceted, complex nature of the social world" (Moran-Ellis et al., 2006: 47). Looking at phenomena from different viewpoints and reaching the same or similar conclusions by analysing two or more different types of data can also serve to strengthen authenticity of research findings (Marsh, 2000). As such, the design for the present study will be cross-sectional and longitudinal.

Thus, the design here is both multi-method and longitudinal in the traditional sense, in that it is conducted over a period to reveal any changes over time (Bryman, 2004). To access the experience of students with SCDs' disability support, two primary target groups were identified as ideal candidates for the study: ESWs and students with SCD. These groups were identified from the existing literature that centred on student disability support (see Ch.3, p.103) and also personal experience as a former ESW (see the Preface, p.12). These two groups were chosen because they have direct knowledge and practical experience in the area of student support and could therefore offer insider accounts of daily support activities, including the 'trials and tribulations', as and when they occur.

Three phases were designed to incorporate participant experience of student disability support. The rationale for this is provided below.

In phase one, interviews were carried out with ESWs to generate preliminary themes concerning their possible contribution in the establishment and maintenance of social support networks of students with SCD and the contribution of formal academic support to student retention and progression. These themes were then used to inform the construction of the student diary schedule in phase two. Phase one was thus exploratory, undertaken primarily to gain an understanding of what was currently taking place in student disability support. Gaining this understanding was important because analytical themes generated in phase one ultimately informed phase two data collection procedures by providing the researcher with specific knowledge as to what students with SCD should focus on whilst reflecting in their support diaries. This was necessary because there is a paucity of literature that specifically details student disability support practice, as such there is little guidance and availability of information for researchers when designing data collection schedules.

In phase two, students with SCD kept diaries to reflect on their daily support provision. However, only seven of 36 possible participants chose to engage in phase two (see sampling and recruitment Ch.6:p.256). On reflection, although those students who participated in the study evaluated the method positively (see Ch.8:pp.381-383),

the relatively small sample may have been because some student had been deterred by the written nature of the data collection method. Finally, phase three constituted comparison and discussion of the findings from phases one and two.

Maintaining this sense of coherence through data collection to analysis in phases one and two provided useful points for comparison of the findings in phase three. Because the nature of qualitative work is data driven the issues are not known until they emerge. As such, ESWs have a wider range of experience regarding the issues of disability support than students, it therefore made sense to explore what ESWs considered important issues first and follow these through into phase two before comparing these with the experiences of students with SCD in phase three. Thus, concordance and disagreement became apparent.

Each phase is addressed in more detail in related chapters. This chapter describes the phase one interviews with ESWs, including method and procedure, and chapter 5 details a thematic analysis of these interviews. Chapter 6 describes the phase two student diary method and procedure, with analysis of these diaries in chapter 7. Finally, chapter 8 (phase 3) allows comparison and discussion of phase 1 and 2 findings in light of the extant literature.

Quality checks undertaken in the present study are set out below, followed by the research context and details of how access was negotiated.

4.4.1 Quality Indicators in Qualitative Research

Qualitative research has indicators of 'quality' that, according to Lincoln and Guba (1985), constitute 'trustworthiness'. This relies on four distinct criteria: credibility, transferability, dependability and confirmability, which "replace the usual positivist criteria of internal and external validity, reliability and objectivity" (Denzin and Lincoln, 2003: 35). Credibility refers to establishing the 'truth value' or accuracy of the research findings. Transferability or transparency of the research process for reproducibility purposes (see also Cohn, 1978) implies not only detailing the research strategy and design, but the research context (ecological validity) and referring specifically to the research methods and procedures. Dependability entails using various techniques such as triangulation of methods (see Brewer and Hunter, 2006), and/or the recording of detailed notes on the research process at every stage, to maintain consistency. Confirmability refers to the crosschecking and confirmation of findings.

However, Johnson et al. (2006) argue that notions of 'trustworthiness', through the use of internally reflexive audit trails, stress how researchers must demonstrate their "hard won objectivity" (p.139). This is more consistent with a neo-empiricist mode of

engagement, that there are "real and inter-subjective worlds which science can neutrally represent and explain" (p.147). In contrast, critical theory posits:

> Reality as-it-is can never be known by science because of the operation of the *a priori* inter-subjective processes which produce realities-for-us. Power asymmetries socially produce hegemonic versions of reality…[*with a methodological commitment*] to facilitate transformational change and emancipation based on reflexive understanding

> (Johnson et al., 2006: 147)

Thus, quality criteria for assessing research should, it is suggested here, include "various forms of authenticity expressed in and through epistemically reflexive dialogue grounded in discursive democracy" (Johnson et al., 2006: 147). To this aim, Guba and Lincoln (1989) subsequently replaced their neo-empiricist quality criteria of 'trustworthiness' with 'authenticity'. Authenticity represents a consensus view of 'truth' and has various criteria based on and evaluated by the extent to which 'new' knowledge/information is provided by a study and the responsiveness of the study to that information acquisition in terms of fairness and ontological, educative, catalytic and tactical authenticity.

Guba and Lincoln (1989) suggest that to demonstrate fairness researchers must show how different stakeholders' realities are represented in any account. Ontological authenticity is the extent to which the understandings of all stakeholders "are improved, matured, expanded and elaborated, in that they now posses more information

and have become more sophisticated in its use" (p.248). Educative authenticity is the extent to which stakeholders "understanding of and appreciation for the construction of others outside of their stakeholder group are enhanced" (p.248). Catalytic authenticity is the extent to which the understanding generated by the research stimulates action from the stakeholders to instigate change and alter the situation. Tactical authenticity is the extent to which the research empowers the stakeholders to implement their action plans.

Authenticity is considered here as a more appropriate quality indicator than 'trustworthiness' as 'reality' is created by people in relationships and some 'views' of reality prevail over others. However, this does not make them 'true'; they are a co-construction and can change over time. The qualitative approach utilised in the present study facilitated the embodiment of various forms of authenticity. Below are general examples of this. However, more specific quality checks were undertaken and reported in individual chapters.

Fairness was addressed by identifying all relevant and interested stakeholders; the University Disability Office was consulted regarding the research aims, sampling and recruitment and was kept informed throughout the research process. ESWs and students with SCDs' perspectives were incorporated into the research through the presentation of numerous supporting quotes from all participant transcripts in each corresponding analysis of the findings (see Ch.5,

p.220 onwards for excerpts of ESW interviews, and Ch.7, p.292 onwards for excerpts of student diaries).

Ontological and educative authenticity were achieved through the dissemination (both conference and paper-based reports made available to the University in question) of unique knowledge in the area of student disability support (see Ch.8, p.335) and through using an overall multi-method design - different types of data can reveal differing perspectives, which can enrich understandings (Marsh, 2000). Moreover, transparency of the research process (see Cohn, 1978) can empower the reader by enabling their understanding of the context in which the findings were produced so that they can judge their legitimacy; this was addressed at various points in the methods and analysis chapters (see chapters 4, 5, 6 and 7) by using rater-to-expert checks (see Smith, 1992).

Catalytic and tactical authenticity was achieved by the research firstly stimulating then empowering the stakeholders to implement action plans. The Disability Office will be presented with a copy of the thesis that includes recommendations of ways of supporting students with SCD, with a view to providing access to the full range of social opportunities available within the HE environment.

4.5 Research Context

The study was conducted at a North of England University, fictitiously named and referred to hereafter as Northtown University, which promotes widening participation agendas. Following scrutiny of recruitment and retention figures of students with SCD at Northtown University by the author of the present study, there has been a general increase in students with SCD since 2000 but the University, in general, has only successfully retained those on short-term, particularly one year, courses.

Northtown University has a Disability Support Office with a dedicated team who aim to ensure students with a disability have access to information, support, reasonable adjustments and accommodations in order to achieve their full academic potential. Information from the Disability Support Office is sent out to all new applicants who tick the disability box on the UCAS form. Disability Support staff liaise with Disability coordinators, based in each School department, on appropriate study support and academic assessment for students with a disability.

To obtain and pay for disability support, students must undergo an assessment of needs to access funding in the form of DSA financed by their LEA. This assessment process is based on strategies to facilitate participation in all aspects of mainstream higher education, such as assistive technology and specialist support (National

Network of Assessment Centres, 2008). Basically, once a student has received an assessment of needs, a report is written based on this that contains recommendations for support provision. A copy of this report is sent to the LEA, who authorises and funds the support, alongside support recommendations sent to the University in which the student is to study. The LEA generally tends to agree with the assessment of needs, which is provided in writing to the student. The student then has two choices; they can either request Direct Payments, in which they organise and manage their own support provision (see Ch.2, pp.67-68), or they can allow the University to oversee their support. If the latter is chosen, the student independently contacts the University to organise this. Once support is in place, the University then sends itemised invoices to the LEA to claim funds from the student's DSA.

An examination of assessment reports (10 out of a potential 36 were made available, as set out below) carried out during the period 2006-2010 for students attending/due to attend Northtown University was undertaken by the researcher to confirm whether or not they take account of students with SCDs' wider academic, personal and social needs in the university context.

Currently, Northtown University works in collaboration with two assessors, one internal and one external. However, the University advise students to use the services of the external assessor because they feel that information used to base recommendations on is

gathered more widely. The internal assessor draws on evidence to make their support recommendations from discussion with the student and the University website. The external assessor draws on discussions with the student, parents, University disability advisor (in the form of a learning support questionnaire that identifies support needs), and available documents from further educational study, the University Course team and medical evidence. Two of the examined reports were carried out by the internal assessor and eight by the external. However, each had similar aims 'to identify the impact on study activities and recommend and cost suitable study aids and strategies to assist students'. Moreover, upon further scrutiny of these reports there appeared to be little, if any, differences in their support recommendations.

In terms of formal academic support provision, all 10 reports made similar recommendations for students with SCD. Typical recommendations included:

- ICT equipment and software
- Access to quiet environments
- Extended library loans
- Overhead slides and handouts in advance
- Flexible assignment deadlines
- The services of ESWs in the form of BSL interpreters (where applicable), note taking, study mentors, exam and campus/library support

As indicated in the literature, when this formal academic support is appropriately applied it 'levels the academic playing field' for students with SCD (see Ch.3, p.126).

In terms of informal personal support provision, 9 out of the 10 reports examined made no recommendation for any type of support with personal or social issues, even though these were commonly identified in all 10 reports. A typical example here states the student has:

> ...a high degree of nervousness/anxiety working with other students, participation in research seminars, undertaking presentations, lacks confidence, difficulties making and maintaining friendships and choosing a partner for group work, prefers email and text to communicate

In the majority of reports examined, a typical recommendation under the heading 'communication strategies' states that communication difficulties are 'not addressed through equipment', or occasionally are addressed through radio aids (sound receiving equipment). However, there was one atypical example here with the potential provision of informal personal support in the form of a 'study buddy' (an ESW note taker appointment with additional short-term 'study buddy' duties) recommended by the external assessor to cover:

> ...free time (catering, library and other campus facilities) to overcome social anxieties, locate resources, and establish routines. This support should be progressively reduced in the first semester and be combined with note taking duties (22hrs a week)

The aforementioned report was a recent document undertaken at the outset of the academic year 2009/2010. The student, in this case, identified both on the University learning support questionnaire (used to identify student support needs and made available to the assessor prior to making recommendations), and during discussion with the

assessor that they required the services of a 'study buddy'. A 'study buddy' is a person employed to discuss and offer practical support with difficulties that students may be experiencing academically, personally and socially (Blamires and Gee, 2002). Thus, receiving this recommendation for a 'study buddy', where other students had not, may have been down to two mitigating factors; student knowledge of the existence of 'study buddies' and/or a change in the format of the learning support questionnaire. Prior to 2008, the University learning support questionnaire comprised a 'tick box' list of available services that did not include 'study buddies' thus, making it difficult for students to request this type of support (see Figure 1 below).

Services

Study skills tutor	☐	Library assistant	☐
Study mentor	☐	Extra time assignments/exams	☐
Note taker	☐	Library extended loans	☐
Teacher of the deaf	☐	Photocopying	☐
Sign language interpreter	☐	Facilities for guide dogs	☐
Amanuensis	☐	Copies of lecture notes/slides	☐
Technology trainer	☐	Copies of material in alternative	
Non-medical assistant	☐	formats	☐
Reader	☐	Access to buildings	☐
Transcriber	☐	Car parking	☐

Figure 1: Northtown University Learning Support Questionnaire Prior to 2008

Subsequent to 2008, the form was redesigned to encompass an open question format where students can now self-identify their needs under headings (see Figure 2 below).

Equipment

Adjustment to Exams/Assignment

Support Worker

Other Requirements

Material

Personal Care and Community Support Worker

Figure 2: Northtown University Learning Support Questionnaire Subsequent to 2008

The more recent form was used in over half of the reports scrutinised. This means that most students had the opportunity to request a 'study buddy' if necessary, but only one in the scrutinised reports did. One plausible reason for this may be because students have little or no knowledge of study buddy schemes because they are not made aware of them during the DSA process and, as such, are unable to request them. Moreover, it is argued here that the responsibility for requesting support services should not lie solely with the student; it should also be the responsibility of assessors. Assessors[11] are clearly aware of the types of support that exist, including study buddy schemes, and clearly have the power to recommend them as illustrated in the above example. However, they appear only to do so when it is specifically requested by the student.

In addition, the student Counselling Services also provide a valuable role in supporting students in times of crisis. The list of potential difficulties that any student could experience is varied. Counselling Services offer students a commitment to listen and to help them to understand and explore their difficulties. Each session lasts around 60 minutes, usually once a week.

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[11] Assessors are qualified professionals employed to assess student study needs, such as educational psychologists and occupational therapists that have "...experience and knowledge of the equipment and support that students with disabilities need to study successfully at university" (National Network of Assessment Centres, 2008: no page number).

Each of these services recognise that Northtown University can be a disabling environment for students with SCD and have a responsibility to provide the necessary support to enable these students to participate fully in their chosen course. It is only by having more knowledge and understanding of the direct experiences of students with SCD that any gaps in support and improvement in support practices can be identified. This can be achieved by paying attention to the issues and problems raised by both ESWs and students with SCD.

4.6 Negotiating Access

Primarily to conform to the Data Protection Act (see Office of Public Sector Information, 1998: Ch.29, Part 1: Schedule 2; preventing disclosure of sensitive personal data), access to the identified target groups (ESWs and students with SCD) was negotiated with Northtown University Disability Support management and School Disability co-ordinators. At each phase of data collection, Disability Support management and School Disability co-ordinators examined their databases for potential participants (see this chapter, p.173 and Ch.6, pp.254-5 respectively for qualification criteria) and sent letters on behalf of the researcher inviting participation (see Appendices 1 [ESWs] and 5 [students]). Those interested in taking part subsequently contacted the researcher independently.

4.7 Phase One Method and Procedure

In accordance with Guba and Lincoln's (1989) notion of authenticity, detailing the research process allows the reader to judge the 'quality' of the research (ontological and educative authenticity, see this chapter, p.162). Thus, provided below are detail of ESW sampling and recruitment, ethical issues and rationale for the data collection method – online interviewing. An in-depth account follows regarding the development of the interview schedule, piloting, online materials and data collection procedures. The conduct of the interviews is also addressed here, with specific reference to the success and difficulties of online interviewing.

4.8 Educational Support Worker Sampling and Recruitment

The sampling approach was purposive rather than representative (see, Silverman, 2001) and conducted in collaboration with University Disability Support Services. Potential participants were contacted by both letter and email by Disability Support Services, to invite participation in the study (see Appendix 1, p.455) if they met the following inclusion criterion: provide/have provided non-medical support for HE students with SCD, in terms that relate to the following University job descriptors:

- Teacher of the Deaf
- BSL communicator
- Mentor
- Note-taker
- Library/campus assistant
- Dyslexia tutor

Participants expressing an interest in taking part responded to the recruitment letter by email correspondence directly with the researcher. In-person meetings were organised at this time to affirm the legitimacy of the researcher, establish rapport and acknowledge participants' commitment to the research project. These in-person meetings also provided the opportunity for participants to practice accessing and using Instant Messenger (IM)[12] through the Meebo.com server utilising the specially devised IM accessibility manual (available for scrutiny upon request). However, if participants preferred no in-person contact, primarily due to busy work/life schedules, recruitment and training was conducted entirely online. If necessary, all ethical formalities (briefing, obtaining informed consent and debriefing) and the IM accessibility manual were sent via email using official University addresses.

Ten ESWs (7 female, 3 male); in particular, 4 mentors, 2 mentor/support co-coordinators, 3 note takers and 1 note taker/campus assistant, each with Internet access both on and off campus, and with a cross-section of ages (20-59), experience and education, were subsequently recruited from a population of 25 (see

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[12] IM is the communication platform used for online interviews in the present study. For an account of IM see this chapter, p.185.

Table 1 below). This can be considered a heterogeneous group - the expectation linked to this was that the different backgrounds would reveal more aspects and different perspectives relevant to the research questions (Flick, 2006).

Table 1: Educational Support Worker Details

Participants[13]	Sex	Job Description	Age Group	Experience in Months	Higher Education
Anne	Female	Note taker	20-25	24	Yes
Brenda	Female	Mentor	50-55	48	Yes
Christine	Female	Mentor/ Mentor coordinator	30-35	108	Yes
Dennis	Male	Mentor	50-55	60	Yes
Eric	Male	Note taker/ Campus assistant	50-55	3	No
Fiona	Female	Mentor	36-39	48	Yes
Glenda	Female	Mentor/ Support coordinator	56-59	72	Yes
Helena	Female	Note taker	40-45	48	No
Ian	Male	Mentor	30-35	36	Yes
Janet	Female	Note taker	26-29	48	No

4.9 Ethical Issues

The present study was approved in its entirety by the University Research Ethics Panel, and University Counselling Services assured the provision of counselling services for all participants should the need arise. All ethical principles, in accordance with the Economic and Social Research Council guidelines (2006: Sect.3.2.1), were applied as follows:

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[13] Pseudonyms were used.

- Fully informed, written consent was obtained from all participants through either face-to-face, or online briefing sessions (Sect. 3.2.2)
- Participants were provided with verbal and/or written assurances regarding confidentiality and anonymity. In particular, participants were not asked to reveal their names or to identify themselves in any way and any potentially identifying information was subsequently deleted from the transcripts. Identification codes were used for analysis purposes; all data were retained in separate, secure storage and deleted upon completion of the study (Sect.3.2.3)
- Written and verbal briefing assured participants of the right to withdraw at any time and the right not to answer questions they may feel uncomfortable with. To ensure personal safety, all face-to-face briefing and training sessions were undertaken on University premises, in rooms booked for that purpose, with the time and locations noted in advance with a supervisor (Sect.3.2.4)
- Debriefing ensured that any questions raised by participants were addressed and any issues that may subsequently arise were dealt with through provision of contacts for University Counselling Service (Sect.3.2.5)

In addition to the ethical principles noted above, further ethical considerations needed to be taken into account when conducting online interviewing. At present, the British Psychological Society (2007) appeared to be the only organisation currently offering specific ethical guidelines for online interviewing, making supplementary guidelines to their 2006 generic ethical principles. The Economic and Social Research Council (2006) had yet to respond, and the British Sociological Association (2002: Sect.41, 5-6) merely expressed a need for caution when carrying out online interviewing:

Ethical standards for Internet research are not well developed as yet. Eliciting informed consent, negotiating access agreements, assessing the boundaries between the public and the private, and ensuring the security of data transmissions are all problematic in Internet research. Members who carry out research online should ensure that they are familiar with ongoing debates on the ethics of Internet research, and might wish to consider erring on the side of caution in making judgements affecting the well-being of online research participants

Therefore, the researcher used what was considered good ethical research practice, which was approved by the University Research Ethics Panel, for protecting both the researcher and participants:

- Prearrangement of usernames and passwords to verify identities during the online interviews
- Verbal and written information informed participants that privacy could not be totally guaranteed over a public network and the need for participants to guard their own privacy and that of significant others by not revealing sensitive information unrelated to the interview

As such, written information informed participants that privacy could not be totally guaranteed over a public network and of the need for participants to guard their own privacy and that of significant others by not revealing sensitive information unrelated to the study (see Appendix 1, p.455).

4.10 Phase 1 Method

4.10.1 Rationale for the Interview Method

Within the qualitative paradigm, there is a variety of means of data collection, such as participant observations and ethnography, interviews, focus groups and diaries (Flick, 2006). Rather than, for example, observe support activities from a second person perspective, then make assumptions based on this, the researcher wanted to understand ESW's thoughts and feelings on current support from their perspective. Participant interviews are an appropriate method for gathering this type of data because they generally allow information that is rich in content (McQueen and Knussen, 2002). The content and form of the participant interview is *researcher-driven*, but not dictated by the researcher's agenda (Powney and Watts, 1987). The use of interviews for data collection purposes are discussed below.

At least three types of interview strategies can be identified for conducting social research; unstructured, fully-structured and the semi-structured interview. Certain assumptions underlie each strategy but the main difference between these interviews is the degree of formality, or rigidity, within the structure of the schedule of interview questions (Berg, 2007). Each type of interview structure is considered below in relation to its appropriateness to research aims 1 and 2 (see Ch.3, p.144).

Questions within unstructured interviews have no set order because they are intended to access participant 'free expression' with regard to whatever 'life' issues they perceive as important. The interviewer assumes no advanced knowledge of what the questions will entail and thus cannot pre-determine a full schedule of questions (Berg, 2007). This type of interview was considered inappropriate here because the focus would be too broad and this may result in more superfluous data unrelated to research aims 1 and 2, than other techniques.

Fixed-choice questions, presented in a set order and worded exactly the same within fully-structured interviews are used by the interviewer to seek confirmation of theoretical and empirical assumptions (Berg, 2007). According to McQueen and Knussen (2002), this interview strategy elicits forced-choice responses, which may result in systematic bias in answers. Strengths of using fully-structured interview strategies are that standardisation with question sequencing and recording of responses can minimise differences between interviews (Bryman, 2004). Although this type of interview can be consistent with research aims 1 and 2, it was also considered inappropriate because the type of data sought here were multiple accounts of the same or similar phenomena that depicted changes and shifts over time.

In relation to degrees of formality within the structure of the schedule of interview questions, semi-structured interviews can be placed somewhere between unstructured and fully-structured interviews (Berg, 2007). This type of interview uses pre-determined questions in a consistent manner. However, the interviewer is expected to digress and probe beyond the schedule of questions. The assumption here is that participants' understanding of the world varies.

Therefore, semi-structured interviews were considered more appropriate here because they allow for active intervention on the part of the interviewer to explore unpredicted avenues of thought, flexibility in selecting aspects of the conversation to follow up and for the purposeful questioning of participants through orienting questions to address research aims 1 and 2. This technique will therefore generate insightful data regarding ESW experiences of students with SCDs' social support.

4.10.1.1 Interviewing dilemma

During recruitment, two participants disclosed D/HI and a preference for non-verbal communication. This left the researcher with a dilemma: how to interview participants with D/HI whose primary communication medium was British Sign Language.

Oralism - the rejection of sign language in favour of speech – (see Branson, 2002 and the Preface of this thesis, p.12) had placed the researcher (non-signing hearing impaired) at a distinct disadvantage concerning data collection with at least two of the intended sample. If the participants were to be verbally interviewed, a sign language translator would be needed. Through reading academic literature (see Bowker and Tuffin, 2003; Temple and Young, 2004), the researcher came to realise the adverse implications of sign language translation for qualitative interviewing. In terms of accuracy and privacy it was impossible to honour anonymity when interviews were mediated and translated via a third person.

Moreover, verbal responses are often inaudible for people with D/HI, which disrupts the conversational flow and audio-transcription has personally proven a laborious experience. The researcher, being hearing impaired, has in the past conducted and transcribed lengthy audio-taped interviews. Listening to and transcribing the interviews is very stressful due to the extra time and effort needed to ensure accuracy. For example, the concentration involved when having to continuously rewind the tape, after only two or three words, causes extreme fatigue and inevitable transcription errors.

However, during a Masters course undertaken by the researcher, an innovative idea for data collection was generated; to conduct synchronous online interviews with University students using Instant Messenger [IM] (for account of IM see related section below, p.187) – an online textual communication medium. This online interviewing technique was evaluated by both the current researcher and the participants involved in using this data collection technique. As a result of this evaluation, two journal papers were published (see Hinchcliffe and Gavin, 2008; 2009). The outcome of this evaluation was that IM was more than just a novel research tool to be exploited, it was a 'cutting edge' communication medium used frequently by students as part of everyday University life. IM was considered by participants and researcher alike as being convenient and easy, a comfortable and very enjoyable experience for research interviewing. IM was an excellent communication platform that lessened interview apprehension and 'levelled the research playing field' for those individuals with shyness, hearing impairments and specific learning difficulties such as dyslexia (see Hinchcliffe and Gavin, 2009).

The researcher was now well placed for interviewing participants who preferred non-verbal communication and was able to offer online interviewing to all interview participants (see p.189). Thus, in addition to conventional data collection methods (verbal interviews), the researcher could now offer the online communication medium IM for interviewing to all ESWs. The rationale for, and the benefits of, using

Internet technology and the particular usage of IM as the communication platform for online interviewing, are presented in more detail below.

4.10.2 Rationale for Using Internet Technology to Facilitate Data Collection

Advancement for research practice may result from the acknowledgement and acceptance that, in contemporary society, technology has become embedded in most aspects of human life (Parton, 2006). Ruch (2005) suggests contemporary research should assume an approach that embraces and combines technology and the 'social'. The opportunity for HE research practice to take advantage of technological advancements should be exploited. Berg (2007: 112) argues:

> As technology advances, methods used in qualitative research must strive to keep up - or at least seek ways to take advantage of these technological advancements because such environments provide the researcher and participant an experience similar to face-to-face interaction insofar as they provide a mechanism for a back-and-forth exchange of questions and answers in what is almost real time

Similarly, Garrison and Anderson (2003) assert "there is sufficient evidence to suggest that writing has some inherent and demonstrable advantages over speech when engaged in critical discourse and reflection" (p.26). A more deliberate and thoughtful process is promoted using Internet-based (computer-mediated)

written communication media because the person thinks, types, reads and reflects on the content, amends if necessary, confirms and then sends the correspondence. Hinchcliffe and Gavin (2008; 2009) report that responses from Internet-based written communication are more succinct compared with verbal-based media – asking a straightforward question promotes a straightforward response; generally, the conversation remains topical and there is less narrative contradiction (contradiction in participants accounts). However, it should be noted that the loss of narrative contradiction may present an 'unnaturalistic', terse account of events and create subsequent research problems for particular types of analysis that seek to understand complexities and contradiction of participant experience.

Therefore, it is important to harmonise the data collection technique with the communication medium, which should endeavor to 'fit in' with the sample. Hine (2008) cautions that the online data collection technique should be both sensitive to the sample and the context; in this case, it was because participants were computer literate academics with familiar usage of the Internet, and the context of busy academia meant that time to meet up in-person to undertake the interviews was limited due to it being term-time and ESW appointments were fully booked with students.

Clarke (2000) asserts that the Internet increases anonymity, which can engender enhanced confidence, facilitate active participation, engagement, reflection and honesty. Thus, the application of technological data collection techniques, such as the Internet that integrate visual, textual and verbal communication may, in turn, enable fuller exploration of ESW's experience of support practices for student with SCD.

4.10.2.1 Wider benefits of using Internet technology

It is argued here that those members of society who are hard to reach by conventional, verbal means of communication are under-represented in academic research (for a review of widening participation research in HE, see Gorard et al., 2006). Boulos and Wheelert (2007) stress the advancement in sociable interactive technologies such as 'the social Web' has provided opportunities for people to connect and communicate through the online medium at a distance, in real time. For example, through the Internet, connections can be made with a broad range of people otherwise difficult to access, such as people who live in remote or rural areas, are housebound through illness, disabilities or fear, the elderly and potentially those with social interaction problems. The Internet can also enhance communication with people where the topic is sensitive in nature, such as drug dealing (see Coomber, 1997).

Using the Internet to cut across time and space means that communication is no longer geographically bound; the Internet can reduce social isolation and engender connectedness with society. Crichton and Kinash (2003) argue "as such, they [*Internet environments*] are embodied, sense dependent, and not fictive" (no page number). However, participants in virtual spaces can:

> …escape their own embodied identities and accordingly escape any social inequalities and attitudes relating to various forms of embodiment. Race, gender and physical disability is indiscernible over the Internet. Any basis for enacting embodiment discrimination is removed; freeing access to participation and granting each participant equal status

> (Wilson, 1997: 149)

Wilson (1997) goes on to warn that caution needs to be taken whilst using the Internet because separation from embodied identity may incur disconnection from "physical action and a sense of social responsibility to others" (p.153). Boulos and Wheelert (2007) disagree, asserting that "the social Web" (p.2) enables the collection, sharing and transferring of information and ideas for specific purposes, thus facilitating the development of stronger, reflective communities. Hinchcliffe and Gavin (2008; 2009) found the latter was the case for participants in their study.

Utilising innovative 'new' communicative technology (see Ch.2, p.117) such as the Internet can therefore be argued to widen the scope for research inclusion and active participation by facilitating connectedness that embraces active citizenship - promoting a sense of membership in a supportive community (Osterman, 2000). Insightful findings from research such as this may better equip HE institutions to alleviate student academic and social problems by providing more appreciation of participant opinions (DiFilippo and Overholser, 2000) and empathy with their predicaments (Hobfoll, 1998).

4.10.2.2 Using Instant Messenger to facilitate online interviewing

Instant messenger (IM) was used as the communication medium for online interviewing with ESWs. IM is an electronic online communication system that combines the facilities of a telephone, synchronous conversations, and "turbo charged email", producing a written record of the conversation; rapid "real-time chat…at lightning speed" (Flynn, 2004: 8).

IM has additional benefits: it is a faster, more conversational way of communicating than email, and has archiving capabilities that save and store conversations (Flynn, 2004). IM is inexpensive (free to download in most cases), convenient and attractive for those who do not like or find face-to-face interviews difficult (Gunter, 2002). IM can

dispel participant apprehension, there is no need for time-consuming transcription, the time and place can be organised to suit participants (Davis, 2004) and IM can generate reflective and descriptive data (James, 2006). Areas of uncertainty can be picked up on and raised in the response, generating richer data than conventional modes of data collection (Morgan and Symon, 2004). IM enables easy entry into a computer assisted qualitative data analysis program (Bryman, 2004) and in some cases, "vid-cams" (computer linked video cameras) can be used to allow the researcher and participant to actually see one another and the interviewer has the ability to ask probing questions to elicit additional information (Berg, 2007: 112).

Security concerns (hackers, eavesdroppers, viruses and spam) can be addressed through up-to-date antivirus software and, as Flynn (2004) advises, giving the management of IM to "your IT department [*will allow*] some control over user identity and passwords, enabling you to kick impostors off your system" (p.17). However, only a reasonable expectation of privacy can be given because the conversations are transmitted via public networks. All IM, email, and other electronic communications, including text and images, can be disclosed to law enforcement or other third parties without the consent of sender or recipient (Flynn, 2004):

> For the receiver, they define a duty of confidentiality. For the sender, they define a right of privacy that is primarily concerned with the sender's ability to exercise control over the exposure of sensitive information

(Yee, 2006: 2)

Therefore, participants were advised as to safe-guarding their own privacy and that of their family and friends when using IM (see ethical issues this chapter, p.175). The interview aims and design are presented below followed by the development and piloting of the interview guide.

4.10.3 Interview Aims and Design

At various points throughout the academic year 2007-2008, through individual participant interviews the researcher aimed to access ESW's subjective experience of both their supportive practices and their perceptions of the social support networks of students with SCD. It was anticipated that these interviews would also reveal any gaps in ESW practice. During recruitment, participants were offered a choice of either conventional or online interviewing. However, all participants chose online interviewing specifically for its convenience to fit around their busy work/life schedules (it was term-time and they were extremely busy supporting students).

A semi-structured interview design was used. This meant that the interview agenda was *researcher-driven* but still flexible enough to allow participants to prioritise their experience of supportive events. The researcher did not want to dictate the interview, but merely guide the agenda to assist participants to focus on aspects of their supportive practice and student support. The interview questions were thus based on the following six 'guiding issues' that aimed to

understand how ESWs contributed to the establishment and maintenance of social support networks of students with SCD :

1. Relevant experience, such as length of support experience, and/or experience in their professional or personal life
2. Supportive roles, such as their roles and the type of support provision expected by the University and any other supportive activities they might be involved in with the students
3. Relationship with students, such as the types of relationships they have with the students they support, and any disparity between the role required by the University and their actual role
4. Peer support, such as social support provided by student peers
5. Current support provision, such as what they consider appropriate support should entail
6. Additional issues

However, participants were encouraged to comment on their feelings, thoughts and emotions, and were prompted to provide examples of events and the circumstances under which they took place. In addition, participants were probed on any unexpected avenues of interest relevant to research aims 1 and 2 (see below and Ch.3, p.144) that arose during the interviews.

Thus, this design allowed participants to actively participate and reflect on their experiences during the interviews. As such, this captured individual understanding as to how they contributed to the establishment and maintenance of social support networks of students with SCD.

4.10.4 Interview Guide Development, Construction, Piloting and Materials

In accordance with Guba and Lincoln's (1989) notion of authenticity, detailing the research process allows the reader to judge the 'quality' of the research (see Ch.4, p.162). Thus, as part of phase one, the sections below provide insight into the development, construction and piloting of the interview guide, the materials used for online interviewing, the data collection procedures and the conduct of ESW interviews.

4.10.4.1 Development of the semi-structured interview guide

The semi-structured interview guide (see Appendix 2, p.458) was constructed to engage with research aim 1: 'Explore how the current role of ESWs contributes to the establishment and maintenance of social support networks of students with SCD' and research aim 2: 'Assess the contribution of formal academic support to students with SCDs' retention and progression'. The content of the questions were drawn from literature that centred on student social support (see Ch.3, p.103) and personal experience as a former ESW (see the Preface, p.12).

Questions were thus constructed under the six areas of interest. In each of these areas, answers were sought that gave insight into the position of ESWs within the support network and the nature of their relations with others in the network. For example, questions were designed to elicit information about their relations with the University and with the students they supported, as illustrated in examples below.

Questions were structured according to a natural progression through each consecutive area of interest; opening, main focus and closure. After the opening introductory questions, subsequent main focus questions were intended to elicit longer, richer, more spontaneous description and relevant examples regarding ESW experience, rather than *ad hoc* answers (Kvale, 1996). At the end of the guide, a closing question was introduced to access any issues participants felt were relevant, but not covered, in the interview. However, wording and ordering of questions were open to modification based on the researcher's perception of each individual interview context and interpretation of participant answers.

Breakwell (1990) suggests a clear interview introduction is needed because "anxiety impairs memory" (p.35); therefore, introductory questions should be non-threatening. Opening questions in the interview guide were aimed at prompting shorter answers; the first area of interest thus centred on ESW's 'Relevant experience', both professional and private. For example, question 1b asked:

> Please describe any relevant experience in your private or professional life

Information elicited by this question was intended to allow an explanation of prior and current support experience held by ESWs and therefore their correspondence with the demands of the students' support network. The introductory questions also allowed participants time to relax and feel little pressure in providing long, complicated answers. As such, this can further allow participants time to acquaint themselves and engage with the interview process (Flick et al., 2004).

Subsequent questions explored the second area of interest 'Supportive roles'; questions were constructed to allow insight into conventional and any unconventional support. For example, questions 2a and 2c asked respectively:

> How does the university define your role as a support worker?

> What other supportive activities might you be involved in with the students you support?

These questions were intended to explore the practical activities undertaken by ESW's in their 'Supportive roles'. Answers from such questions may highlight any differences between prescribed roles set out by the University and actual activities within their supportive role.

Questions within area of interest three 'Relationship with students', were intended to shed light on ESW thoughts and feelings concerning what they considered a supportive relationship to be and what qualities they considered ESW's should develop. At the end of this area of interest, question 3f asked:

> How do other students communicate with students with social communication difficulties?

This question broadened the exploration of social network relations by exploring relations between students with SCD and their peers.

In area of interest four 'Peer support', questions were designed to enable the position of ESW's within 'peer support' relations to be explored. For example, questions 4a and 4b asked respectively:

> Do students with social communication difficulties receive social support from friends?

> Are you included in this?

Area of interest five, 'Current support provision' sought ESW views on issues highlighted in the literature relating to student social support networks. For example, question 5a asked:

> Research indicates that support should continue for students with social communication difficulties outside of lectures to encourage development of social support networks. What are your views on this?

This question sought to further explore alternative roles within the support network.

Questions were thus written into the guide to address research aims 1 and 2, and to engender subsequent theoretical engagement with the data. However, during the online interviews it was essential that a conversational flow was maintained between the interviewer and participants and therefore priority was ascribed to this aspect of the guide (this point is discussed alongside other issues in more depth in the section detailing the conduct of these interviews, see pp.201-206).

The subsequent semi-structured interview guide was then piloted. The guide was piloted with an expert (external to the University) in student support to assess how useful the guide was at gathering the type of information being sought. The pilot participant was considered an expert in the area because they have several years experience in both disability support provision, and co-ordination of student disability support (rater-to-expert reliability) (see Smith, 1992).

Set out below are 5 guidelines used during the pilot interview to facilitate outside 'expert' formal assessment of the preliminary interview questions. These guidelines were provided to the 'expert' immediately following the pilot interview:

1. Has the researcher included all of the questions necessary to test aims?
2. Do the questions elicit the types of response that were anticipated? [*including facilitating meta-theoretical engagement*]
3. Is the language of the research instrument meaningful to the participants?
4. Are there other problems with the questions, such as double meaning or multiple issues embedded in a single question?
5. Finally, does the interview guide, as developed, help to motivate participants to participate in the study?

(Adapted from Chadwick et al., 1984: 120, quoted in Berg, 2007: 105-106)

Most questions were retained because they were considered productive in relation to research aims 1 and 2 in facilitating theoretical engagement, and in eliciting appropriate responses and motivating participation (see guidelines 1, 2 and 5 above). However, in line with guideline 3 above, pilot questions 1c, 2b, 3a, 3c, 3f and 4c were revised to ensure the language was more meaningful for the participants. For example, question 2b was rephrased from 'what type of support does the University expect you to provide' to '*do you think that students require other forms of support that have not been recognised by the University*' (see pilot and post-pilot guides, Appendix 2, p.458 and Appendix 3, p.461).

In line with guideline 4 above, pilot question 5b was relocated as question 2d because it was perceived as being related to earlier areas of interest in the guide. A newly formulated question was inserted at 5a to allow additional information relating to current

support (see Appendices 2 and 3 for all other revisions, which are signified by *italics*).

Presented below is an in-depth account of the online materials and data collection procedures, followed by critical reflection of the conduct of the online interviews using IM as the communication platform.

4.10.4.2 Materials

Illustrated below is the use of IM for online interviewing. Two separate accounts set up with Yahoo Messenger Client, one for the researcher and one for participants, were developed with a 'user-friendly' IM accessibility manual to facilitate participant access and usage[14]. This manual included visual screenshots at each of the relevant stages; for example, how to access the IMVironment, enter usernames and passwords, and specific usage of IM for online interviewing (available for scrutiny upon request).

4.10.4.2.1 The Researcher's IMVironment

Figure 3 below shows the IMVironment used by the researcher during the individual online interviews mediated through IM.

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[14] Technical advice was sought from the University regarding Internet security, suitable IM client and development of the IM 'user friendly' manual.
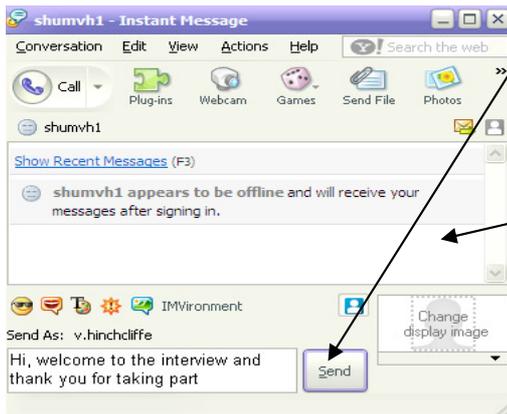
The researcher types a question in the box, clicks send and the question is instantly received by the participant.

The question and subsequent response both appear in this box and remain visible throughout the interview. It is therefore possible for the researcher to see, read and review the script throughout the interviewing process.

Figure 3: Screenshot of the Researcher's IMVironment Used for the Online Interviews

The researcher's account was accessed directly through Yahoo, which was password protected to allow accessibility only by the researcher. This enabled the researcher to have full control over privacy and archiving settings during the online interviews (see Figure 4 below).
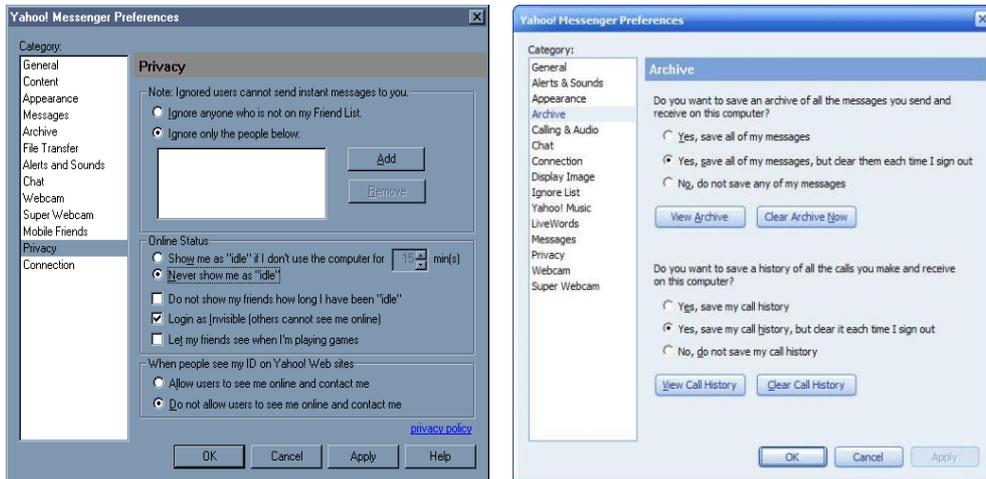
Figure 4: Screenshots of Researcher's Preference Settings for the IMVironment

Both participant and researcher security is taken into account because the IMVironment remains invisible to outsiders, thus making the likelihood of entry by an impostor unlikely.

4.10.4.2.2 The Participant's IMVironment

The separate participant's account was accessed through the 'free' server Meebo.com (see Figure 5 below), primarily to avoid participants having to download and install Yahoo IM and because this account had no archiving facilities. Account preference was username and password protected by the researcher, preventing data storage by participants, which enhanced security. In addition, accessing this account through Meebo.com, rather than directly through Yahoo, enabled the researcher to set the participant account so that it only allowed access to the researcher's account; when activated it was 'invisible' to other Internet users.
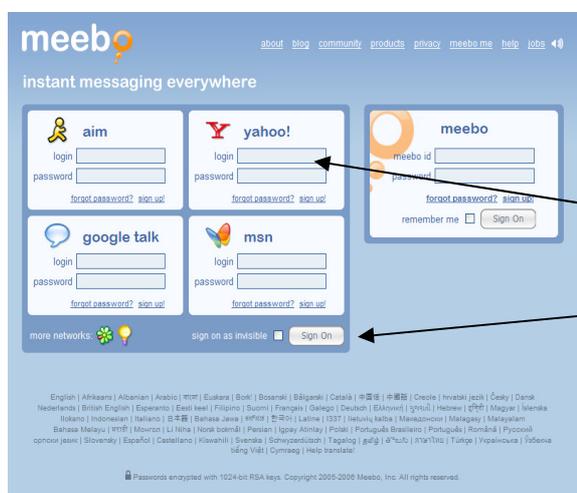
Participants type in the following details to log on to the Yahoo messenger client:

Username: shumvh1
Password: ******

Then click the 'sign on' button. Once signed on, participants enter the participant IMVironment.

Figure 5: **Screenshot of Participant Access through the 'Free' Server Meebo.com**

Figure 6 below shows a visual representation of the IMVironment used by participants during the individual online interviews mediated through IM.

Participants type a response in the box, press 'send' and the response is instantly received by the researcher.

The response and question both appear in this box and remain visible throughout the interview. It is therefore possible for both parties in their IMVironments, to see, read, and reflect on the content and review the script (if necessary) throughout the interview.
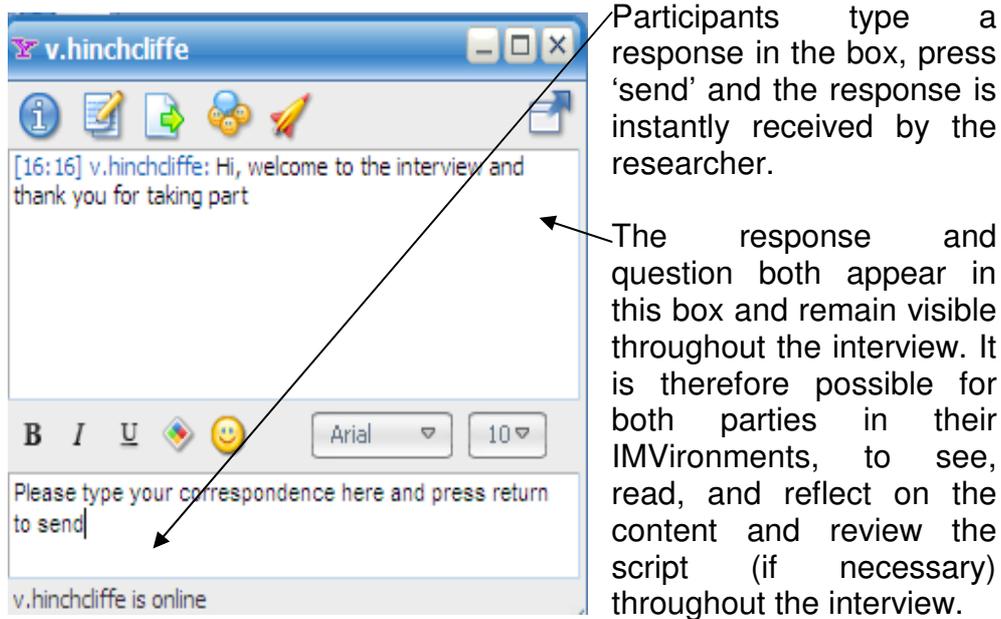
Figure 6*:* **Screenshot of the Participant's IMVironment Used for the Online Interviews**

4.10.5 Data Collection Procedure

After a mutually convenient time and date were set, participants were interviewed, using the amended guide (see Appendix 3, p.461), individually online with no prior time restrictions. The interviews lasted approximately 2 hours with the content based on the six areas of interest.

After the interviews were completed, and whilst still online, participants were thanked for taking part, reminded that they would remain anonymous and asked if they had any questions or concerns regarding the interview. No questions or concerns were raised by any of the participants. When participants exited the participant account, all data in this account were deleted automatically as part of the central programming.

Following each interview, data in the researcher's account was copied, saved into a Microsoft Word document, printed and then deleted from the researcher's IM archive. The researcher then changed the password of the participant account. This prevented participants re-entering the participant account and provided a secure setting for subsequent interviews through the provision of previously unused passwords. Due to the textual nature of the online interviewing technique, transcription was unnecessary. However, the interviews were read to ensure anonymity by changing or removing and any identifying information, such as names and places. For analysis purposes, pseudonyms were used to protect the participant's identity.

4.10.6 Conduct of ESW Online Interviews

In accordance with Guba and Lincoln's (1989) notion of authenticity, the conduct of the interviews was noted (see Ch.4, p.162). Discussion of the conduct of these interviews is provided below using examples of questions from the guide and interviewee responses.

Critical reflection of the conduct - the successes and difficulties of the online interviews - was guided by Kvale's (1996: 145) criteria for evaluating a research interview:

- The extent of spontaneous, rich, specific and relevant answers from the interviewee
- The shorter the interviewer's questions and the longer the subjects' answers, the better
- The degree to which the interviewer follows up and clarifies the meanings of the relevant aspects of the answers
- The ideal interview is to a large extent interpreted throughout the interview
- The interviewer attempts to verify his or her interpretations of the subjects' answers in the course of the interview
- The interview is "self-communicating" - it is a story contained in itself that hardly requires much extra descriptions and explanations

However, more specific to online interviewing, Hine (2008: 311) recommends a:

> …focus on building a relationship. You should aim to put people at their ease by telling them something about the research and giving them enough information about you for them to feel comfortable opening up to you…

Before each interview, ESWs were provided with written information concerning the professional integrity of the researcher and purpose of the interview (see Appendix 1, p.455).

Paying close attention to the construction of the interview guide entailed a clear, temporal structure that enabled participants to relax, provided opportunities for the use of participant's own words, clarification of meanings and resulted in engagement with the areas of interest throughout the online interviewing process.

The interviews took on a friendly and relaxed conversation flow. However, gaining a good level of rapport was difficult using online interviews due to the absence of non-verbal encouragement; for example, nodding, smiling and maintaining eye contact, which according to Arthur (2005), establishes interest in what the participant is saying, thereby encouraging them to provide additional information. This, in turn, may lessen effects of impression management, with participants presenting only favourable images of themselves (Bond, 1982).

However, according to Clarke (2000) it may be advantageous that there is an absence of non-verbal cues in Internet mediated research because "there are no nods, frowns, or yawns to discourage or distract, and misreading of non-verbal cues that result in second-guessing the expectations of the other" (no page number). Nevertheless, Hine (2008) suggests online interviewers "need to make a point of encouraging people to replace the nodding and signs of interest you would display in a face-to-face interview" (p.312).

Hine's (2008) suggestions were applied when conducting these online interviews. As the researcher developed more skills in online interviewing, complimentary phrases were used to compensate for the lack of non-verbal encouragement, such as 'that's very interesting or insightful', and prompts were frequently used to motivate and encourage participant active participation, engagement

and reflection; for example, 'how did you manage that?', or probes to encourage participants to describe their feelings. Thus, a good level of rapport was encouraged by establishing interest, which, in turn, encouraged additional information.

Intentional interruptions can have positive effects, through expressions of enthusiasm or agreements in conversation (Coates, 1988). However, firing off questions and interrupting too quickly can indicate impatience, which may not always be productive; participants should be given time to think (Breakwell, 1990; Kvale, 1996). The online interviewing process promotes good conversational turn-taking skills (see for example, Ng, et al., 1995). For example, a message is displayed when a person is typing, reducing untimely interruption; this promotes a more thoughtful process to be practised, through acceptance of inactivity and short pauses.

Whilst conducting the online interviews, requests were received from some participants for confirmation of understanding of their responses to questions. This presented a challenge for the researcher: how to clarify meanings during online interviewing. Consequently, other interviewing techniques were considered and adapted to make online interviewing more effective. One that proved particularly useful here was the enhanced cognitive interviewing technique, a reconstructive technique based on established

psychological principles concerning memory (see Fisher and Geiselman, 1992). For example, by using various cognitive techniques such as retrieval cues, interviewers can enhance interviewee performance by allowing people to recall, clarify and expand on their accounts. This is achieved by feeding participants statements back to them, word for word. Moreover, Schacter (1996) suggests recollection of an event is likely to be more successful when a retrieval cue reinstates a person's subjective state at the time of the event, including thoughts and feelings.

Thus adapting this technique, it became good online interviewing practice to facilitate expression of feelings and steer subsequent interviews by following up participant answers throughout the rest of the interview series. For example:

> I'm not sure how much help they would be happy with. They would want to have time to be just with other students but I think that they need to learn how to include people who can't communicate with them into a conversation more, by asking more questions with people for themselves, if they can (Anne)
>
> To clarify, are you saying that support outside of lectures could do more harm than good in establishing social support networks? (Interviewer)
>
> I feel that yes, having support workers there makes it less personal as they are usually older. The student might use their own skills to make friends but they might on the other hand be stressed and unable to do this, if they are unable then they need the networking support (Anne)

Thus, statements were differentiated, elaborated and reflected back, sometimes by copying, pasting then re-sending phrases back to the participants for them to clarify their meanings.

A noteworthy advantage for online interviewing was that both parties had access to previous responses, so they did not have to commit information to memory. This was beneficial because it enabled follow-up of unexpected avenues of thought that may have been otherwise missed in conventional interviews.

In total, utilising 'new' communicative technology (see Ch.3, p.117), such as online interviewing techniques, are argued here to have widened opportunity for research inclusion and active participation generally, and specifically for those participants who initially disclosed D/HI and a preference for non-verbal communication (see also O'Neil, 2008; Hinchcliffe, 2009).

Chapter five presents the analysis of the findings from the ESW interviews.

Chapter Five – Analysis of ESW Interviews

5.1 Preamble

The preceding chapter provided an overview of sampling procedures and an in-depth account of data collection methods in relation to phase one. This chapter presents a rationale for the chosen analytical technique - template analysis, and development of the template. This is followed by analysis of the findings from the ESW interviews. Analytical findings are presented pertinent to these interviews, before a summary of the main findings and progression of research within this phase of data collection.

5.2 Rationale for the Analytical Technique

Thematic analysis, using inductive code development (see Boyatzis, 1998), was employed because it is conceptually consistent with both the research aims and data generated from the semi-structured interviews. According to Boyatzis (1998), thematic analysis is a systematic technique used for identifying patterns in, and explicitly encoding qualitative data, it "…offers a vehicle for increasing communication [*between academics*] in ways that researchers using various methods can appreciate" (pp.5-6).

Moreover, using a thematic analytical technique encourages explicit code development that can foster research inclusion between academics through "facilitating communication with a broad audience of other scholars or researchers" (Boyatzis, 1998: 5). Through self-reflexive code development, thematic analysis can aid transparency of the research process and thus may facilitate authenticity (see quality checks in qualitative research Ch.4, p.162). According to Woolgar (1988), self-reflexivity minimises authority and invites other voices into the research relationship, which entails:

> An understanding of the social conditions of social science knowledge (*re*)production and its relation to knowledge reception and context and thus its capacity for action
>
> (May, 2004: 183)

Template analysis (see King, 2006) was utilised here, a coded template representing participant views that researchers perceive relevant to research questions. This type of thematic analysis can be aligned with social constructionism because it does not assume a theoretical perspective. Moreover, thematic analysis is considered conceptually appropriate with the study's highly qualitative data because it is oriented toward researcher reflexivity (von Kardorff, 2004), is flexible enough to handle multiple interpretations of the phenomena in question and allows the presentation of rich description, and comparison of differing, often conflicting, accounts (Watson, 2006). Therefore, an unpretentious analysis of the data is presented. No assertion is made that this is *the* only reading as all

findings "are always ultimately fallible" due to the unpredictability of human behaviour (Pearce and Woodiwiss, 2001: 52). However, the view maintained here is that this reading is as credible as any other.

Participants were thus positioned as expert sources of information; an *emic* type approach (see Harris, 1976) - each version of support experience was viewed as equally credible and presented *in-vivo* - using participants' actual words. The researcher was positioned as a contributor to the research process - "on a par with those they study…albeit with different instruments and for different professional callings" (Latour, 2005: 34).

5.3 Development of the Template

The sections below detailing the template development are intended to describe how codes were developed and changed to produce the final template. Thus, this is not analysis *per se*; rather it is documenting the transparency of the research process, in accordance with Guba and Lincoln's (1989) notion of authenticity in qualitative research (see Ch.4, p.162). Content of the coding is addressed in the forthcoming analysis section (see this chapter, p.218).

The development of the template is set out below coupled with a description of each stage (initial, intermediate and final templates), and how the issues that arose were addressed (more detail of the template developmental process is provided in Appendix 4, p.464).

The template development is guided throughout by King's (1998a; 2004; 2006) techniques, which place emphasis on the use of hierarchical coding.

5.3.1 Creating the Initial, Intermediate and Final Templates

5.3.1.1 The Initial Template

A sub-set of two transcripts were read several times in order to gain an understanding of, and grounding in, the text. To create the initial template *a priori* codes were generated based on the six areas of interest in the interview guide. However, these were modified and added to as the template was developed:

1. Relevant experience
2. Supportive roles
3. Relationship with students
4. Peer support
5. Current support provision
6. Additional issues

Relevant responses to these areas of interest were colour highlighted in the text (a sample transcript is available for scrutiny upon request), and as new codes emerged the initial template was developed

accordingly (see Appendix 4, pp.464-5 for the initial template and further detail of its development).

5.3.1.2 The Intermediate Template

Creation of the intermediate template was not unproblematic. For example, the researcher found it difficult to refrain from analysing the data too early. These issues and others are discussed further (see p.244). Nevertheless, to create the intermediate template, codes with similar content (words/phrases with similar connotation) from various levels, both within codes and across the initial template (see Appendix 4, p.465), were clustered together to produce more general higher-order codes (see Appendix 4, pp.466-8, for further details of the development of the intermediate template). Clustering within codes aimed to prevent overlap in content, whilst clustering across different levels prevented similar content in codes spread across the template. This further facilitated placement of, and distinction between, the content of individual codes, which, in turn, prevented repetition. Two higher–order codes emerged from this clustering; 'Formal Academic Support' that comprised general formal support activities and 'Informal Personal Support' that comprised any support activities outside of formal academic support (see Appendix 4, p.468, for examples of what the intermediate template now comprised within these new higher-order codes and why new lower-order codes were created).

5.3.1.3 The Final Template

The intermediate template was then re-developed by applying it to the whole data set, again by identifying and colour highlighting sections of text relevant to the corresponding codes. These were noted in the margins (an example of a coded transcript, is available for scrutiny upon request). King (2006) notes that this allows flexibility to, "consider multiple interpretations of the data, and discourage you from closing down to one "best" reading too early" (p.1). This technique can also enhance reader confidence in the judgements of similarities and differences (ontological and educative authenticity, see Guba and Lincoln, 1989 and this thesis, Ch.4, p.162). This further allowed insight into the distribution of codes across the transcripts, helping to draw attention to (required) modification of codes.

Revisions were made to the intermediate template (see below for explanations) when relevant pieces of text were inconsistent with an existing code. Insertions (new codes identified in the transcripts not covered by existing codes), deletions (codes that overlap or are no longer of use), changing scope (codes that are too narrowly or broadly defined) and changing higher-order classification of codes (changing sub-category classifications) were made to develop the 'final' template (see King, 2004: 261-263).

A summary of the major changes, made primarily to lower-order coding, is presented in *italicised* text below, and all further changes are shown in *italics* in Figure 7: p.217. The higher-order codes as set out in the intermediate template (see Appendix 4, p.468) were unchanged in the 'final' template (see Figure 7), aside from the incorporation of '*Support skills*' into both '*Professional*' [1.1.1] and '*Personal*' [1.1.2] experience.

Formal Academic Support

Insertions

Arguably, the most noteworthy insertion in the development of the template was '*Mediation of communication*' [1.2.1.1.2.1], added as a descriptive sixth-level code (see Figure 7: p.217 under the second-level code 'Prescribed role' [1.2]). This was in recognition of the researcher's increasing awareness over the course of analysis that mediation of communication was a key theme in much of the ESW's accounts of disability support. However, it represented many existing negative, rather than positive, consequences of 'Formal academic support', such as the difficulties of trying to provide comparable academic experiences for students with SCD in relation to their peers.

Deletions

On reflection, it was decided that the fifth-level code 'Poor support skills' [1.1.1.1.2] (see the intermediate template, Appendix 4, p.468, under the second-level code 'Relevant experience'[1.1]) and its related lower-order codes should be deleted for two reasons: 1) they directly opposed what was considered by ESWs as 'Professional' [1.1.1] formal academic support skills and 2) they overlapped with the 'Poor support' [1.2.2.1.1.5] consequences, subsumed under 'Role confusion' [1.2.2.1.2]. Deletions here prevented parallel coding where "...the same segment is classified within two (or more) different codes at the same level" (King, 2004: 258). The former fifth-level code, 'Covert support' [1.2.1.1.2] (see the intermediate template, Appendix 4, p.468, under the second-level code 'Prescribed role'[1.2]) was also deleted because, being hidden in its nature, it directly opposed any supportive role in the contribution and maintenance of social support networks for students with SCD. Thus, its counterpart 'Overt support' [1.2.1.1.1] (see the intermediate template, Appendix 4, p.468, under the second-level code 'Prescribed role' [1.2]) was also deleted because only this type of 'Formal academic support' remained.

Changing scope

The researcher used this kind of modification extensively throughout the development of the template, primarily to add clarity. 'Support skills' [1.1.1.1] (see the intermediate template, Appendix 4, p.468, under the second-level code 'Relevant experience' [1.1]) was

relocated from the fourth-level to the third-level and integrated with both 'Professional' [1.1.1] and 'Personal' [1.1.2] concepts (see Figure 7: p.217, under the second-level code 'Relevant experience' [1.1]). '*Quality of support*' [1.2.1.2] developed as a fourth-level 'Prescribed role' [1.2] code for the intermediate template (see Appendix 4, p.468), was established as more consistent with the newly-defined '*Professional support skills*' [1.1.1] (see Figure 7: p.217, under the second-level code 'Relevant experience' [1.1]). Therefore, it was relocated as a fourth-level code where it could be integrated to reflect the benefits of '*Standardised training*' [1.1.1.2.1] on 'Professional' formal support (see Figure 7: p.217, under the second-level code 'Relevant experience' [1.1]).

Informal Personal Support

Insertions

In relation to '*Peer support*' [2.2] networks of students with SCD (see the intermediate template, Appendix 4, p.468), the term '*Networking*' was added because it brought to the fore issues around '*Individual support needs*' [2.2.2.1.2.3], also newly inserted but at the fifth-level (see Figure 7: p.217, under the second-level code '*Peer Networking Support*' [2.2]). '*Encourages social integration*' [2.3.1.1.2] was also inserted as a level-five code (see Figure 7: p.217, under the second-level code 'Peer mentoring' [2.3]) as it provided more detailed description of what ESWs considered to be an important '*Positive*

consequence of peer mentoring' [2.3.1]. No further changes were made to 'Informal personal support'.

The above coding is shown in an integrated manner in Figure 7 below.

Findings concerning 'ESW views of their current role in the contribution of establishment and maintenance of social support networks of student with SCD' are presented in the following analysis section.

1 Formal Academic Support

1.1 RELEVANT EXPERIENCE

1.1.1 Professional *support skills*
1.1.1.1 Good communication
1.1.1.1.1 Establishes rapport
1.1.1.1.2 Opens support channels
1.1.1.1.2.1 Access to resources
1.1.1.1.2.2 Access to information
1.1.1.1.2.3 Access to Disability Office
1.1.1.1.2.4 Access to academic staff
1.1.1.1.2.4.1 Mutual satisfaction
1.1.1.1.2.4.2 Mutual confidence
1.1.1.1.2.4.3 Academic integration
1.1.1.2 *Quality of support*
1.1.1.2.1 *Standardised training*
1.1.1.2.2 *Understanding SCD*
1.1.1.2.3 *Support coping strategie*s
1.1.2 Personal *support skills*
1.1.2.1 Confidence with students
1.1.2.2 Acceptance of difference
1.1.2.3 *Insight into support needs*

1.2 PRESCRIBED ROLE

1.2.1 Support priorities and boundaries
1.2.1.1 Formal support
1.2.1.1.1 Positive consequences
1.2.1.1.1.1 *Student achievement*
1.2.1.1.2 Negative consequences
1.2.1.1.2.1 *Mediation of communication*
1.2.1.1.2.2 Disclosure of SCD
1.2.1.1.2.2.1 Student stigma
1.2.1.1.2.2.2 Student non-acceptance
1.2.1.1.2.2.3 Student unrelatedness
1.2.1.1.2.2.4 Student low confidence
1.2.1.1.2.2.5 Student dependency on ESW
1.2.1.1.2.2.6 Peer jealousy
1.2.1.1.2.2.7 Peer distrust in student ability
1.2.1.3 Personal support
1.2.1.3.1 Student referral
1.2.1.3.1.1 Disability Office
1.2.1.3.1.2 Academic staff
1.2.2 Working flexibly
1.2.2.1 Qualifications
1.2.2.1.1 ESW exclusion
1.2.2.1.2 Role confusion
1.2.2.1.2.1 Awkward
1.2.2.1.2.2 Distanced
1.2.2.1.2.3 Time constraints
1.2.2.1.2.4 Poor rapport
1.2.2.1.2.5 Poor support

2 Informal Personal Support

2.1 ESW NON-PRESCRIBED SUPPORT

2.1.1 Extracurricular activities
2.1.1.1 Positive consequence
2.1.1.1.1 Enhances student settling in
2.1.1.1.2 Access to personal information
2.1.1.1.2.1 Medical care
2.1.1.1.2.2 Uni support system
2.1.1.1.2.3 DSA allowance
2.1.1.1.2.4 Entitlements
2.1.1.1.3 Access to additional advice
2.1.1.1.3.1 Enhances student wellbeing
2.1.1.1.3.1.1 Psychological
2.1.1.1.3.1.2 Emotional
2.1.1.1.3.1.3 Understanding
2.1.1.1.3.1.4 Cultural diversity
2.1.1.1.3.2 Increases student social skills
2.1.1.1.3.3 Opportunities to encourage peer interaction
2.1.1.1.3.4 Independence
2.1.1.2 Negative consequence
2.1.1.2.1 Age differences
2.1.1.2.1.1 Power imbalances
2.1.1.2.1 2 Student inadequacy
2.1.1.2.1 3 Dependency
2.1.1.2.2 *Professional boundaries*
2.1.1.2.2.1 *Intrusion into personal lives*

2.2 PEER *NETWORKING* SUPPORT

2.2.1 Close friendships
2.2.1.1 In-depth communication
2.2.1.1.1 Limited peer support
2.2.1.1.1.1 Stifling
2.2.1.1.1.2 Loud
2.2.1.1.1.3 Classroom seating positions
2.2.1.1.2 ESW not involved
2.2.1.1.2.1 Concentrate on formal support
2.2.2 Acquaintances
2.2.2.1 Brief communication
2.2.2.1.1 Polite acknowledgement
2.2.2.1.2 Mediated by close friends
2.2.2.1.2.1 Acquaintance convenience
2.2.2.1.2.2 Enhances close friends Confidence
2.2.2.1.2.3 *Individual support needs*

2.3 PEER MENTORING

2.3.1 Positive consequences of peer mentoring
2.3.1.1 Similar aged
2.3.1.1.1 Sharing experiences
2.3.1.1.2 *Encourages social integration*
2.3.2 Negative consequences of peer mentoring
2.3.2.1 Student commitment
2.3.2.1.1 Mentor frustration
2.3.3 Withdrawal of peer mentoring
2.3.3.1 Human resources
2.3.3.1.1 Financial support

Figure 7: 'Final' Template for ESW Views of their Current Role in the Contribution of Establishment and Maintenance of Social Support Networks of Students with SCD

5.4 Analysis of Findings from ESW Interviews

A list of all codes was compiled for each transcript that corresponded to the 'final' template (see Appendix 5, p.469). "The distribution of codes within and across transcripts can help to draw attention to aspects of the data which warrant further examination" (King, 2004: 266). King's (2004) valuable advice to researchers was taken here in relation to selectivity of themes to pursue "…you must seek to identify those themes which are of most central relevance to the task of building an understanding of the phenomena under investigation" (p.267). It became apparent that 'Support priorities and boundaries' and 'Working flexibly', both indexed by 'Formal academic support', 'ESW non-prescribed support activity' and 'Peer networking support' all relating to 'Informal personal support', were prominent 'common threads' central to research aims 1 and 2 (see Ch.3, p.144) and evidenced by participants throughout the transcripts.

'Professional and Personal support skills' and 'Peer mentoring', were not common threads across the transcripts. Upon re-examination of these themes, the researcher decided that these themes did not add any additional understanding to what was already evident in the aforementioned themes regarding the role of ESWs in the contribution of establishment and maintenance of students social support networks.

King (2004) explicates three possible approaches to presentation of the findings from template analysis – 1) discussion of similarities and differences between cases, 2) using singular cases to illustrate each theme, 3) an account structured around the main themes – utilising extracts from each transcript was chosen because it "most readily produces a clear and succinct thematic discussion" (King, 1998a: 132). At this stage, the analysis will show ESW's views regarding 'Support priorities and boundaries' and 'Working flexibly', 'Non-prescribed support activity' and 'Peer networking support' because they were directly relevant to research aims 1 and 2; these main themes will be presented below, using quotes from all ten transcripts to achieve authenticity (fairness through representing different participant realties, see Ch.4, p.162).

5.4.1 Formal Academic Support

ESWs in this study indicated that the support boundaries of ESW's are set out by Northtown University[15] and national policy. This ensures that formal academic support is prioritised and the consequences of this are presented below. As such, these issues are addressed in the following sub-sections 'Support priorities and boundaries' and 'working flexibly'.

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[15] A fictitious name.

5.4.1.1 Support priorities and boundaries

The issues presented here consider the importance and prioritisation of formal academic support for good student experience, satisfaction and sense of achievement, and its provision as a right and moral necessity. In addition, the importance of social support and how it may be compromised by the boundary between formal academic support and informal personal support is addressed. Moreover, this section looks at how ESWs can find themselves as a barrier to the formation of social support networks.

Those trained and experienced - in this case, mentors - have the confidence to do what they perceive needs doing, regardless of formal academic support boundaries. However, those less trained and experienced - in this case, note-takers and those who provide campus assistance, have less confidence to move beyond supportive practice that is formally set out by Northtown University. This relates to prioritisation of formal academic support, the first issue addressed here.

Glenda, with 6 years' experience in mentoring and co-ordinating student support services, provided a response that typically represented the views of ESWs. She defined formal academic support priorities as purely of an academic type that takes place on the university premises:

> Providing support of an academic nature. In lectures to encourage concentration for SCD/interpreting for deaf students or when meeting with academic staff or structuring essays

This is hardly surprising in the current new-managerialist climate that has created a HE environment in which the focus is almost exclusively on formal academic need (see Riddell et al., 2007).

All participants considered formal academic support to be of utmost importance, to ensure student academic experience is the best it can be:

> I think there should be priorities and first and foremost, formal support should always put the academic support at the top of the agenda and ensure a quality learning environment for a student (Christine, with 9 years' experience in mentoring and co-ordinating/training of mentors)

> I think that being able to let the student know that you understand them is important and being able to provide good physical, mental and technical support is a good thing too (Anne, with 2 years' note-taking experience)

For the majority of participants in the present study, like those in Cremer's (1991), Weiner and Wiener's (1996) and Stanley and Manthorpe's (2002) studies, the priority ascribed to formal academic support had important consequences, including the positive impact upon the sense of satisfaction and achievement experienced by the student:

> Personally I feel that as long as the student is satisfied with their academic work and feels they are achieving the best they can, that is what higher education should be about (Fiona, with 4 years' mentoring experience)

> ...the important thing to remember is the personal perspective of the student and whether or not they are satisfied (Brenda, with 4 years' mentoring experience)

Eric, with 3 months' note-taking and campus assistance experience, sets out a further important consequence of the academic success that prioritising academic support can facilitate such as social inequalities:

> I often feel their academic success is a moral victory – it puts right what is wrong – not with them but with the world we live in and what it does to them, and for that matter, what it does to all of us, sadly

In part, this can be argued to be linked to the competence aspect (feeling capable) of self-determination theory (see Patrick et al., 2007). Participants in the present study seem to be in agreement with Field et al's. (2003) view of self-determination in that wide-ranging academic, personal and social benefit can accrue with the prioritisation of formal academic support. This included a positive learning environment that could lead to a sense of satisfaction and achievement for students and ultimately to a sense that the 'academic playing field' has been levelled and a social inequality mitigated. This is comparable with the growing body of current research findings that argue for a more holistic approach to student support to facilitate retention and progression (see for example, Putnam, 2000; Blamires and Gee, 2002; Elias, 2006).

ESW participants acknowledged another valuable attribute of the positive learning environment, with lectures and seminars being viewed as prime locations for creation and maintenance (or otherwise) of social support networks "...lecture time is really important to them in forming and maintaining relationships" (Ian, with 3 years' mentoring experience). This lends support for Mollenhorst et al's. (2008) survey results, indicating that meeting opportunities are essential for the creation and maintenance of social support.

In this respect, participants also noted that support boundaries can have important negative consequences. Prioritisation of formal academic support also means the opportunity to play a part in the establishment and maintenance of social support networks may be lost as ESWs are unprepared to cross the boundary between formal and informal support:

> ...there is a lot of social activity between students that I don't support, well really I can't support because that's not what I'm there for. So I guess if they can't communicate well enough for themselves or other students aren't willing to accommodate them somehow, the whole friendship thing goes out of the window (Eric, with 3 months' note-taking and campus assistance experience)

Moreover, ESW presence may constitute barriers to students' developing and maintaining positive support networks with their student peers; it is little wonder then that they may feel ambivalent about providing informal personal support. This tension is an interesting issue:

Well just being there I'm kind of in the way; even if by being there I'm helping. I worry most when I see students not talking to the student with communication difficulties directly but talking to me instead - it disrupts any sense of a normal interaction and I just feel that insulates the student from contact with their peers, sometimes I think it isolates them (Eric, with 3 months' note-taking and campus assistance experience)

I worry that doing what I do in some way prevents the student from engaging with the experience like their peers (Glenda with 6 years' mentoring experience and co-ordination of student support services)

These types of negative consequences, both kinds of barriers mentioned above, have been argued to impact on student engagement and connection with the learning community (Levett-Jones and Lathlean, 2007), their feelings of belongingness (Taylor and Palfreman-Kay's, 2000; Martin and Dowson, 2009) and subjective well-being (Pontius and Harper, 2006). Furthermore, they could impact on subsequent development of collective intellectual and personal growth (see Brown and Lauder, 2000).

For example, one participant in the present study explained that the barriers imposed as a result of formal academic support boundaries meant there were instances when she was unable to offer more 'flexible' support and consequently felt the student suffered both academically and personally. This was because the student did not have peer networking support in informal settings. When students get together in informal settings they often discuss academic work and also provide social support to overcome academic related stress:

> It was not just in structured [*formal academic*] sessions that the student needed my support. For example, the student's peers often met informally to discuss academic work but the student I supported was not confident communicating with their peers unsupported. Therefore the student did not attend these informal sessions and may have possibly missed out on support students provide each other with… having friends around may prevent feelings of isolation and alleviate the inevitable stress of meeting deadlines and forthcoming exams. Having someone to talk to can help students to feel cared about (Fiona, with 4 years' mentoring experience)

This lack of social support has been argued by Bronfenbrenner (1974) to be a source of great unhappiness and distress. This finding was not dissimilar to those found repeatedly in the literature, which suggests extracurricular activities are an important part of student experience (Hirst and Baldwin, 1994; Martin and Dowson, 2009). These activities can prevent social isolation (Richmond and Ross, 2008) and can increase a sense of belonging in the academic community (Griffen, 1997; O'Connell, 2005). This is important because research suggests that an increase in student participation with student peers increases the chance of academic success (Lang et al., 1998; Dowaliby and Lang, 1999).

In terms of the establishment and maintenance of social support networks, then, there are clearly identifiable negative consequences relative to formal academic support priorities and boundaries that may have a significant impact upon students with SCD. This issue will be returned to in chapter 8.

5.4.1.2 Working Flexibly

ESWs are aware that level of training and experience affects the degree to which they feel able to 'work flexibly'. Indeed, they are fully aware of the importance of informal support networks for students' sense of satisfaction and their academic achievement. As such, they show awareness as to how they could help develop informal support networks and feel hampered by a lack of appropriate communication skills, such as signing and sense lost opportunities here. They argue that ESWs with the most training and experience should (and do) attempt to fulfil informal support needs. However, they also acknowledge the difficulties in doing so; ensuring they do not act unprofessionally by behaving inappropriately or becoming involved in inappropriate contexts. Level of support experience[16] is considered by ESWs as an important indicator of the extent to which they feel comfortable to work flexibly concerning student support needs.

ESWs indicated that their level of training and experience not only serve to identify types of academic support practice sanctioned by Northtown University's Disability Support Services, but also affect their confidence to work flexibly regarding students' wider support needs.

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[16] In accordance with Northtown University's employment requirements it is essential that mentors are qualified to degree level and undergo specific mentor training, whereas it is not essential that note-takers/campus assistants are qualified to degree level. All ESWs must have knowledge of the Disability Discrimination Act (1995a), some experience of supporting people with disabilities is desirable and they should be prepared to undergo additional training if necessary.

For the majority of ESW participants, working flexibly within a student's support network either reduces or increases, according to their level of training and experience. ESWs pointed out that the less trained and experienced an ESW is, the less likely it is that they will act flexibly concerning students' support needs. Lack of training and experience can also impact on effective working relationships. This left one note-taker feeling excluded from a student's support network; she expressed little flexibility and was resigned to her lack of communication skills as long as professional standards were maintained:

> Note-takers are not as skilled as other support workers…I can't sign to deaf students – it is difficult to build a relationship to give them my advice on where things are, or what I know about the University, as they are much more involved in conversations with the signer, so I go through them [*the signer*]. Once I worked with a deaf student who didn't have a signer and it was hard to know how to communicate with them, so I pointed to the support worker pay slip…but I still felt lacking in skills…There I was mainly a separate entity but I wrote great notes for them so I felt that was enough, it's best not to interfere (Anne, with 2 years' note-taking experience)

It is important to note this link between ESW's training/experience and working flexibly within students' support networks because if ESWs feel unable to work flexibly when the need arises, it may lessen opportunities to promote students' wider social support networks. Another note-taker commented that his lack of training, coupled with formal academic support requirements, impeded the opportunity for integrating the student into academic life, peer

support and friendship networks. This was a shame because peer mediation could offer advantages for students without disabilities; they could have greater opportunity to develop their awareness of the personal experience of SCD and thus enhance student support

> There's a difference for me between doing what I'm there for - academic support - and what happens in a classroom or lecture, well really that I can't support because I'm not educated enough…In lectures and such like I could be more of a mediator, help with communication beyond the academic and try to integrate these students more into the whole group – get the other students to be more aware of the difficulties of living and working with communication difficulties and helping them to become more involved and supportive. Beyond that, I could support friendships by facilitating communication for both students with and without communication difficulties, but don't forget I have no training in this and no formal role requirements (Eric, with 3 months' note-taking and campus support experience)

This lack of training and formal academic support requirements places restrictions on ESW's flexibly within students' support networks; this may amount to a lost opportunity to develop student social support networks and ESWs are well aware of this potential shortfall:

> Academic support – going beyond that is discouraged, well more than that actually…I just want to emphasise the unfairness of the situation I suppose, I'm there to help but in the sense of helping with friendships and social support I am not allowed and I'm not educated enough (Eric)

Less trained and experienced ESWs recognise how this impacts on their role within the students' support networks and would welcome extra training to facilitate not merely peer friendships but effective working relationships:

> …they taught me about autism in the job but I don't think they have offered to teach me signing yet. I would like to know what signs are best in the role of a support worker…if I could sign that would help me to easily build the friendships and I could have made them trust my advice more (Anne, with 2 years' note-taking experience)

However, when asked to discuss formal academic support, an experienced mentor recognised social difficulties experienced by students with SCD and thus the importance of widening participation at university:

> With these students the problems or issues are quite often social and to my mind they do not engage fully in uni life… (Brenda, with 4 years' mentoring experience)

According to the current literature, when students do not feel they have a legitimate place in the learning community this can put them in danger of low self-esteem (Goodenow, 2006), increased stress and anxiety (Saenz et al., 1999) and a tendency toward depression (Sargent et al., 2002). Thus, this recognition by Brenda is important because it may be the starting point of facilitating the widening of social support networks for students with SCD.

Brenda further found that with increased training and experience, came increased flexible working and recognition of individual student need; referring to other services if necessary:

> I find I can interpret it [*formal academic support*] for myself. Support varies enormously from student to student in terms of expectation and need. I see my role as being able to recognise support needs for each individual student and trying to fulfil those as much as I am able within my role and knowing when to bring in other professionals when I can't do anything

As Weiner and Wiener (1996) pointed out there are individual differences among students with regards to their needs and concerns and according to ESWs this may entail working flexibility to meet those needs. For those professionally trained in mentoring students with SCD, working flexibly within formal academic support amounts to advice on student integration and wider student support networks:

> Some mentors are highly trained and will suggest strategies for SCD students to encourage integration with their peers, which is an essential part of both social and academic university life (e.g. working in teams) (Glenda with 6 years' mentoring experience and co-ordination of student support services)

Despite the aforementioned, the boundaries within formal academic support do not necessarily mean that informal personal support needs should be neglected. On the contrary, Christine, with 9 years' mentoring experience and co-ordinating/training of mentors, allows insight into another important aspect, beside formal academic support, that contributes to a quality learning environment.

Addressing students' personal needs may be paramount to students' academic success:

> …we also need to ensure the students holistic needs, at the same time are met. This may mean the personal needs may have to be met in an attempt to meet the academic needs. When using the term 'personal needs' by definition, I believe the formal support should always remain professional…

Moreover, most participants agreed with Glenda's definition of informal personal support as being anything that contributes to "the encouragement of social integration…and widened participation". Fiona, with 4 years' mentoring experience, suggested this is achieved through providing "students with the confidence to communicate with their peers…and access to extracurricular activities", whereas Christine, with 9 years' experience, felt informal personal support further constituted access to "knowledge of the different support systems, like access to medical care".

ESWs at the higher end of the qualification spectrum often work flexibly by exceeding formal academic support boundaries if they consider it central to a student's academic need. Dennis, for example, with 5 years' mentoring experience, sometimes considers it necessary to go beyond formal academic support boundaries to lessen the danger of students with SCD experiencing social isolation, which in turn may affect students' progression:

In some cases it is clearly not enough to give just academic support or even academic plus general personal support. If physical support or other problems are likely to cut a student off from others socially, then his/her experience of university may not be a happy one, and in addition his/her academic work may suffer as a result

Although maintaining professional standards remains paramount, ESWs will work flexibly and offer more than advice by having encounters with students outside of formal academic settings:

If we get along I go to lunch with them, where I provide additional advice often of a personal nature such as, emotional support with relationships, family, friends and student peers. Some support workers go for a drink with the students. I don't usually go beyond the university, just to the café in the uni (Ian, with 3 years' mentoring experience)

In particular, one experienced mentor admitted to 'stepping beyond' formal academic support boundaries; working flexibly was evident on at least one occasion when she organised a reading group to widen a student's social support network. Nevertheless, the success of this venture was difficult to determine:

Although this is not in my remit, I lend a 'listening' ear when I consider this appropriate in relation to easing the working environment and I once organised a reading group to try and facilitate a student with autistic spectrum disorder in making friends on the same course, which contrary to popular opinion, the student was desperate to 'fit' in. However, I do not know how this went because I had to keep a professional distance; I am not allowed to attend student informal activities (Fiona, with 4 years' mentoring experience)

This lends support for the view that informal support is important for students with SCD. Muller et al's. (2008) findings indicate that students with SCD can thrive on social connectedness through activities based on shared interests. However, like Stinson and Whitmore (1992), Kluwin and Stinson (1993) and Stinson and Kluwin (1996) before them, these authors argue that students with SCD are unlikely to participate in extracurricular activities unless ESWs provide mediation of communication.

The stark contrast between those less and those more experienced is an important indicator of the extent to which ESWs work flexibly within students' support networks. Those trained and experienced have the confidence to do what they perceive needs doing, regardless of formal academic support boundaries. Through working flexibly, formal academic support, at least in some cases, can be extended to include the establishment and maintenance of social support networks for students with SCD. Providing opportunity to widen participation, integration and enhance student well-being all has important implications for HE policy and practice; this will be discussed later in chapter 8.

5.4.2 Informal Personal Support

The issues presented here consider the highly contentious activity of informal personal support. Informal personal support made ESWs feel uncomfortable due to the large age gaps often present between ESWs and the students they support and because they considered it inappropriate as it crosses professional boundaries. Nevertheless, it was performed by experienced mentors at the higher end of the qualification spectrum through non-prescribed support activities and by student's peers. Issues around both non-prescribed support activity and peer support are presented in more detail below.

5.4.2.1 ESW non-prescribed support activity

ESWs feel that if the need for student informal personal support during the transition period is not recognised students may experience difficulties accessing support systems and developing social skills essential for peer integration. This may leave students' in danger of experiencing isolation from their peers and in turn affect their well-being.

For one ESW, there is an uncomfortable blurring of boundaries between formal academic and informal personal support:

> …there's a debate where the support should end i.e., whether it should become more than providing a service to meet the student's academic needs and cross over into meeting personal needs of students (Christine, with 9 years' experience in mentoring and co-ordinating/training of mentors)

Glenda, with 6 years' mentoring experience and co-ordination of student support services, provides insight into the reasons why she advocates the provision of informal personal support for students. The transition period - not just moving away from home but into tertiary education - can prove particularly difficult because of student unfamiliarity with HE support practices:

> Some are aware of the help that is available and are very secure when they arrive. For many it is the first time they will experience independence and life away from home and the support structures that they are familiar with…Many don't realise that the support system is different from in school/college and may turn up at the Disability Office expecting a mentor or signer to be available "on tap"

This lends support for Lowe and Cook's (2003), Wilcox et al's. (2005), Heiman's (2006), and Goode's (2007) research findings, that the transition period can be a difficult time for some students. This is because students struggle to adjust to university life, feeling homesick due to a lack of familiar support from family members, which can impact on their self-confidence and in turn affect retention and progression.

Regardless of level of experience, ESW's non-prescribed support was considered by most participants to be an activity that was instrumental in balancing formal academic and informal personal support. One reason was to alleviate student isolation:

> I think support shouldn't end at the classroom door so to speak. If students feel isolated and are prepared to admit it, then that is a need that is a consequence of the way we structure academic experience and we should address it. Why is it we think students need support in academic situations but not social ones? The logic doesn't follow – unless we have some reason to think social lives aren't important (Eric, with 3 months' note-taking and campus assistance experience)

However, such an interest in informal personal support was not construed by ESWs as simply a response to what they considered was lacking in student disability support: support for students outside of formal classroom environments to integrate them into all aspects of university life. Contrary to previous research findings on integration, such as those from Griffen (1997), Pescosolido (2001), and Blamires and Gee (2002), ESWs recognised informal personal support as a way to meet an individual student's need to develop social skills through widened participation "whilst ever we don't recognise this we run the risk of isolating these students" (Eric, with 3 months' note-taking and campus assistance experience).

Moreover, the findings in this study compliment Hirst and Baldwin's (1994) and Martin and Dowson's (2009) call for support to be extended to extracurricular activities to alleviate social isolation

(Richmond and Ross, 2008) and increase a sense of belonging in the academic community (Griffen, 1997; O'Connell, 2005). In particular, participants in the present study, like those in the aforementioned, considered that there was a need to facilitate the establishment of student social support networks outside of the formal classroom environment to gain wider university experience and facilitate student access to network capital - social capital such as resources that are flexible, efficient and effective (Plickert et al., 2007: 406). This can enable students to integrate in the learning environment:

> One student with SCD did not take up opportunity for social support from potential friends because they did not feel confident enough in social situations, so the relationship here was restricted to a classroom environment. Lots of other social activities are occurring daily at university, such as students meeting for coffee and other extracurricular activities that are also part of the university experience, whether students meet to discuss academic work or not be the case, just having a friend around may prevent feelings of isolation (Fiona, with 4 years' mentoring experience)

In addition, it is argued in the literature that to maintain efficient educational communities, it is important that communication frequency (Wood and Smith, 2005) and student-to-student discussion channels remain open (Palloff and Pratt, 1999). Similarly, most participants in this study agreed that: "Support workers should be able to deal with students desire to fit in" (Anne, with 2 years' note-taking experience); this was considered crucial during the transition period for the development of social support networks and student well-being outside of the classroom:

> I believe support for students with any disability should be provided outside of lectures to encourage development of social support networks, especially in the early days at university when social networks are fragile as I believe it's difficult making the transition to university and even harder still with a disability (Christine, with 9 years' experience)

This coincides with Blamires and Gee's (2002) assertion that "the role of support workers may just begin when the lecture ends as the student with social communication difficulties may need support in unstructured time" (p.22). Glenda, having 6 years' mentoring experience and co-ordination of student support services, supports this view and sums up what she and others consider as *the* major limitation in formal academic support. Funding bodies' interpretation of student disability support overlooks the significance of social integration:

> Whilst the bodies who hold the funding continue to interpret support at university in the narrowest possible academic way it seems that the importance of social integration will be passed over

ESWs feel that failing to recognise the need to facilitate the establishment and maintenance of wider social support networks outside of the classroom environment is important. This is because students new to the University may experience a difficult time accessing support systems and developing the social skills needed to ensure effective peer integration. This may result in student isolation and may affect student well-being. This will be further discussed in chapter 8.

5.4.2.2 Peer networking support

Currently, there is tension between ESWs regarding their provision (or not) of informal personal support in terms of providing students with relationship advice, developing their social skills and peer networking. ESWs do recognise that if there is a clear need, students with SCD should have access to peer networking support to encourage establishment and maintenance of social support networks and enhance integration. However, some ESWs who undertake peer networking support feel uncomfortable doing so because it is age inappropriate and crosses professional boundaries. This tension between ESWs is presented below.

Students' peers also undertake informal personal support. Current theory and research suggests this is reliant upon student proximity, opportunities for meeting (Mollenhorst et al., 2008), and quantity of peer friendships (Ueno, 2005). Contrary to this, participants in this study raised the issue that this may be associated with ESWs generally being older than the students they support, a point, to date, which appears not to have been identified in the literature. The importance and success of student peer support was construed by the majority of ESWs as being a consequence of ESWs age and similar aged peers, who can give students with SCD confidence to communicate:

> If you have communication difficulties you are confident
> with people your own age…They [*similar aged peers*]
> talk to them more than other students – they ask them a
> lot of questions to encourage conversation out of them
> (Anne, with 2 years' note-taking experience)

This mirrors Avis et al.'s (2002) notion of the formation of communities of practice through dialogic engagement where it is argued "the importance of peer relations and dialogue anticipates the acquisition and formation of collective intelligence" (p.34). However, establishing and maintaining these important peer relationships is not straightforward, nor should it be the sole responsibility of the student, rather the university should take some responsibility for this:

> Some make supportive friendships but others find it
> difficult to get into those kinds of relationships and
> some don't try. There are a lot of unhappy students out
> there because of this but this really hides the issue that
> should be addressed – it shouldn't be left to the student
> with communication difficulties to tackle these issues –
> they have a need and we should address it (Eric, with 3
> months' note-taking and campus assistance
> experience)

Fiona, with 4 years' mentoring experience, expands this point by drawing attention to the importance of ESWs striking a balance between student interdependency and independency - a contentious issue surrounding mediation of peer relationships:

> Just being there for this particular student provided
> them with the confidence to communicate. If they
> needed me to mediate between them and their peers
> through interpretation of both verbal and/or non-verbal
> communication, I could be 'on hand' but this should not
> be intrusive because students also need the time and
> space to develop their own coping strategies

Because mediation of peer relationships is an unrecognised, non-prescribed support activity, this left Fiona feeling agitated at not being allowed to assist in the establishment of peer support networks. Particularly, as she felt the student would subsequently have maintained these networks for themselves:

> Frustrated. I felt that once this particular student had an established social network that they would have been more confident, at least with peers on their course, to maintain these friendships for themselves. I felt that if I had facilitated this interaction initially, then I would have been able to have pulled back slowly until the student was confident enough to manage their social interaction independently

Age again plays a part, but this time in an adverse way. Due to the large age gap often found between themselves and the students, the majority of ESWs considered mediation of peer relationships an inappropriate activity. Students could be perceived as lacking in confidence, and incapable of taking responsibility for their own learning, which reinforces arguments that power relations may be implicit between people of different ages (see Case and Marshall, 2008):

> Having support workers there makes it less personal as they are usually older. People tend to prefer those of the same age and therefore when an older support worker is added to a group where most students are younger they might feel less powerful or less intelligent or less confident with older people there to interact with their peer group (Helena, with 4 years' note-taking experience)

It is not surprising then that most ESWs consider providing mediation of communication between students and their peers too risky and problematic; it is not their job, nor should it be: "I think it would be difficult for an academic support worker to fulfil this role because of the blurring of boundaries" (Glenda, 6 years' mentoring experience and co-ordination of student support services). Pertinent to this point is that ESWs are not allowed to include themselves in student peer relations because "it crosses professional boundaries, intruding into student personal lives" (Janet, with 1 years' note-taking experience). Similarly, Darwin (2000), Murray (2001) and Eby and Allen (2002) imply that the negative consequences arising from unequal power relations can impact on student independence and autonomy. This, in turn, may be argued to hinder, rather than, foster social support networks.

Nevertheless, all participants alike called for networking support, but not provided by ESWs, to develop peer relationships, alongside formal academic support "if there is a clear need" (Dennis, with 5 years' mentoring experience) and "especially if this is supported by evidence" (Christine, with 9 years' experience in mentoring and co-ordinating/training of mentors). Although, participants were unsure about the amount of peer networking support that students would consider appropriate, they did comment on the value of this as a way in which the quality of the university experience could be improved for all concerned through the encouragement of social networks:

> I think it is a good idea but I'm not sure how much help they would be happy with. They would want to have time to be just with other students but I think they need to learn how to include people who can't communicate with them into a conversation more…I think that they could communicate but didn't know it, well didn't want to perhaps…but they might on the other hand be stressed and unable to do this, if they are unable then they need the networking support (Anne, with 2 years' note-taking experience)

In part, this lends support for Blamires and Gee's (2002) and Zellers et al's. (2008) findings where they suggest using more than one support worker, or team support, to provide both formal academic and informal social support if there is a need to do so. However, these ESWs make it clear that providing peer networking support should not be part of their role.

ESW's construction of students with SCD as diverse, having unique needs, necessitates for them the consideration of all issues relating to student experience whilst attending Northtown University:

> This uniqueness should be appreciated more and taken into account when allocating student support, wherever possible support should be tailored to fit student individual need, which will inevitably change over time (Fiona, with 4 years' mentoring experience)

Support should be responsive to students' need on their terms: "Support that is given should respond to the needs of the student which is driven by the student" (Christine, with 9 years' experience). Moreover, consulting students with SCD is a good way of discovering how to support the development of positive social support networks

"we need to know how to encourage friendships and support, only the student with communication difficulties can tell us how" (Eric, with 3 months' note-taking and campus assistance experience).

ESWs currently provide informal personal support through non-prescribed support activities, giving additional advice and developing student social skills. However, they feel uncomfortable providing peer networking support because they feel it is age inappropriate and crosses professional boundaries. Nevertheless, they do recognise that if there is an identified need, students with SCD should have access to peer networking support to encourage establishment and maintenance of social support networks and enhance integration. This is discussed further in chapter 8.

5.4.3 Reflections on the Analytical Process

Template analysis was utilised to analyse a set of data from semi-structured interviews with ten ESWs. These interviews addressed research aims 1 and 2 (see Ch.3, p.144). This analytical technique was flexible enough to be conceptually appropriate with the highly qualitative and naturalistic approach taken throughout this thesis. The participant-oriented and self-reflexive social constructionist stance sought to explore student social support networks from the unique perspectives of ESWs, whilst taking account of the researcher's personal actions, thoughts and prior experience (Steier, 1991). This allowed the researcher to address the first and second

research aims by providing interesting and insightful information that extended existing knowledge in the area.

Although the researcher aimed to ground the analysis in the experiences of ESWs, the researcher's academic knowledge inevitably informed the research process. The selection of aspects of the data to concentrate on, the types of questions asked and interpretation of the findings were those of the researcher. Each was ultimately open to the effect of prior academic experience (Lincoln and Guba, 1985). This meant that coding of the themes may have been unduly influenced by prior knowledge and can be argued to be problematic, with the findings merely artefacts of the research process. This was addressed through rater-to-expert checks (see Smith, 1992). As such, an outside 'expert' in template analysis checked the development of the template and was confident in the clarity and comprehensibility of the final template.

It is recognised that in qualitative research, the researcher has a central role in data generation, analysis and interpretation, and therefore cannot remain detached (Mason, 1998). The researcher drew upon experience as a former ESW to stimulate thoughts about various emerging codes during analysis, and obtain insight into what participants were describing. However, the researcher did not impose this experience on the data; rather, she remained aware of and

questioned assumptions and interpretations of the data before any decisions were made (critical self-awareness, see King, 1998b).

The structured approach of creating, developing and revising the template in accordance with research aims 1 and 2 was straightforward to administer and delayed commitment to a set template. Frequent comparative techniques such as revisions, insertions, deletions and changing scope of the codes strengthened the dependability of the findings (King, 2004). However, the researcher 'got into' analysis too early, particularly in the intermediate template, interpreting the meanings of the codes, rather than providing rationale of the development. Getting into analysis too early can amount to a loss of meaningful units of analysis because the researcher closes down to one 'best' reading, preventing consideration of multiple interpretations. Thus, a conscious effort was made to ensure rationale of the developmental process by reviewing explanations and phrases/words, checking that they related to the intermediate template development, rather than analysis. This reiterates the importance of employing rater-to-expert checks (Smith, 1992).

Furthermore, data is almost inevitably lost through any data reduction techniques, narrowing responses to those relevant to the research aim and seeking out of prominent 'common threads' was not unlike quantitative content analysis (King, 2004). King (2004) suggests

deviant case analytical techniques to raise the efficacy of the findings and prevent the loss of individual participant voices - missing vital perspectives from 'single views' that may be just as important as 'majority views' (see Silverman, 2005). This entails seeking out 'unique' codes, in this analysis 'Peer mentoring' and its withdrawal. In future, these can be derived from the aggregated list where text from the ten transcripts was indexed to the final template (see Appendix 5, p.469).

5.5 Chapter Five Summary

A template analysis of ESW interviews produced a number of important themes, which have contributed to 'new' knowledge in the area of student social support networks by addressing the relative paucity of ESW research.

Those ESWs with the least training and experience tend to be more rigidly constrained by formal academic support priorities and express little flexibility, both inside and outside of the classroom environment. As a consequence, they do little to contribute to the establishment and maintenance of social support networks of students with SCD.

Although they are also somewhat constrained by formal academic support priorities, ESWs with more training and experience express greater flexibility. Currently, they are willing to extend formal academic support outside of the classroom environment by giving

students advice and helping to develop their social skills to facilitate the establishment and maintenance of social support networks. However, they are reluctant to engage in peer networking support because by practicing this type of activity they are in danger of crossing professional boundaries and evoking unequal power relations. This can have serious negative consequences, such as increased student dependency, lack of autonomy and subsequent isolation from their peers, which may serve to override any positive outcomes.

Nevertheless, all participants, regardless of training and experience, agree that if there is a clear identified need, supported by evidence, students should have access to peer networking support to encourage social integration. However, who should provide this peer networking support remains unclear at this phase of inquiry.

In total, these findings have added to previous literature in the area of student social support networks. However, Boyatzis (1998) suggests a further cross-validation study is always desirable to further authenticate that the themes identified are "not an episodic or idiosyncratic occurrence" (p.51). To progress this research, these findings will be compared with findings from student views, this could add strength by clarifying the relative importance of factors such as the effect of formal academic and informal personal support to the retention and progression of students with SCD.

Phase two, see forthcoming chapters 6 and 7, will thus focus on gaining the views of students with SCD to meet research aim 1: 'Explore how the current role of ESWs contributes to the establishment and maintenance of social support networks of students with SCD', and research aim 2: 'Assess the contribution of formal academic support to students with SCDs' retention and progression'.

THE SOCIAL SUPPORT NETWORKS OF UNIVERSITY STUDENTS WITH SOCIAL COMMUNICATION DIFFICULTIES: THE ROLE OF EDUCATIONAL SUPPORT WORKERS AND THE IMPLICATIONS FOR RETENTION AND PROGRESSION

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Table of Contents

List of Tables and Figures

Tables

Figures

Chapter Six – Phase Two Method and Procedure

6.1 Preamble

This chapter provides sampling and recruitment procedures, diary schedule development, and an in-depth account of data collection methods in relation to phase two.

A number of issues relating to sampling, recruitment and data collection need to be considered when undertaking disability related research, such as definition and classification of impairment and disability and the suitability of the data collection method, not only epistemologically but its appropriateness with the sample. Sampling and recruitment issues, followed by the rationale for the data collection method, its design, materials and procedures are each addressed below.

6.2 Student Sampling and Recruitment

Assuming a social model stance, by rejecting a medical model framework - disability as a disadvantage/restriction caused by social organisation (see Oliver, 1996; Barnes, 1997; Finkelstein, 2001) - is problematic for any researcher within disability-related studies. Sampling issues, for example, can invoke sharp contrasts between a practical application and legal specification of definitions of impairment and disability. Research under the social model

framework aims to address barriers in society, whilst official legislative definitions, such as the DDA (1995a), classify disabilities as the inability to perform an activity due to the presence of impairment. Researchers, regardless of their conceptual stance, have to acquire a sample that is representative of a group within society. Without the use of classification criteria and diagnostic terminology, so frowned upon by the social model of disability, this task would be impossible because medical discourse of disability is grounded in medical description, which is the only one currently available to obtain a group of people experiencing similar difficulties (Disability Rights Commission, 2007c).

Nevertheless, tension exists concerning differentiation of the sample from the population without classification. It is recognised here that universities use medical definitions as the criteria to determine student need and allocate support services such as Disabled Student Allowance (DSA) – financial assistance to pay for non-medical educational support and equipment (Riddell et al., 2005). These criteria were used only as descriptors for sampling, not classification purposes, to avoid stigmatisation and stereotyping often found within the medical model of disability (Hahn, 2001).

As with the ESW sample, this sampling approach was also purposive. Again, potential participants were contacted via letter and email by the University Disability Support Services, inviting

participation in the study (see Appendix 6, p.475) if they met the inclusion criterion: university students with SCD in receipt of a formal assessment of needs that qualifies them for DSA to pay for non-medical support (as noted above).

Participants expressing an interest in taking part independently contacted the researcher to arrange a meeting via an official University email address. Participants were met individually to affirm the legitimacy of the researcher, establish rapport and acknowledge participants' commitment to the study. So as not to compromise anonymity for those who were deaf, interpreters were not used during these meetings. Instead, following a recent course in British Sign Language, the researcher communicated with these participants using basic BSL and a miniature dry wipe whiteboard. These in-person meetings also provided the opportunity for the diary-keeping procedures to be explained, and allowed participants to practice accessing and completing the web-based diary using the specifically devised manual (available for scrutiny upon request). If participants preferred no in-person contact, recruitment and training was conducted entirely online. If necessary, all ethical formalities (briefing, obtaining informed consent and debriefing) and the web-based diary accessibility manual were sent via email using official University addresses.

Seven student participants (2 female, 5 male), each with Internet access both on and off campus, were subsequently recruited from a population of 36. Ages ranged from 18-45 and 50% were repeating a year. It is interesting to note that the entire sample had comorbidity - other conditions alongside SCD which may have impacted on their studies from time to time (see Table 2 below). This being a heterogeneous group, the expectation was that different backgrounds would reveal more aspects and perspectives relevant to the research aims (Flick, 2006).

Table 2: Students with SCD Details

Participants[17]	Sex	Age Group	Year of Study	Comorbidity
Alan	Male	41-45	Repeating 2nd year	Severe dyslexia; dyspraxia (see British Dyslexia Association, 2009)
Matthew	Male	18-20	Repeating 1st year	Attention Deficit Hyperactivity Disorder (see Faraone et al., 2003)
Cassandra	Female	21-25	2nd year	Mild dyslexia
Maria	Female	31-35	Repeating 3rd year	Social Avoidance Disorder (see Bruce and Saeed, 1999)
Dean	Male	31-35	2nd year	Profound dyslexia
Phil	Male	26-30	3rd year	Visual impairment
Joshua	Male	21-25	2nd year	Brain damage

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[17] Pseudonyms were used.

6.3 Ethical Issues

As with the ESW online interviews, all ethical principles in accordance with the Economic and Social Research Council guidelines (2006: sect.3.2.1) were applied (see Ch.4, p.176). In addition, written information informed participants that privacy could not be totally guaranteed over a public network and of the need for participants to guard their own privacy and that of significant others by not revealing sensitive information unrelated to the study (see Appendix 6, p.475).

6.4 Phase 2 Method

6.4.1 Rationale for the Data Collection Method

A significant limitation in research conducted into student support is the use of methodologically narrow research designs that mask the fluid, ever-changing nature of support networks. The support network literature is dominated by studies using static designs that capture snapshots of human experience as fixed and unchanging. This presents important methodological concerns, such as the potential for making false inferences of within-person change from results using between-person comparisons (Affleck et al., 1999). For example, evidence indicates that estimates of student support obtained from static designs can mask variation in within-person support in terms of both extent and direction (Kenny et al., 2002). It is

important to capture change because, as Allan (1993) asserts, social support networks are not static; they alter according to levels of both interdependency and dependency, and they change, not only in relation to choice but also social context.

Silverman (1996) and Plummer (2001) both assert that preferred data collection methods for qualitative research tend to use not only static designs, but are over reliant on verbal, in-person interviews. However, conventional interviewing is unsuitable for this sample of students with SCD because they tend to prefer text-based rather than verbal-based communication (see Blamires and Gee, 2002; Frith, 2003).

Conventional in-person interviews have been found to be problematic for people with D/HI, both for the researcher and respondent (see Ch.4, p.181 and Bowker and Tuffin, 2003). Translation of British Sign Language raises issues of correctness of interpretation (see Temple and Young, 2004). Similarly, in-person interviews have also been found to be problematic for people with ASD, who are argued to be more comfortable with alternative forms of communication, such as text-based email and mobile telephone text (Blamires and Gee, 2002).

The text-based diary is an alternative data collection technique to interviewing, albeit less frequently used in qualitative research (Elliott, 1997; Plummer, 2001; Milligan et al., 2005). The primary strengths of end-of-the-day diary designs are the ability to capture the individual's daily accounts of activities/events (Symon, 2004) and "their flexibility to capture and examine fluid phenomena" in their immediacy (Bass et al., 2007: 57). Diaries can collect participants' subjective knowledge, reflective experience, emotions and meanings of their support networks (Välimäki et al., 2007). A fluid conceptualisation of student social support is necessary because student experiences of social support networks can be transient in nature and/or changeable (Allan, 1993). It is argued below that diaries are a viable data collection tool that is suitable for this particular student sample.

Although diaries do not offer the nuances (distinctions achieved through tone of voice) present in verbal communication (Begley, 1996) being a text-based medium, they may ease the communication pressure for participants with SCD. This may, in turn, enhance access to their experience and data quality:

> Face-to-face contact during normal conversations is too stressful, they [*people with SCD*] are under less pressure and can think better when they read and write

> (Frith, 2003: 125)

Furthermore, participant diarists have a major part to play in the decision-making process of which activities/events to record, making their reports self-initiated. This may facilitate the capturing of participants' own priorities and understandings about activities/events in question (Milligan et al., 2005). The use of diaries for data collection purposes is discussed below.

6.4.2 The Use of Diaries for Research Purposes

The researcher found it helpful to follow Allport's (1942) lead, in which three types of diaries were distinguished. These are framed here under the terms: research 'log', unsolicited 'intimate' diary and solicited 'impersonal' diaries. The research diary provides a 'log', with relatively little commentary, of the researcher's activities and reflections. The diary, as an unsolicited 'intimate' document, is pre-existing, written spontaneously by the diarist, not at the request of a researcher. However, the solicited 'impersonal' diary is a *researcher-driven-diary* devised by a researcher with specific questions for the participant diarist to record current activities/events of interest to the researcher (Elliott, 1997).

Bryman (2004) considers the *research-driven diary* as being akin to a self-completion questionnaire or structured observation when questions are framed in terms of quantitative research, or alternatively as ethnography when questions are framed in terms of qualitative research. The former version of the *research-driven diary*

(framed in terms of quantitative research) focuses on *time sampling* and has a general appearance of a questionnaire, largely with closed questions used to record current 'time-use' – the amount of time engaged in a particular activity/event. Elliott (1997: 2) explains this design can be regarded as more credible than questionnaires because the proximity to the present allows:

> …the closeness between the experience and the record of experience means that there is the perception at least that diaries are less subject to the vagaries of memory, to retrospective censorship or reframing than other autobiographical accounts

However, this design, having no contextualisation, is inappropriate for the purposes of this research because it would not invite 'rich' descriptions (see Geertz, 1973) that can facilitate a deep and broad understanding of student experiences.

The latter version of the *research-driven diary* (framed in terms of qualitative research) centres on *time and event sampling* with more open questions. This allows information on sequential time-use (which activity/event followed which) and researchers can track activities/events as closely as possible to when they occurred. Additionally, this design has the added benefit of providing increased opportunity to understand the context in which student support is subjectively experienced; the participant diarist can therefore be instructed on both the context and content provision, such as:

- The nature of each activity/event
- Participant details and location
- Duration of the activity/event
- What participants thought and how they felt about the activity/event
- What activities/events preceded and followed
- How they might do things differently next time

(Adapted from Bryman, 2004: 141)

Thus, notable strengths of qualitative research diaries, which use *time and event* sampling methods, include precise estimates of time frequencies, the ability to capture activities/events close to when they happened and the potential to trace activities/events over continuous time enhanced with contextual information (Mechanic, 1989). Moreover, through anonymity participants are more likely to divulge sensitive information than in a face-to-face interview (Verbrugge, 1980).

Three main diary templates are used by researchers for data collection purposes – traditional paper and pen booklets, electronic devices and web-based interfaces. Each of these is assessed in more depth below.

6.4.2.1 Traditional paper and pen diaries

The primary data collection technique for daily or weekly diaries has traditionally been paper and pen booklets. Bass et al. (2007) considered several disadvantages of this method, suggesting the most problematic is the inability to monitor diary completion. During

the data collection period, the researcher cannot determine if participants are completing the diaries when they should be, or if they are completing them at all. Another major limitation of paper and pen diaries is that they can be subject to back-or-forward filling - participants complete a diary entry one or several days late or in advance, consequently their responses may be influenced by retrospective reconstruction, fabrication, memory lapse and/or current mood. According to Piasecki et al. (2007), this "defeats the purpose of using diary data to gain a recall-minimising perspective on daily experiences" (p.28).

Jamison et al. (2001) report that when compared with electronic data collection techniques, paper and pen diaries have lower completion and satisfaction rates, they are less private and may not promote complete honesty of answers. This is of particular importance when researching personal information about student social support networks. Overall, paper and pencil modes of data collection for diary studies may be problematic in terms of participant satisfaction and compliance, suggesting the need to review and develop alternative data collection strategies (see below).

6.4.2.2 Electronic diary devices

Collecting diary data electronically is mainly undertaken in basic health-related and clinical research settings, using Personal Digital Assistants (PDAs). Research evidence suggests that when compared with traditional paper and pen methods PDAs may yield more high-quality data (Wright et al., 1998; Velikova et al., 1999; Jamison et al., 2001; Stone et al., 2003; Bass et al., 2007). Collecting data electronically using PDAs provides the potential to address some of the aforementioned issues faced when using traditional paper and pen diaries.

Using PDAs allows greater privacy for participants as others cannot access their diary entries because they are password protected. Therefore, more honest reports of activities/events may be recorded because of increased anonymity (Wright et al., 1998). PDA devices are portable, allowing experience to be captured as it occurs. The ability to time and date stamp entries raises the credibility of the data because researchers can verify each diary entry and identify those submitted outside of specified time and date protocols, drawing attention to any cases of back-and-forward diary completion. Software can be programmed to prevent back-and-forward filling once participants submit an entry (Piasecki et al., 2007).

However, there are disadvantages when using PDAs for data collection; they are expensive to purchase and costly to replace if lost, both in terms of finance and data. PDAs have a short battery life, therefore limiting the amount of data that can be entered in one day, and, worse still, Bass et al. (2007) experienced both data and programming loss through a total loss of battery power. The screens are particularly small making data entry difficult, and the data needs to be downloaded to a central computer (Piasecki et al., 2007).

6.4.2.3 Web-based diary interfaces

It is argued below that creating an exclusive web-based diary interface using an Internet website for collecting *researcher-driven* data[18], may alleviate the aforementioned disadvantages associated with PDAs and provide advantages for data collection outside of health and clinical settings.

Web-based diaries have disadvantages for data collection purposes relative to PDAs because they require participants to have Internet access, and logging on to a computer may be inconvenient at times (Piasecki et al., 2007). However, according to Hookway (2008) they offer several advantages over PDAs:

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[18] As opposed to using a 'Weblog' data source of existing unsolicited diary information, such as 'Blogster' and 'Livejournal', see Hookway (2008) and 'Facebook' see Steinfield et al. (2008).

- There is no need to download or transcribe data as the textual diary entries can be submitted and instantaneously received into a secure email account
- The opportunity for daily or weekly completion monitoring
- The viewing screens are larger and more user-friendly than PDAs
- Anonymity may produce relatively unselfconscious accounts of activities/events
- Access to geographically or socially isolated participants
- They are low cost, relatively free in most cases

Moreover, participants can modify the web-based computer-mediated environment to suit their particular needs. Pietra et al. (2005) set out a range of computer modifications that can enable people with difficulties or disabilities to access and utilise Internet and computing technologies. For example, people with visual impairments and severe dyslexia can utilise computer technologies such as screen readers, "a software program that reads the contents of the screen aloud to a user,…text magnifiers, such as Zoom Text to enlarge and view defined sections of a computer screen,…talking word processors,…text-to-speech readers to hear audio voice feedback for text and obtain automated help with word choice and spelling" (p.8). In addition, people with mobility difficulties, for example, cerebral palsy, can utilise personal computer modifications such as 'Tablet PCs' - the computer screen converts into a horizontal writing tablet and hand written text is converted into a word processed document, which can "be used with other programmes to send email or to chat with friends" (Baddeley, 2007: 165).

The computer environment is adaptable for people with visual, physical, medical or specific learning difficulties such as dyslexia - difficulty with words, dyspraxia - difficulty with fine motor skills (see Holford, 2007), thus facilitating opportunity for active research participation. Pertinent to this research, Eminovic et al. (2004) replaced the National Health Service Direct telephone advice line with a web-based format as the communicative medium. Findings suggest that the public regarded the web-based format as an innovative communication method that was particularly emancipatory for people with speech problems, those who are deaf, shy, or have dysphasia or other types of speech difficulties.

In light of the research participants in the present study being computer literate HE students with SCD, research in this area can be enhanced through emerging web-based technologies, which can carry great potential for providing innovative and individualised participation. For instance, Goodwin (2008: 126-127) considers emerging technology for enhancing autism research and claims:

> Many people with autism are highly interested and motivated by computers…in a way that is more engaging and less stressful than face-to-face human interaction…[*they can*] organise their materials, establish schedules, and provide cues for completing day-to-day tasks

In addition, Valentine et al. (2006) surveyed 419 people with D/HI concerning the role of the Internet in providing inclusion in the information society. Evidence here suggests 79% of deaf/hearing impaired people were more likely to use web-based technology for instrumental purposes on a daily basis than the general population (59%), such as health information, employment, online banking, email and to chat with other deaf/hearing impaired people. In addition, 45% of deaf/hearing impaired people who utilised web-based technology felt that it raised their self-confidence due to feeling less discriminated compared with everyday face-to-face situations. Moreover, 70% of deaf/hearing impaired people specified that web-based technology had improved their quality of life.

Thus, web-based technologies have additional advantages because they support text-based and visual forms of communication with the potential for people with SCD being threefold:

- Easier access to information resources and services, which enhance personal information
- Computer-mediated communication may enable people with SCD to communicate more easily with others
- Provides a platform for others without SCD to access information about and develop ways of communicating with people with SCD

(Adapted from Valentine et al., 2006: 2)

Therefore, it was decided to use web-based diaries for the present research.

6.4.3 Diary Aims and Design

Symon (2004) considers a one month period the optimal time for keeping a solicited diary because diarists become familiar, relaxed and more fluent with their diary-keeping after a week, whereas attrition problems and loss of interest occur more often after one month. Over a period of four weeks, at various points during term time, the researcher aimed, through web-based, end-of–the-day diaries, to gather student participants' recorded daily support experiences whilst at university. It was anticipated that these daily diaries would reveal both positive and negative aspects of student support.

A time and event sampling design (over time and situations) was used. This type of self-report design was *researcher-driven* but user-initiated. The researcher did not want to pre-categorise what constituted daily support activity but wanted to understand this from participants' perspectives. However, to assist participants to focus on aspects of their student support whilst attending university, the diaries were semi-structured; based on the following five specific but open 'guiding questions', which oriented students to support issues:

> 1) Think about your day and the people you have spent time with; please tell me about anything that has happened, or any person, which has made you feel unhappy or happy about your studies
> 2) Please tell me how this made you feel
> 3) Where did this happen, time of day and duration?
> 4) Who was involved?
> 5) How might things have been better?

However, participant diarists were free to initiate entries, identify relevant events, the circumstances under which they took place and recount their thoughts, feelings and emotions (for an overview of qualitative diary designs, see Symon, 2004):

> Such approaches place control of the data in the hands of participants, enabling them to not only consider their written responses but also offering them opportunity to reveal as little or as much as they feel willing to do so

> (Milligan et al., 2005: 1882)

This allowed participant diarists to actively participate in both recording their considered priorities within student support practice, as well as encouraging self-reflection. As such, this captured individual understanding about types of formal academic, informal personal and peer networking support (identified from phase one, see Ch.5, p.247) and the level of impact that participants attach to these different support practices.

6.4.4 Diary Schedule Development, Construction and Piloting

In accordance with Guba and Lincoln's (1989) notion of authenticity, referring specifically to the research process allows the reader to judge the 'quality' of the research (ontological and educative authenticity, see Ch.4, p.162). Thus, as part of phase two, this section presents an account of the development, construction and piloting of the student diaries.

6.4.4.1 Development of the semi-structured diary schedule

The semi-structured diary schedule was constructed to engage with research aim 1: 'Explore how the current role of ESWs contributes to the establishment and maintenance of social support networks of students with SCD', and research aim 2: 'Assess the contribution of formal academic support to students with SCDs' retention and progression'. The content of the diary schedule was primarily drawn from the findings of phase one of the research (see Ch.5, p.247), literature that centred on student social support (see Ch.3, p.103), and personal experience as a former ESW (see the Preface, p.12).

The schedule was thus designed to elicit information about student support experiences and the contribution of support relationships to their retention and progression, as illustrated in examples below. Discussion of the construction, materials used and piloting of the diary schedule is provided below using examples of questions from the schedule.

6.4.4.2 Construction of the diary schedule

Ganz et al. (2008: 79-80), as a result of their research which examined the impact of social scripts and visual cues on people with SCD, recommend supporting people with SCD to ensure task completion by using:

> …social scripts through modelling, prompting, and reinforcement, their interactions with peers and adults increase…[*and*] using visual schedules to improve task completion promotes the continued use of unscripted exchange in settings other than those were the scripts were taught

Thus, to facilitate and improve task completion the semi-structured diary schedule[19] included the use of written scripts and visual cues. For example, a 'prompt' instruction page contained a clear set of instructions on how and when participants should complete the diary, a checklist of what could and could not be included and how to enter multiple contacts on the same day, with the same or a different person. A 'model' example was provided which comprised a completed diary entry (see the pilot diary schedule, Appendix 7, p.478) and 'reinforcement' as suggested above by Ganz et al. (2008) was undertaken through progress checks with participant diarists.

Diary questions were structured according to a natural progression - the activity, feelings about the activity, the location, time and duration, those involved and reflection - to encompass each entry, as perceived relevant to the support activity reported. Each page was clearly marked up with prominent headings and enough space to enter all the desired information.

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[19] Technical advice was sought from the University regarding the construction of the web-based template, Internet security, and setting up of a suitable website within the University system.

6.4.5 Piloting the Web-Based Diary

Prior to and during piloting, the initial web-based diary interface (see the pilot diary schedule, Appendix 7, p.478) contained a front page detailing how often participants should complete their diaries, how long they should spend on completion, and researcher contact details should a participant have any diary-related queries/problems. Guidance and direction was prominent at the start of each new diary entry as to what participant diarists might write about, setting the expectation that activities based on student support would be reported. The subsequent page represented the five questions to be completed by participant diarists and diary submission procedures. Once participants had clicked on the 'submit' button, the researcher automatically received each individual diary entry into an official University email account. It was anticipated that this would facilitate the researcher in monitoring daily diary submission, determining who sent each diary entry, and recording the time and date each entry was submitted.

Piloting was undertaken to ensure the questions elicited responses relevant to student support, ease of access and usability of the web-based interface, and smooth submission of the daily diary entries to the researcher's official University email account. Piloting recruitment was facilitated by a University disability co-ordinator, who identified a student candidate with SCD currently using disability support services. This student piloted the web-based diary for three

consecutive weeks. During the fourth week, the researcher met with the student face-to-face to discuss the piloting outcomes. Although the piloting was successful in obtaining information relevant to research aims 1 and 2, "the interface was easy to use, took no time at all to complete and it was compatible with voice activation software" (Pilot participant, also severely dyslexic), the following amendments were made to the central programming, diary guidelines, the questions and the interface (see the post-pilot schedule Appendix 8, p.481).

A major issue that arose from the piloting was that if the diary entry was submitted with the student number box uncompleted, the entry would be erased and not received into the researchers account. To guarantee submission and prevent potential loss of data, it was therefore vital to move the student number login box to the first page. Participants now had to login in their student number (see Figure 8 below) before proceeding to the next page, which now contained the diary guidelines.
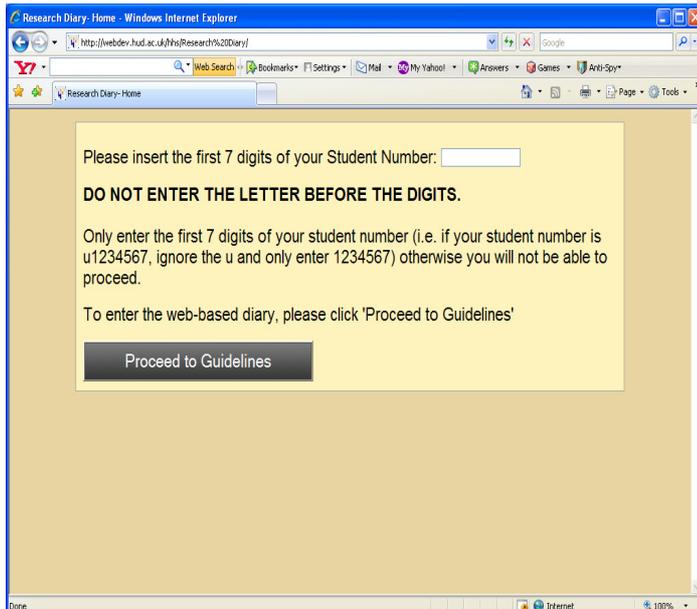
Figure 8: Screenshot of the Research Diary Homepage

To relieve the pressure of the participant having to fill in the diary on a daily basis when they felt they had nothing to report, such as cancellation of classes or illness, it was very important for them to acknowledge their continuing participation. A further diary guideline was added to encourage participants to still access the diary and report why there would be no entry that day (see Figure 9 below).
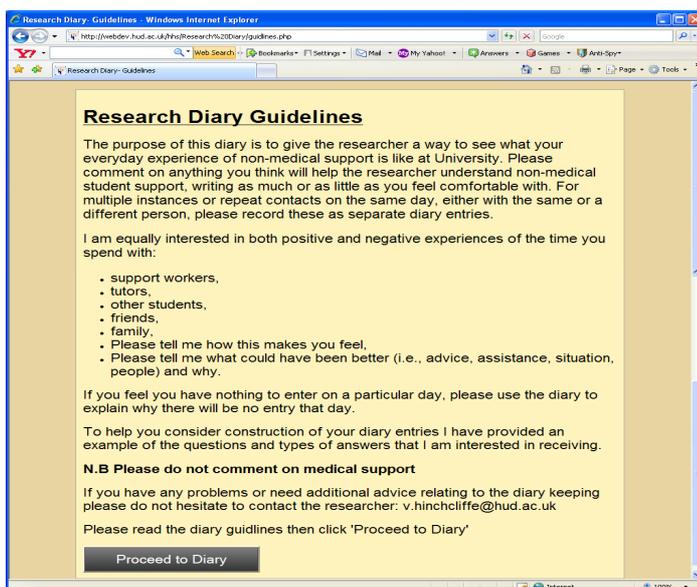
Figure 9: Screenshot of the Research Diary Guidelines

The pilot participant felt that the information sought by questions three and four: 'Where did this happen, time of day and duration?' and 'Who was involved?' was unnecessary as it was adequately provided in the narrative whilst answering question one. However, although these questions were felt to be unnecessary for this particular participant it may not be the case for subsequent participants. Rather than delete questions three and four, they were thus incorporated into question one. Three questions remained in the web-based diary:

1) Think about your day and the people you have spent time with; please tell me about anything that has happened, or any person, which has made you feel unhappy or happy about your studies. Please include location, time of day, duration and who was involved
2) Please tell me how this made you feel
3) How might things have been better?

To prevent over-stimulation[20] but maintain a good level of interest, a pastel colour was used in the diary interface and participants were encouraged to use emoticons - graphic representations of facial expressions "smiley faces or relational icons" (Walther and D'Addario, 2001: 324) to personalise their entries if they so wished (see Figure 10 below). Moreover: "the diary keeping became more than just data, it was personal and I wanted to put my own stamp on it" (Pilot participant). Therefore, emoticons may further facilitate the

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[20] Mesibov and Howley (2003) suggest that one area of strength mutually shared by students with ASD "is the ability to process visual information more effectively than verbal" (p.20). However, the presence of novel or powerful visual stimuli may become overpowering. The student with ASD may focus inappropriately on such stimuli (relevant or otherwise), to the detriment of the task.

diarist to express, check, and if need be, to edit that which they felt may be unclear in their diary entries.

Figure 10: Screenshot of the Research Diary Entry and Submission Page

The final page (see Figure 11 below for an example of a completed entry) showed participants their completed diary entry that had been received into the researcher's email account and allowed either re-entry to the research diary Homepage to add another diary entry or exiting of the web-based diary. Once participants exited this page, as part of the central programming the current diary entry was deleted.

Today is Thursday 22nd January 2009

1) Think about your day and the people you have spent time with, please tell me about anything that has happened, or any person, which has made you feel unhappy or happy about your studies:

I arrived early to the lecture to make sure that my support worker was there and that I had a front seat so that I could hear some of the lecture. This is not always the best place to sit because tutors tend to fire off questions at those nearest to them and most think I am a swat, my fellow students probably think this too. I felt very lonely again this morning; as usual the other students all sat behind me leaving me to sit on my own with a support worker, I should be used to this by now as people tend to distance themselves due to my deafness – it bothers some people if they are sat on my left side, as they have to constantly repeat themselves. I just want to 'fit' in and wish other students would ! move nearer to the front so that I do not stand out as much. This made me feel self-conscious and then I started to think that maybe I'm just being paranoid and it isn't my deafness but my personality, or that I talk too loud that puts people off. I find it difficult to mix with others and worry what people might think of me. I needed someone to discuss these feelings with and seek advice on what to do, so at the end of the lecture I asked my support worker if we could have a chat at lunchtime. They agreed and I was very grateful as I had no one else to turn to at the time and I don't want to bother my family because they would only worry about me. The advice given was very good, and helpful. This took place in the Student Union bar area; it was lunchtime and lasted about 1 hour

2) Please tell me how this made you feel:

At first I felt very lonely, self-conscious and a little down but after talking with my support worker I felt a lot happier, less self-conscious and comforted by their advice

5) How might things have been better?

It might have been better if other students are encouraged to fill the seats at the front so that I do not stick out like a sore thumb. Discussing things with a friend may have been better because it felt awkward revealing my personal feelings to a support worker and because they were not being paid for the extra time spent with me

To add an additional entry on the same day please click 'Return to Homepage'

To exit click on the 'X'

Return to Homepage

Figure 11: Screenshot of the Research Diary Completion Page

6.4.6 Data Collection Procedure

The diary-keeping information (see Appendix 6, p.475) and procedures (see Appendix 8, p.481) were explained in advance during the recruitment process (see Ch.6, p.255), either in-person or via email correspondence, and completion instructions were available at the start of each new diary entry on the diary Homepage (see Figure, 9, p.275). Participant diarists kept a diary for a period of at least four weeks during the academic term of 2008/2009. They were encouraged to fill in the diary at the end of their academic day when things were still fresh in their mind and instructed to record separately multiple activities/events that occurred on the same day, either with the same or a different person.

The end-of-the-day (this generally amounted to 2-3 days per week for each student), diarists recorded any formal academic support issues they had experienced, both positive and negative, any action they had taken, how they felt and how things might have been better. As well as informal support from peers, friends and family, diarists also commented on ideas about what had caused any problems, self help and any alternative support they used and how everyday University life had affected their support. Once they were satisfied with the written content, diarists submitted each individual entry, which was instantly received into the researcher's email account.

Following each diary submission, data was saved into a Microsoft Word document, printed, collated and stored corresponding to student number and then deleted from the researcher's email account. Transcription was unnecessary; however, each diary entry was edited to ensure anonymity by changing or removing and any identifying information, such as names and places. Diary lengths varied from 300-550 word responses, with an average of 8-10 entries received per participant. For analysis purposes, participants were assigned pseudonyms.

The researcher emailed each participant after seven, fourteen and twenty-one days of diary-keeping, to investigate potential problems and answer any diary-related questions. If participants failed to submit a diary entry the researcher initiated email contact to encourage continued completion. This was modified according to individual participant's desire for privacy, or requests for reminders.

After the diaries were completed, participants were thanked individually for taking part, reminded that they would remain anonymous and asked if they had any questions or concerns regarding the diaries. No questions or concerns were raised by any of the participants.

Following completion, the link to web-based diary interface was de-activated, preventing any future access.

An exit survey (see Appendix 9, p.485) was arranged, where participants completed a short online evaluation survey about their experiences, both positive and negative, of web-based research diaries. These experiences, followed by researcher responses to the challenges posed by using web-based diaries as a tool for data collection, are set out in chapter 8 (see p.379 'Methodological contributions' and also Hinchcliffe, 2009).

In total, utilising new communicative technology (see Ch.3, p.117), such as web-based diaries, like the ESW online interviews (see Ch.4, p.201), is argued to have widened opportunity for research inclusion and active participation for those participants with SCD (see also O'Neil, 2008; Hinchcliffe, 2009).

Chapter seven presents the analysis of the findings from students with SCDs' diary accounts of their support experiences whilst studying at Northtown University.

Chapter Seven – Analysis of Student Diaries

7.1 Preamble

This chapter aims to address research aim 1: 'Explore how the current role of ESWs contributes to the establishment and maintenance of social support networks of students with SCD', and research aim 2: 'Assess the contribution of formal academic support to students with SCDs' retention and progression' through the analysis of student diaries. The rationale for the chosen analytical technique – qualitative content analysis, and the process of analysis of the diary data is presented here. Analytical findings are subsequently presented. A summary of the main findings and progression of research thus far is then provided.

7.2 Rationale for the Analytical Technique

Phase one interviews with ESWs identified two main types of support; 'Formal academic support' and 'Informal personal support'. Both contribute to the establishment and maintenance of social support networks of students with SCD (see Ch.5, p.247) and are recognised within the current literature (see Ch.3, p.103). As these were directly relevant to student support, in this current phase it seemed sensible to structure the diary design according to these types of support (see Ch.6, p.269) and follow this through to analysis.

However, it was also anticipated that student diaries may reveal further issues in student support. As such, diary questions asked about experiences of student disability support. In addition, students were asked to record their feelings about these support experiences and explain how things might have been better. To some extent, analytical categories could be framed *a priori* around these diary questions and data coded accordingly, but categories could also be derived from the emergent material. Therefore, an analytical technique was required that would be sensitive to both, and qualitative content analysis was considered here as a technique that could sufficiently meet these requirements. The rationale for using this technique is presented below.

Qualitative content analysis is a technique for analysing written, verbal or visual communication (Krippendorff, 1980; 2004). It is noted that thematic analysis may have again proved a useful technique here. Even so, generating additional themes was not the aim here; rather the aim was to authenticate the themes identified from the ESW interviews and reveal further issues in student support. In addition, qualitative content analysis can be argued to offer a more structured approach than thematic type analyses, facilitating the inclusion of *a priori* codes whilst providing more flexibility in the incorporation of emergent material. This technique permits the collation and categorisation of a variety of multifaceted accounts, such as those from daily diaries (Elo and Kyngäs, 2008).

This technique is intended to reveal meanings, intentions, the consequences of events and the context in which the events took place (see Elo and Kyngäs, 2008). Qualitative content analysis is thus to be utilised here to categorise data into meaningful units of analysis (such as words, paragraphs or phrases) that correspond with, or exemplify previously identified analytical categories – and accommodate and categorise emergent material such that, as far as possible, the meaningfulness of the data is retained. The process of analysis was informed but not prescribed by Elo and Kyngäs' (2008) techniques for qualitative content analysis, as set out below.

7.2.1 Process of Analysis

Elo and Kyngäs (2008) describe how qualitative content analysis may be both used deductively and inductively. A deductive approach is used "when the structure of analysis is operationalised on the basis of previous knowledge" (p.109), as is the case here with the identified types of support, formal academic and informal personal. An inductive approach is used "if there is not enough former knowledge about the phenomena or if this knowledge is fragmented" (p.109). This would be useful in dealing with emergent material. Both approaches were utilised here. The process of qualitative content analysis has three main phases: preparation, organisation and reporting/analysis. Each of these phases is described below.

7.2.1.1 Preparation

The first step in the preparation phase was to select the unit of analysis. Single words from the diary entries may be argued to be insufficient because meanings can change according to the context and thus single words can have confusing interpretations (Chandler, 2002). Paragraphs can be argued to be too broad and could contain data that may usefully be coded into more than one category, detracting from the clarity of analysis as there are "various and often numerous thoughts stated and implied in a single paragraph" (Berg, 2007: 313). Thus, phrases, defined here as a string of words that are used together that have a distinctive meaning and can be categorised with little or no interpretation from the coder (see Baxter, 1991), were considered the most feasible unit of analysis.

Next, each diary entry was read several times to gain a deeper understanding of how diary participants experienced formal academic and informal personal support, their affective responses to this support, and how things could be improved relative to their retention and progression.

7.2.1.2 Organisation

Data was initially organised around five *a priori* analytical categories based on the diary questions. Along with the research aims, these categories are presented as headings in Table 3 (see p.287), the first

and third of which were congruent with those derived from phase one of this research, (formal academic support and informal personal support), plus three additional categories that were congruent with new information sought during this current phase (affective response to formal academic support, affective responses to informal personal support, and how things may be improved). The next step was to code the data according to these *a priori* categories.

The whole data set was thus re-examined and relevant text was coded according to these five analytical categories by making notes in the margins (an example of a coded diary entry is available upon request). For example, any time diary participants mentioned activities that represented 'Formal academic support' (this included descriptions of formal support within the academic environment, teaching practice, issues around non-disclosure of disability, as well as ESW practice), that information was coded accordingly. This coded data was then gathered and sorted into the five *a priori* categories (formal academic support, affective response to formal academic support, informal personal support, affective responses to informal personal support, and how things may be improved) and placed into the table according to the five corresponding category headings (see Table 3 below). An 'expert' in qualitative content analysis checked the organisation of the data into the five categories (see Table 3, below) using a sample of diary transcripts and provided good agreement (see Smith, 1992, for rater–to-expert checks).

Table 3: Gathering and Sorting of Data into the Five Categories

Research aims	Formal academic support	Affective response to formal academic support	Informal personal support	Affective response to informal personal support	Making improvements
1. Explore how the current role of ESWs contributes to the establishment and maintenance of social support networks of students with SCD 2. Assess the contribution of formal academic support to students with SCDs' retention and progression	Lecture/classroom/work placement context Good teaching/ESW support practice – accommodations, progression at both modular/course levels Appropriate accommodations - retention and progression Student non-disclosure, staff non-communication of needs, poor teaching and ESW support - no accommodation Group work difficulties, no modular/course retention or progression	Good teaching practice/ESW support – academic competence, confidence, satisfaction with performance, progression at modular/course levels Non-disclosure of disability - exhaustion, irritableness, disadvantage Tensions within relations, tolerating inappropriate or lack of support Non-accommodative practice - exclusion, prejudice, discrimination, ignorance, labelling, untrustworthy, triggers bad memories, worries, feeling singled out, insulting, disappointing, self doubt, unconfident, frustrating, upsetting, anxiety, embarrassing, unfocused, lack of motivation, defensive Singled out, panicky	Importance of friendships with ESWs and tutors Peer support, integration, progression, retention, completion Importance of socialising, break from studying Reciprocal peer support Peer integration Non-reciprocal peer and family support, intrusion on personal relationships Confrontations with peers and family Non-integration, isolation Disclosure of disability, self reflection, self determination	ESW and tutor friendships - enjoyment, encouragement Self disclosure of disability - positive attitude, optimism Informal personal and reciprocal peer support – student satisfaction, confidence Non-reciprocal peer/family support - guilt, upset, anger, non-integration, isolation	Wider disability awareness Wider communication of needs/difficulties Putting accommodations into practice Meeting holistic needs

Once all the relevant coded data from the whole set had been gathered and sorted into Table 3 (as set out above) it was possible to meaningfully group this data based on similarity and difference into phrases that captured participants' experiences of student support. These groupings are presented in italics in Table 4 (see p.290) and further allow the highlighting of emergent codes in each category. It is important to note here that coded data were not simply grouped by similarity of responses but as distinctly 'belonging' together in comparison with that which did not (mutual exclusivity, see Fielding, 2008).

For example, under the category heading 'Formal academic support' coded data in Table 3 (see above) were similarly grouped together. 'Lecture/classroom/work placement context' was grouped with 'good teaching/ESW support practice - accommodations, progression at both modular/course levels' and 'appropriate accommodations - retention and progression' were grouped to form a single more meaningful group, '*Good teaching and support practice in lecture, classroom work placement environment, appropriate accommodations – retention and progression at modular/course levels*' (see Table 4, p.290). This was because good formal academic support practice was evident in the formal environment and thus resulted in appropriate accommodations. Whereas, '*Non-communication of needs*', '*Inappropriate teaching practice*', '*Tensions in relationships between students and ESWs*' and '*Group work*

difficulties' (see Table 4, p.290) were distinctively different here because they often resulted in no accommodations or modular/course retention and progression.

In addition, coded data under the category heading 'Informal personal support' (see Table 3, p.287) that represented the 'Importance of friendships with ESWs and tutors' were grouped together as, '*Importance of good working relationships with ESWs and tutors*' (see Table 4 below) to reflect the informal working relationships between ESWs and tutors because this showed similarities indicative to employees of the University. These relationships were distinctively different from other informal working relationships, such as those involving student peers and family, '*Peer support*' and '*Tensions within peer/family support*', who were not employees of the University (see Table 4 below). The subsequent groupings under the category headings, 'Formal academic support' and 'Informal personal support', were then mapped on to the corresponding categories, 'Affective responses to formal academic support' and 'Affective responses to informal personal support'. No groupings were made to the category 'Making improvements' as these were all emergent codes.

Table 4: Subdivision of the Data to Highlight Emergent Codes

Research aim	Formal academic support	Affective response to formal academic support	Informal personal support	Affective response to informal personal support	Making improvements
1. Explore how the current role of ESWs contributes to the establishment and maintenance of social support networks of students with SCD 2. Assess the contribution of formal academic support to students with SCDs' retention and progression	*Good teaching and support practice* in lecture, classroom, work placement environment, appropriate accommodations - retention and progression at modular/course levels *Non-communication of needs* - staff/student non-disclosure of disability - no accommodation *Inappropriate teaching practice* - no accommodation *Tensions in relationships between students and ESWs* *Group work difficulties* - no modular/course retention and progression	*Good teaching and support practice* - academic competence, confidence, satisfaction with performance, progression at modular and course levels *Non-communication of needs* - non-disclosure or delay in disability disclosure - exhaustion, irritableness, disadvantage *Tensions within relations* - tolerating inappropriate, lack of support or non-accommodative practice - exclusion, prejudice, discrimination, ignorance, labelling, untrustworthy, triggers bad memories, worries, feeling singled out, insulting, disappointing, self doubt, unconfident, frustrating, upsetting, anxiety, embarrassing, unfocused, lack of motivation, defensive *Group work* - singled out, panicky	*Importance of good working relationships* with ESWs and tutors *Peer support* - integration, progression, retention and completion, importance of socialising - break from studying Self disclosure of disability as a coping strategy - peer integration, self reflection, self determination, reciprocal peer support *Tensions within peer/family support* - intrudes on personal relationships and causes confrontations	*ESW and tutor friendships* - enjoyment, encouragement *Peer support* - student satisfaction, confidence Self disclosure of disability - positive attitude, optimism *Tensions within peer/family support* - guilt, upset, anger, non-integration, isolation	*Wider disability awareness* *Wider communication of needs/difficulties* *Putting accommodations into practice* *Meeting holistic needs*

7.3 Analysis of Findings from Student Diaries

For the purpose of presentation of the findings, the initial five categories were reduced to three. Although, 'Affective responses to formal academic support' and 'Affective responses to informal personal support' were initially treated as different analytical categories, it was more appropriate to analyse them with the support events they described. Thus, they were used to strengthen context and clarify specific points made within the three remaining categories: 'Formal academic support', 'Informal personal support' and 'Making improvements' and their related subdivisions.

Berg (2007: 308) suggests that qualitative content analysis should be "related to the literature and broader concerns and to the original research question" in order to learn about how participants view their social worlds and how these "fit into the larger frame of how social sciences view these issues and interpretations". Findings are therefore presented with reference to relevant theory, and correspondence with, earlier studies reviewed from the literature (see Ch.3, p.103).

7.3.1 Formal Academic Support

Findings from the present study suggest that students indicated that there are a number of people supporting (or not supporting) them at Northtown University. Lecturers and ESWs can and do provide good teaching and support practice, which can ensure that formal academic support is prioritised. The success or otherwise of formal academic support can impact on both modular and course retention and progression (Weiner and Wiener, 1996; Stanley and Manthorpe, 2002; Christie, 2004; Raab and Adam, 2005). As such, these issues are addressed in the following sub-sections 'Good teaching and support practice', 'Non-communication of needs', 'Inappropriate teaching practice, 'Tensions in relationships between students and ESWs' and 'Group work difficulties'. The consequences of these issues are presented below.

7.3.1.1 Good teaching and support practice

The issues presented here consider, in terms of formal academic support, the importance of good teaching and support practice for students with SCDs' access to the learning environment, their sense of satisfaction and confidence to achieve their full academic potential and belief in their own ability. In addition, this section considers how formal academic support may unintentionally increase peer isolation and compromise students' access to peer support. This can occur

through the nature of the accommodations themselves or through peers' misperceptions of accommodations.

Consistent with mandatory legislation and HE institutional policy (see HEFCE, 2006), students in the present study evidenced in their diary accounts that teaching staff and ESWs can and do provide accommodations (lecture notes in advance, extra time in exams, assignment extensions, note-taking, mentoring, library/campus support) in formal academic settings, such as lecture halls, classrooms, the library and work-based placements. When this was appropriately carried out it facilitated better access to the formal learning environment and had a positive impact on students' achievement. This relates to good teaching and support practice, the first issue addressed here.

Findings from students' diaries, in turn, mirrored findings from Weiner and Wiener (1996), and Stanley and Manthorpe (2002), where students similarly indicated that it enabled them to feel competent, satisfied with their academic performance, and 'levelled the academic playing field'. Cassandra, a 2nd year direct entry student,[21] provides a typical response that represents the views of students:

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[21] A direct entry student is defined here as a young adult (18-21 years of age) who has entered university directly from an FE college programme of study.

> I was feeling positive because I was able to do the
> exam on the computer, and have 25% extra time.
> For the first time ever I felt totally satisfied with my
> exam because I had plenty of time to check it over
> and remember the things that I had learned…it has
> given me the confidence to think that I can do well
> and I can get just as good marks as anyone else

Appropriate accommodations also raised Alan's confidence, a 2nd year returnee to learning[22]. He wrote in one diary entry that he enjoyed formal academic support because it left him feeling invigorated:

> Today I had a mentoring session which I always
> enjoy as this is with my note taker and again later in
> the day I had 20 reading sessions which I always
> come out of feeling refreshed and confident

This is interesting because findings from Cremer's (1991) survey results indicated that 69% of respondents identified note-takers as the most important for academic achievement.

According to these students, these types of accommodations, when appropriately applied, could give students like Cassandra the incentive to aim higher because it raised their attainment, which in turn positively enhanced their self-belief:

> Today I went to collect my assignment and to my
> surprise I got an A. This came as a real surprise as I
> have never got an A before while at uni…I feel that
> my attitude has now changed as I have the belief
> that I can actually do better

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[22] A returnee to learning is defined here as an adult (over 21 years of age) who has entered university either via an Access Course, FE programme of study or an unconditional offer.

> I had a good day; I handed in my first piece of work.
> This is a major breakthrough for me as I am doing
> year 1 again (Matthew, a 1st year direct entry student)

However, Phil, a 3rd year returnee to learning allowed insight into how some accommodations unintentionally increased peer isolation, making a student resent being detached from the learning environment and from accessing essential peer support This made Phil feel upset at having to subsequently answer unwelcome questions from his peers regarding his absence:

> What bothered me today is being alone for the exam
> rather than being with the others I had spent time
> with to prepare for it…It felt like I was being isolated
> from my friends and treated differently, which I don't
> like. All my friends are so supportive it feels bad not
> to be with them and I know they'll ask how I went on
> and then I feel like I have to explain myself or justify
> not being there which I resent

Similarly, Kurth and Mellard (2006) found evidence that 27% of their student sample found that exams undertaken in separate locations resulted in student isolation and negatively impacted on student sense of belongingness in the learning community.

Students in the present study revealed other coping strategies that they used when things got tough in the learning environment. Dean, a 2nd year returnee to learning reflected a particularly negative incident with a student peer, who after observing him during a mentoring session in the library accused him of "getting his support worker to do the work for him". Consequently, he resolved to isolate

himself at the expense of both his social integration and academic progression:

> I think I will not use the labs for that sort of work anymore; I will have to find a place where we can work alone but that means I'll be shut away from people again and won't be able to talk to them about my work. Sometimes I wish I could do the work like everyone else but I can't so I'll just have to adjust

Darwin (2000), Murray (2001), and Eby and Allen (2002) have previously drawn attention to the negative aspects of student mentoring. Like Dean above, these authors suggest the mentoring experience is not always positive; it can result in distancing and manipulative behaviour from student peers and ESWs and can imply helplessness. This, in turn, the authors argue, can create social stigma by exposing deficiencies and weaknesses.

7.3.1.2 Non-communication of needs

Students are aware that non-communication of their academic needs can impact negatively on their learning experience when, in particular, there is no formal academic support in place to support their studies. However, the university is not entirely to blame for this; some students have to take responsibility here.

Often, and for a variety of reasons, no accommodation took place at Northtown University. One student in the present study reported that she did not fully disclose all her difficulties at entry for fear of not

gaining a place on her chosen course. However, others complained that the recommended accommodations, notably in teaching delivery, did not take place in practice.

Riddell et al. (2005) suggest institutional responses to the DED (2006 see Disability Rights Commission, 2007b) were limited to manifestations within the 'audit culture' and the associated 'categorical' approach to disability, which may discourage students from identifying themselves as disabled. However, this did not appear to be the case for one student in this study, who assumed personal responsibility for not receiving accommodations by recognising that this sometimes stemmed from student non-disclosure of difficulties and disability. Cassandra revealed how she chose not to disclose all her difficulties when applying to Northtown University for fear that she would not gain a place:

> When applying to go on to the course I didn't dare put that I had dyslexia as well as being hearing impaired because I thought it would slim my chances of getting in to uni…

The consequence of this was that although she gained a place, Cassandra did not have any formal academic support in her first academic year and at the beginning of her 2nd year, this left her feeling fatigued, short tempered and disadvantaged:

> My work placement is exhausting in itself because straining to hear all the time is very tiring, to then have to come home and start writing all evening is beginning to take its toll as I am becoming irritable and tired all the time. I feel that I am at a disadvantage and feel unsupported at this moment

Bronfenbrenner (1974) identified the loss, or lack of, support, as a source of great unhappiness and stress. However, after disclosing dyslexia alongside being hearing impaired, with hindsight Cassandra later realised how essential it was to get academic support in place as early as possible to facilitate academic progression:

> I missed out on receiving the equipment and support that was there to help me with my studies. Now that I am aware of just how vital this support is within my studies, it has shown me that things could have been better if I had sorted out the support earlier so that I would have had the help in the first year

Similarly, several participants in Stanley et al.'s (2007) study felt that disclosure of disability would preclude entry to university and thus, like Cassandra, had not or only partially disclosed their difficulties during the application process. As such, participants in Stanley et al.'s (2007) study had experienced similar consequences of non-disclosure as Cassandra had, such as missing out on support and having to work harder. In response to these fears, Stanley et al. (2007) suggest that universities could encourage disclosure of disabilities at application through making it explicit that they were positive about including students with disabilities on courses. Moreover, the process of disclosure could be more transparent for

example, making it clear "what it means to disclose and what should be expected as a result" (p.73).

The process of obtaining formal academic support for students with a disability at Northtown University should be as follows. Once a student agrees in writing to the disclosure of their academic needs, the Disability Office passes this information to the Disability Co-ordinator in the relevant Department in each School, who then passes this information to the student's Personal Tutor and Module Leaders, Module Leaders should then pass this information to all Module Tutors that the student is likely to come into contact with.

However, according to Alan, there appeared to be a broken link in the aforementioned chain, particularly with the communication of students' needs. He described being excluded from a group work session because the activity was not provided in advance, as recommended in his assessment of needs. This left Alan feeling frustrated at having gone to the trouble of undergoing an assessment of need when his tutors did not adhere to the recommendations made in it:

> With no forewarning of this activity I was excluded from the lesson…it clearly shows no foresight or planning is being applied by the Lecturers (*Module Leaders and Module Tutors*), to the lecture needs of people with disabilities. This is becoming a weekly occurrence in one lecture or another. This begs the question, why bother with a disability support programme…This frustration is still and will prevail unless this Department and the School actually get their act together and start facilitating the recommendations made after we spent our time being assessed and then having assessment plans drawn up

Following a similar incident to this, Cassandra also felt that events such as these were difficult solve due to a lack of communication of students' needs:

> ...will not be resolved until lecturers are given some sort of knowledge on different disabilities and their effects…When the university was made aware of my difficulties I was told that my teachers would be notified of this but I don't' think they all have

This can be argued to possibly impact upon students' self-determination - autonomy [feeling un-coerced in one's actions], competence [feeling capable] and relatedness [feeling connected and a sense of belonging with others] (see Patrick et al., 2007). This is because when recommendations concerning students are not effectively put into practice barriers to learning can persist. This may leave students feeling let down and could affect their motivation, which in turn could impact on their progression and retention. Patrick et al. (2007) would support this claim as unless students feel able to participate with their student peers (relatedness), they may find it very difficult to take responsibility for their education (autonomy),

academic progression and subsequent employment (competence). Indeed, a student who feels a loss of relatedness with their peers may not participate in communities of practice (see Lave and Wenger, 1991). An example of a community of practice is where students may plan essays, research a topic area together or share resources. As such, autonomy may develop through the pooling of intelligence to achieve a common goal (Brown and Lauder, 2000). Limiting access to collective intelligence may lead to a loss of students' competence and empowerment (Avis et al., 2002).

Moreover, Field et al.'s (2003: 339) research demonstrates that "positive communication patterns and relationships, and availability of supports" are essential parts that go toward student achieving self-determination. This specifically relates to the difficulties outlined above by the students in the present study because when communication, in terms of encouragement and motivation, and relationships are affected in a negative way, this impacts negatively on their achievement of self-determination. This has been further argued to be important in the current climate that perceives students as self-responsible agents (see Ch.3, p.109).

7.3.1.3 Inappropriate teaching practice

The issues presented here consider how inappropriate teaching practice, intentional or unintentional, may possibly affect the success (or otherwise) of formal academic support. Inappropriate teaching practice appears to include ignorance about the importance of colour of materials/PowerPoint slides, as well as insensitive comments and use of inappropriate examples in lecture content. This can lead to both physical and psychological consequences for students with SCD, such as pain, embarrassment, frustration and anger.

One issue that appears not to be evidenced in contemporary student support literature is inappropriate teaching practice, and thus is argued here to provide 'new' insight in this area. For example, all student participants in the present study alike indicated that teaching staff should equally take responsibly when no accommodation took place at university. Inappropriate teaching, both unintentional and intentional, was a barrier that prevented some accommodations taking place. For example, Alan provided examples similar to those of other students; he described some inappropriate, yet recurring and frustrating incidents that he recently experienced:

> …when the PowerPoint background is white it can give me an excruciating headache and the feeling that my eyes are being drawn out of my head. I have made this known on numerous occasions to all lecturers and year tutors, however again today I had to ask for this to be changed

Later that week, another particular situation, albeit unintentional, made him feel self-conscious, embarrassed about his difficulties and quite disheartened:

> There was an analogy used with the example of someone who couldn't be bothered to read using the excuse of dyslexia. As most of my classmates are aware of my learning disability this added to my embarrassment. This was quite a demoralising statement for me

Alan went on to explain that incidents like this not only affected how he felt but had an impact on modular and course retention too:

> This made me feel disappointed and the victim of prejudice from the people who you are expected to go to discuss your problems. To hear someone in that position describe your disability as just an excuse for not reading takes you back to the dark days of frustration, anger and actually at that point made me want to walk out as I had done on my education throughout my youth

Similarly, Cassandra describes an incident that made her feel embarrassed at her difficulties and demoralised, this, in turn, potentially affected peer relations:

> She (the lecturer) told the class how after reading the last assignments, there are a few students who need to learn the differences between 'being' and 'been' and 'weather' and 'whether' I felt myself go red because I knew she was referring to me as one of those people. She went on to say that there is no excuse for this 'sloppy'; and 'lazy' work and that people will continue to lose marks if they don't check their work properly. I honestly thought that she would mention about the hearing impaired and dyslexic students (due to their poor spelling) and that this didn't apply to them but she was definitely referring to the whole class

Consequently, this upset Cassandra who felt singled out as academically inadequate, indolent and labelled as such. Moreover, Cassandra felt wrongfully judged on her weaknesses and as a consequence, she was a little defensive:

> Hearing that my work was never going to be good enough made me feel upset and frustrated…I felt I was being labelled as lazy and sloppy…I also felt like I wanted to go up and tell her that I actually do try to correct all my mistakes but because there are so many, I don't often realise that I have got mixed up with 'being' and 'been'…Maybe if she knew more about different disabilities and there effects then she would realise how upsetting it is to be singled out in class for something that I really can't help

Actions like these can be again argued to create social stigma by exposing student deficiencies in the current HE climate that values independence and autonomy, which, in turn, may be argued to impede student social support networks. Murray (2001) would support this claim by suggesting that when student deficiencies are exposed it implies helplessness and, as such, people are stigmatised as not being responsible for their own development; dependent, needing someone to accomplish things for them, rather than being independent and self-determining. As a consequence, students with SCD may feel embarrassed, ashamed and may be reluctant to ask for assistance. This in turn may negatively impact on their academic progression and retention. For example, Dean, a 2nd year returnee to learning was instructed by his tutor to take notes during a small group discussion, of which he was then to feed back the information to the class. However, during the discussion the tutor commented

that she was concerned that he was not taking enough notes. Dean

felt this served to expose his hearing difficulties, leaving him feeling

panicky, anxious, embarrassed and inadequate. As a result of this he

withdrew from peer contact:

> Taking the notes whilst everyone was talking made me panic, in case I misheard what someone had said or missed a point. Because of this panic I could barely read my notes afterwards...Having my tutor comment on how concerned she was only added to my panic and worry. I was also embarrassed that she said this in front of everyone and made me feel inadequate...I would have preferred it if my tutor had waited until afterwards to express her concerns around my note taking and I would have liked it if she had been a bit more supportive for example: asking people to slow down a little so I could catch up on the notes...I think I will avoid this group next time or maybe not attend the seminars

Experiencing stigma in this way, students may isolate themselves

from their peers for fear of further embarrassment. This may prevent

students forging positive social support networks and affect their

access to network capital. Plickert et al. (2007) provide evidence for

the consequences of this possible isolation. They suggest that when

students cannot exchange emotional and material aid, information

and companionship, this may have a significant and negative impact

upon academic experience and achievement.

Smith (2010), following a large scale study at a UK university, claims

that teaching staff are not resistant to inclusive practice. One major

reasons for inappropriate teaching practice was confusion regarding

what inclusive practice is and what reasonable adjustments are.

Moreover, the problems of implementing accommodations are exacerbated by an increase in student numbers. As such, Smith recommends that teaching staff are informed on the legislation of reasonable adjustments and anticipatory inclusive practice, and through disability awareness training they are made aware that inclusive practice is expected of them. To this point, disability training at Northtown University is voluntary.

However, counterargument is presented here from students who point out that sometimes they are requested by lecturers to carry out activities in group work sessions that contradict their needs assessments and, as a consequence, this may threaten otherwise positive peer relationships. Contrary to Smith's (2010) findings that teaching staff at university are not resistant to inclusive education, some students in the present study felt that they sometimes had to tolerate what they considered intentional un-accommodating conduct in group work situations. Joshua, a 2nd year direct entry student presented a tough exterior when he noted a particularly upsetting incident: "I have developed quite a thick skin regarding my disabilities...I would have just put up with it". However, the situation to be explained below caused not only disruption for himself but also his peers. This incident made him feel singled out from his peers and potentially disrupted future peer relations. During a group work session, even though the group had nominated a representative speaker and contrary to recommendations in his needs assessment,

Joshua was requested to read out material with no warning. His group work peers came to his defence but this was futile, and subsequently this caused disruption to the whole group's learning experience. Joshua was worried that similar incidents to this may affect the quality of their relationship and his future acceptance during group sessions:

> When it was time to give our answers the lecturer pounced on me and demanded I answer one of the questions. We all said we'd elected a spokesperson and it wasn't me, but she was determined to make me do the speaking. My brain injury means I speak very slowly, but I had a try and she let me speak for so long then cut me off, moving onto another group. One of my group challenged this saying I hadn't finished but she said we don't have time. My group protested that I shouldn't have been made to speak in the first place and when they were ignored two of the group walked out…I get on well with the other students, but I am scared that incidents like this will spoil our relationship…they might not want me in their group and I worry that I will be on my own

This can be argued to negatively impact upon students obtaining 'network capital' that is "social capital that is embedded in interpersonal relations that can provide custom-tailored helpful resources that are flexible, efficient and effective" (Plickert et al., 2007: 406).

7.3.1.4 Tensions in relationships between students and ESWS

The issues addressed in this section mainly involve consideration of power imbalances and the effect this may have on relationships between students and ESWs. Students have mixed perceptions concerning the poor advice that they can receive from ESWs and their inability to challenge this for fear of reprisals, which may leave them feeling irritated whilst also expressing appreciation for ESWs efforts and assistance. Disagreement between students and ESWs may sometimes lead to awkward relations.

Involved in all kinds of human interactions are tensions in relationships (see Archer, 1990). However, contrary to Darwin (2000) and Eby and Allen (2002) who suggest mentoring can incorporate an abuse of power by ESWs, such as distancing and manipulative behaviour through deceptiveness, neglect and abuse, power is not always one-sided or bestowed on professionals. For example, students in this study did not mention any of the above behaviour categories that can incorporate an abuse of power. Moreover, some claimed to exert resistance and influence over the type and administration of their support, particularly when it is difficult to get what they think they need:

We [*ESW*] started off well enough but I am finding it difficult to get her to accept the extent of my disabilities and it makes me angry to have to explain myself constantly, but apart from that we are getting on fine. She told me straight off what she would and wouldn't do to help me and she was quite firm about this which is good as I tend to push the limits a bit, not because I'm lazy but because there is always some aspect of my work I need help with that I never realised I did. I think maybe though this will cause a bit of friction between us as it has in the past with other support workers who just have a routine and won't think beyond it (Alan, a 2nd year returnee to learning)

There is evidence within the present study of more tension in relations between ESWs and students. Maria, a returnee to learning noted that she "appreciated the time allocated" for her academic support; however, she felt that ESW advice was not always appropriate or helpful, which left her feeling confused and discouraged:

I feel as though I am receiving conflicting advice. On the one hand, I'm being asked to "just get the work in, it doesn't matter about the quality of it" (study support worker); on the other hand, I'm being told that my work is of a good standard and to maintain this quality of work (from academic staff). It really frustrates me that someone just wants me to hand in work, regardless of its content/quality. I appreciate that I am repeating my final year and that I have to get the work in, but I'd like to do it to the best of my ability. I lose motivation when asked to forego doing my work well just to get the degree

Alan, although clearly in the minority, after a series of negative incidents with previous ESWs still felt strong enough to persevere with his studies:

> One good thing is that I am mentally strong and will
> continue no matter what

However, not everyone in the present study felt strong enough to address inappropriate support because they worried that it may do more harm than good. Maria felt powerless to act against what she considered inappropriate support, having learned that challenging her support worker was not helpful and even though she felt irritated consequently, she tolerated her situation:

> It frustrates me that my study support worker (mentor) doesn't know the subject I am studying and sometimes gives me advice that I know is wrong - I've learnt not to question this, as this appears to offend/frustrate and creates an uncomfortable atmosphere

This is consistent with Archer's (1990) point that people with disabilities are often unaware of power imbalances and, as such, are powerless to change them. Darwin (2000) would support this claim, stressing that mentoring is an autocratic system for handing down knowledge and bestowing power. The above issues can be understood in terms of power imbalances for example, Maria specifically referred to "I've learned not to question this". Also, Alan suggests that he feels his only course of action is to be strong and carry on; he has to cope with the situation, rather than possessing the power to change it.

Nevertheless, there are alternative ways of understanding students' dissatisfactions with their ESWs, such as ESW competence, motivation and training. For example, it is not necessarily, or only, the power imbalance that is the issue here. Tensions in the relationship appear to be due to the view of at least some students that their ESW is not knowledgeable in the appropriate discipline area, or gives them what they consider inappropriate academic advice. In order to overcome such shortcomings, Zellers et al. (2008:563) propose a network of specifically trained mentors to meet students' array of "technical and personal needs in the context of modern society".

7.3.1.5 Group work difficulties

Even with the provision of ESWs, some students may find group work situations intolerable. If student group work difficulties are unresolved they are likely to affect retention and progression, because some students feel they cannot remain in an environment that causes extreme discomfort and stress.

Students with SCD in the present study often found group work difficult and many needed ESW mediation. However, even with this mediation in place, group work still presented problems and concerns. For example, even when her note taker took additional notes Cassandra still found it difficult to follow the gist of the conversation when more than one person spoke during group work. She found it too embarrassing to bring in equipment that may have

lessened her anxieties and assisted her studies because she felt that

it may appear unprofessional to her peers:

> We [student peers] had a meeting to identify the roles
> and responsibilities of everyone involved in the group
> work. I was responsible for taking notes which would
> later form a part of a reflective learning exercise,
> which must be signed by everyone involved. I found it
> extremely difficult to listen and take notes at the
> same time as well as looking interested in what they
> were saying. I could have brought my laptop in as a
> note taking tool to ease my nerves but this would
> have been embarrassing as I am aware that when I
> practice in my profession this will be an area I will
> have to have developed in

Matthew, a 1st year direct entry student, also agonised over group

work and the negative impact, not just on himself, but his modular

retention and overall course progression. The group work

environment made him feel apprehensive enough to make a swift

exit from class but this left him worried about how this would impact

on his studies. More so, he was considering withdrawing from the

module:

> It was group work again this morning!!! I felt very
> anxious in the classroom and I was so aware of the
> surroundings and everyone around me that I felt
> panicky I couldn't take the situation anymore and got
> up and left. This really upsets me because I know I
> am capable of passing the course but missing
> classes like this has an effect on my work and exam
> performance. I am thinking about dropping this
> module because I do not gain anything from it, it is a
> waste of my time

Situations like these can be argued to negatively impact upon students' opportunities for dialogic engagement (conversation), development of critical thinking skills (see Fink, 2003) and opportunity to share resources. Wood and Smith (2005) argue that communication frequency and Palloff and Pratt (1999) student-to-student discussions, are necessary to sustain a learning community. However, some students with SCD do not 'fit' neatly into the conventional (face-to-face, in-person) learning community.

Appropriate accommodations clearly 'levelled the academic playing field' for students with SCD in formal academic settings, raised student confidence and facilitated modular progression and course retention at Northtown University. However, quite often no accommodation took place because students did not disclose difficulties at application, or there was inappropriate conduct from teaching staff and ESWs. Not receiving appropriate accommodation for their academic needs had detrimental consequences and sometimes impeded peer integration. This left students with SCD feeling powerless to act in these situations and they experienced a host of negative feelings, such as disappointment, frustration, anger and sometimes victimisation which, in turn, negatively affected their motivation and belief in their academic abilities. When students and their peers tried to protest against discriminatory treatment, they felt the only solutions were to exit the distressing situation, or tolerate it for fear of reprisal. This culminated in students, and sometimes their

peers, missing out on vital teaching, which increased the risk of peer isolation, opportunities to obtain 'network capital' and thus overall had negative implications for their academic progression (Plickert et al., 2007).

7.3.2 Informal Personal Support

Findings in the present study, evidenced in students' diaries, indicated that there were a number of people that supported them informally: ESWs, teaching staff, student peers and family. Providing appropriate informal personal support, albeit invisible to Northtown University quality systems, generally facilitated both integration and student access to the full range of opportunities within the learning environment. This, too, alongside formal academic support, could be argued to enhance the student's sense of belongingness in the learning community (Ueno, 2005; Taylor and Palfreman-Kay, 2000), and retention and progression (Weiner, 1999; Blamires and Gee, 2002).

However, students in the present study suggested that informal academic support was often undertaken by inexperienced student peers and family - a somewhat problematic issue previously noted by Chelser and Chelser (2002) and McCauley and Van Velsor (2004). Through training, experience and qualification, ESWs' formal academic support had minimum standards. For example, formal academic support is undertaken by ESWs who all have support

training provided by Northtown University and often have specialist knowledge, experience and additional qualifications. These skills help to ensure their work achieves at least a minimum standard of performance in their support practice. Whereas, in terms of informal academic support undertaken by peers and family who often have none of the above skills, this was outside the University's quality systems. As such, lack of training here could cause intrusion and confrontations within personal relationships. These issues are addressed in the following sub-sections 'Importance of good working relationships', 'Peer support', and 'Tensions within peer and family support'. The consequences of this are presented below.

7.3.2.1 Importance of good working relationships

The issues addressed here focus on the importance of informal personal support for effective working relationships between students, teaching staff, ESWs and student peers. In addition, the impact of this is presented with regard to student learning experience, and how, when this is positive, it may relieve student isolation and provide a sense of belonging at university. The students note easing their social isolation, building trust and a sense of belonging, desiring friendship with their ESW and in a sense that they understand them as a whole person, not just academically.

Students in the present study indicated that teaching staff, ESWs, peers and family can and do provide support which is of a more personal nature, such as helping to build supportive relationships and giving relationship advice, all of which can support peer networking, facilitate integration into the wider learning environment, and may lessen student isolation (see for example, Garrison-Harrell and Kamps, 1997; Kamps et al., 1997; McGee et al., 1992; Morrison et al., 2001). Teaching staff at Northtown University occasionally stepped beyond their formal academic requirements, into a realm way beyond their expected remit. One participant, Phil, a 3rd year returnee to learning, explained the benefits of informal personal support and how it eased his experience of social isolation and enhanced his sense of belongingness in the learning community (see Levett-Jones and Lathlean, 2007). Phil, having no family to approach, or peer support at university, was happy to receive informal support from a lecturer. This support went some way in rebuilding his trust in people and his sense of belonging at university:

> I have no family I can turn to and few friends willing to make the effort to keep in touch. I have been thinking about this because just now the phone rang and it was a mate from Uni (one of my lecturers in fact) who was in the area and asked if he could call in to see me. I was just so bloody glad to think I would not be alone for a while…It's easy to feel like you don't belong at Uni with more able bodied people, so for a lecturer to make that kind of contact kind of gave me back a bit of faith in humanity and made me feel like I belonged

Alan, another returnee to learning explained the difficulties, particularly due to time constraints, that he experienced when trying to establish a good working relationship with his support worker:

> My support worker and I don't have much time to spend together discussing everyday things, because of this we have struggled to build a friendship. It should be more than just her taking notes for me

Nevertheless, the one day a week they did find time, Alan considered this mutually enjoyable:

> I always enjoy Friday as I have a two-hour slot of reading with my support worker, which always sets me up for the weekend and we usually have lunch together and discuss other things apart from university life, which is always nice for the both of us

Dean, also a returnee to learning allowed insight into the importance of building a good working relationship. He was optimistic about an impending meeting with his new support worker, anticipating whether or not she would be flexible and provide informal personal support to lessen his feelings of isolation during his studies:

> I hope I can talk more to her about the rest of my life rather than just study and she will understand me better. It's important to me to be able to have a good relationship with her because I have so few friends and everyone needs someone to talk to otherwise it becomes harder to carry on, to stay involved with Uni. Sometimes it's easier to cut all the social stuff out and just do the work but that's only having half the experience I think

However, like the disability advisors in Blamires and Gee's (2002) project previously suggested, ESWs in the present study were reluctant to perform this informal personal support because it went beyond Northtown University's established roles and responsibilities. Currently, ESWs only have insurance to support students on the University premises. As such, some students in this study felt left out from activities in the wider learning environment, especially when they felt it reasonable to exchange one support activity for another:

> …we decided that we were going to do some structured observations in a local cafe looking at turn taking in conversations. We planned a schedule to record our observations but I realised that although I could go along and see what happened I would not be able to record the observations because I cannot hear adequately…I explained to my support worker what we were doing and asked her to come with me and just note down what I observed, instead of helping me with other work so that I was not asking her to do extra. I just assumed this would be ok but to my surprise she refused saying it wasn't her job to help off the University premises…It was too late to re-arrange things with the group so I got left out (Joshua, 2nd year direct entry student)

Therefore, good working relationships, in more relaxed settings that are distanced from the rigidity of formal academia, seem to help to ease students feeling of isolation. This is particularly important when students are experiencing difficulties building and maintaining social networks at university. These findings mirror those of Goode (2007). For example, students in Goode's study acknowledged difficulties not just in accessing learning and teaching but 'fitting in' and feeling included at university. Similarly, Levett-Jones and Lathlean's (2007)

research findings support the view that when students feel they belong at university they experience a greater sense of empowerment to access learning opportunities. This is because they feel they have a rightful place in the learning community. Alternatively then, a lack of a sense of belonging can be detrimental to students' self-esteem (Goodenow, 2006) and may increase stress, anxiety (Saenz et al., 1999) and depression (Sargent et al., 2002).

7.3.2.2 Peer support

Issues relating to peer support address how and why peers sometimes support students with SCD in the formal, as well as the informal learning environment and the importance of this for student retention. Peers often provided both formal academic and informal support that students with SCD considered essential to their retention. Academic support included organisation of coursework and note taking in lectures whereas, informal support included relaxation and socialising. However, peer support could work in favour of students' peers too; as students with SCD gained more confidence with their peers they felt more able to join forces with them to challenge inappropriate teaching practice and share their personal academic expertise and practical resources.

Peers would often step in when support was not in place, not just in the wider informal environment but also in the formal learning environment and, as suggested by Allan (2001), Pahl and Pevalin

(2005) and Sullivan (1998), may become more important than family. In accordance with Taylor's (1996) findings that peer support was an everyday occurrence for students with SCD, Joshua sheds additional light here by explaining how student peers undertook 'unseen' and unrecognised support at Northtown University and its importance for student retention. Peer support was vital because it may entail both formal and informal support activities:

> They help me with absolutely everything, keeping track of my work and my social life and without them I doubt I would manage at Uni. I really need help all the time not just in lectures as I am so slow at everything I get left behind so easily and I can't catch up. I wish I could explain to people how important friends are and how by helping me to be independent and to stay in Uni they are saving me from being treated like a child at home. That is so important to me right now

Thus, peers provided both informal academic and personal support for students with SCD who, for whatever reason, did not have appropriate support in place. Another example of this 'unseen' support was provided by Cassandra. She wrote in a diary entry that when she had to concentrate, listen, think and record information in a classroom/lecture environment, it proved to be just too much for her to cope with. This created overload – there was only so much room in her 'stress box', it became overfull and she showed signs and symptoms of stress and anxiety which manifested in the deterioration of work:

I usually sit next to another student, Bill who has dyslexia. I find this really helpful as we help each other and he records the lectures for me on his Dictaphone. I told Bill that I often panic during lectures because I find it really difficult to keep up with the rest of the class. I don't seem to have the ability to listen to the lecturer, read the slides and take notes without becoming terribly behind. After Bill expressed that he also finds it hard to keep up we have decided to approach the lecturers tomorrow and ask if they would consider going a little slower

Students indicated that spending time socially with other students from Northtown University could facilitate peer integration, inclusion in the wider learning environment and alleviate potential isolation. This coincides with a plethora of increasing research evidence (see, for example, Hirst and Baldwin, 1994; Griffen, 1997; O'Connell, 2005; Richmond and Ross, 2008; Martin and Dowson, 2009). Matthew, a 1st year direct entry student allowed insight into the importance of this for his sense of belonging at university:

I do like to socialise and go clubbing even though I don't like making eye contact, it is a very big and important part of my university life that I enjoy…because I spent so much time being separated from people when I was younger

However, Cassandra, also a direct entry student reflected that missing out on the opportunity to socialise with her University peers had a negative impact on her. The heavy academic work load she had to complete alongside her full time work placement left her fatigued. This also left her little time to socialise, which she felt boosted her energy levels and in turn enhanced her academic prowess:

> I have no time for socialising which I feel is important because it is a break from studying and a chance to recharge my batteries so that I can work effectively…

Not all students established these helpful social support networks at Northtown University. One such student, Alan revealed in his diary that following three years of study: "I know of very few people by name". However, purposely disclosing his disability had a positive payoff: "My note taker and I were actually invited for a beer by a group from the class". This, Alan felt, was a good coping strategy that widened opportunities to make peer friendships, increased his chances to share academic expertise and released some of the burden that he felt disability can impose on a person:

> I always feel better within myself when all those around me are aware of my hearing, reading and writing limitations…my honesty is and always will be one of my coping mechanisms. I feel that I have strengths to offer a class which people will benefit from and in return for my honesty today I feel that my classmates will offer me a helping hand along the way. All in all today has been one of the best days, perhaps I feel that I have cleansed my soul and removed a rather wide weight from my shoulders

Therefore, peer support can be mutually beneficial both for students with and without SCD. When students' peers provided support, both inside and outside of the classroom, students with SCD gained confidence to reciprocate this, strengthening their social support networks. To this point, Steele et al. (2005) assert that strong social support networks are based upon trust and sharing. Moreover,

Muller et al. (2008) found evidence that although people with SCD experience difficulties with social communication; they long for intimacy, social connectedness and desire to contribute to the well-being of others.

7.3.2.3 Tensions within peer and family support

Issues considered here concern unsupportive behaviour from peers and less directly, family. In particular, sometimes students' peers misunderstood the nature and practice of ESW support. This left students feeling bewildered and angry at the ignorance displayed with regard to their academic needs and could result in increased student isolation. In addition, academic support provided by inexperienced family and peers could do more harm than good. This was because it was often unreliable, or unhelpful, and as a consequence could cause unwanted confrontations. To this point, students with SCD shed light on why provision of academic support in particular, should only be provided by trained ESWs.

Students indicated that informal personal support was all fine and well when peer relationships were supportive. However, quite often peer relationships were not supportive and this often created tension between those providing and those receiving support which, in turn, caused upset and possible confrontations. Dean, a 2nd year returnee to learning supplies a good example of a disturbing incident during a mentoring session with his ESW in the university library. To his

surprise, he was accused by a course peer of not completing work for himself:

> I was discussing with my support worker what I wanted to put in the essay as quietly as I could as I didn't want to draw attention to myself. One of the students on my course overheard this and stood right behind me looking at what I was doing. After a while he asked what I was doing for my essay and I said I wasn't sure yet and he said is that because she (my support worker) is doing it for me. I was a bit shocked and annoyed so I didn't reply at first and before I could he announced very loudly that it must be nice to have someone doing your work for you. Everyone must have heard him and I just got up and walked out (Dean, a 2nd year returnee to learning)

Moreover, students felt that it was sometimes inappropriate that some of the responsibility for academic support was undertaken by family and peers. However, unlike Parker (1999) and Richmond and Ross's (2008) findings, these findings allow insight into the impact this can have on students. Indeed, student in this study indicated support from family and peers intruded on personal relationships, causing feelings of guilt and unwanted confrontations:

> Because I often depend on other people to check my work for me I feel guilty because I know Joanne [*course peer*] is also very busy trying to do her own work and me and my mum sometimes have arguments because she feels that I am asking her about things that she has no knowledge (Cassandra, a 2nd year direct entry student)

Then, after failing an assignment Cassandra felt that peer and family support was unreliable. In particular, student peers had enough to do trying to meet their own assignment deadlines. She was "upset" and

her "confidence had lowered" because of this. She felt unsupported by the University and argued that things could be improved if full responsibility for academic support was taken up by Northtown University. In particular, she called for a proof reading service to be made available:

> Things would have been better if my work could have been proof read. But this wasn't possible because of the deadlines and all the work that needed to be done, Joanne just didn't have time. If I would have had more support from the university at this time and someone else could have proof read it for me maybe things would have been better

Therefore, peers are sometimes unsupportive because they misunderstand the role of the ESW. Indeed, Murray's (2001) research findings would support the view that the practice of mentoring can result in the mentee being wrongly construed as helpless, deficient or weak, which in turn may impede social networks. Yet, Murray offers little solution to this. In addition, students can feel guilty about peer support and this can lead to arguments; it is also unreliably available and students understand this. This coincides with previous findings that peers are limited in depth and breadth of support experience and training (see Chelser and Chelser, 2002; McCauley and Van Velsor, 2004). Moreover, McGee et al. (1992) and Morrison et al. (2001) argue that if peer support is to be at all successful, peers should be provided with training in how to support students with SCD.

Informal personal support, although invisible to Northtown University quality systems, was sometimes undertaken by teaching staff and ESWs, and quite often by student peers. This type of support encouraged peer networking through the development of wider understanding of difficulties and disabilities. Thus, students with SCD could be appropriately integrated into the wider learning environment. This lessened student isolation and gave a welcome sense of belonging at the University (see Ueno, 2005; Taylor and Palfreman-Kay, 2000) which, in turn, could possibly enhance their progression and retention (see Weiner, 1999; Blamires and Gee, 2002).

When appropriate formal academic support was lacking at Northtown University, peers and family often stepped in. This was helpful when it was supportive. However, when it was not it could cause conflict and upset because it intruded into personal relationships. To improve their retention and progression, students with SCD felt that formal academic support should remain the University's responsibility.

7.3.3 Making Improvements

This section looks at student's suggestions for improvements to disability support practice. Students in the present study were asked to record in their diaries how things could be made better in relation to their support needs at Northtown University. Although it is important to heed what students have to say about student disability support practice this, in a sense, was a type of 'wish' list. As part of

the DSA process at Northtown University students complete a 'wish' list of things they would like to facilitate their studies, but may not necessarily get[23]. What is presented below follows a similar line.

Each participant, based on their individual experience, called for improvements to be made to student disability support services to enable appropriate integration and access to the wider learning environment, which may be argued to enhance social connections and improve their retention and progression. These are presented below.

Although good practice was evident and Northtown University had come a long way in meeting the needs of students with SCD, all participants agreed that more compulsory disability awareness training was needed for teaching staff. One participant, Cassandra, a 2nd year direct entry student, expanded on this point and called for Northtown University to put its policies into practice, by ensuring University teaching staff are provided with "...knowledge of different disabilities and their effects". According to another participant, Alan, a 2nd year returnee to learning, the aforementioned could possibly lessen discriminative practice because it was highly probable that offence would be taken by students with disabilities when lecturers used examples of disability that may be interpreted as inappropriate:

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[23] It is noted here that not all student requests are reasonable, whether the student has a disability or not. All students ask for things that teaching staff feel would not benefit them.

> ...there is almost a 100% chance that somebody in that class could be offended or even feel as if they were being berated publicly

Moreover, all student participants called for specific improvements to be made at Northtown University. Alan recommended better all round communication of individual needs:

> …the paperwork being read and some form of methodical action put in place or if the lecturer could possibly make an effort to enquire to your needs with other lecturers or your course tutor, thus allowing this to become knowledge among the other teaching staff

Matthew, a 1st year direct entry student suggested that there should be an alternative option to modules that have compulsory group work sessions, particularly when students have a needs assessment that confirms group work difficulties may affect their attendance and academic performance:

> Universities should be aware that people have problems with working in groups, which causes low attendance, poor concentration and inability to work to deadlines because I have not had the experiences I need to complete the work. They should not enforce attendance in group sessions and should offer an alternative

Cassandra called for a proofreading service (to check clarity, structure, spelling, grammar, punctuation) to help improve the quality of her assignments and show her work at its best:

> It would be useful if the university could provide some sort of service where the work of hearing impaired and dyslexic students is checked over with the student; I feel if this was in place not only would I be able to show my full potential, but to be able to sit with someone who can show me where I can improve in my essays would be extremely beneficial to me

Although Phil, a 3rd year returnee to learning, recognised that sometimes it is difficult for people to include him academically and socially, it did bother him being alone for his exams, rather than being with the peers he had spent time preparing with. He wanted more exam provisions to be in place so that he could take advantage of peer support and peers could learn from the experience:

> I could have done my exam with my friends if my equipment were portable, I type rather than write which may be a bit distracting but my earphones (*he uses a screen reader*) are quiet (I'm told) so I wouldn't disturb them unduly. I think it would be good for them to see me work more often so they understand my problems and how I overcome them

Maria, a 3rd year returnee to learning recommended that students had an ESW with subject knowledge, who encouraged them to achieve their full potential, rather than just turning out assignments; quality not quantity. It was important:

> To have a study mentor who wants me to do well and who may know a little more of the subject I am studying

To lessen possible confrontations, Dean, a 2nd year returnee to learning recommended a less rigid support worker service that provided individualised accommodations on an individualised basis:

> My previous support workers have been inflexible and sort of rule bound…this can cause a bit of friction between us as it has in the past with other support workers who just have a routine and won't think beyond it. I am an individual with individual needs not just some label or some problem that can be solved by applying predetermined solutions. That kind of thinking makes me so mad!

Joshua, also a 2nd year direct entry student agreed with Dean on the above point and instigated the question, 'who is really supporting us in the wider University context?'. To enhance his academic performance and social skills, Joshua felt he needed support both in the formal and informal learning environment:

> I need support wherever I need to be and whatever I'm doing not just in classrooms and that is just not going to happen it seems. That makes me worried about my relationship with other students and my grades and I don't need to be worrying about this when I have enough trouble coping as it is. I don't need the extra stress this has caused and it looks like it's up to me again to either accept this or have an argument to change it…Some people may not need support outside the Uni but I do - why can't I have it?

In sum, students presented a range of improvements that they felt could foster inclusive practice. Similar to participants in Smith's (2010) study, it was felt here that more disability awareness training and better all round communication of needs was essential for teaching staff. In addition, and specific to this study, was that

practical provisions could generally be improved, such as the use of computer software to enable students to feel more integrated with their peers during the exam periods and a less rigid support worker service that allowed access to informal personal, as well as formal academic, support.

7.3.4 Reflections on the Analytical Process

Qualitative content analysis was utilised to analyse a set of data from diaries undertaken by seven students with SCD currently studying at Northtown University. This technique was flexible enough to be conceptually appropriate with the social constructionist stance which sought to explore support networks from the unique perspectives of students, whilst taking account of the researcher's personal actions, thoughts and prior experience (Steier, 1991). This allowed the researcher to address research aims 1 and 2 by providing interesting and insightful information that extended existing knowledge in the area.

The structured approach of coding and sorting data within the categorisation frame provided a means in which to collate student accounts of their support over a four week period and consider these in light of current literature. Generally, this captured how students in this study came to understand disability support in the university setting; how they accounted for and responded to support activities, took or suggested any actions and generally managed their daily

university life. This revealed gaps in both student formal academic and informal personal support at Northtown University.

7.4 Chapter Seven Summary

Qualitative content analysis of student diaries provided interesting and insightful information that extended existing knowledge in the area of student disability support. Students who took part in the present study concurred with current literature that appropriate accommodations allowed integration into the formal university setting; this could facilitate academic retention and progression (see Weiner and Wiener, 1996; Korinek et al., 1999; Peat et al., 2000; Stanley and Manthorpe, 2002; O'Connell, 2005; Christie, 2004; Raab and Adam, 2005). However, inappropriate practice from teaching staff, ESWs and student peers at Northtown University were shown to have detrimental consequences for appropriate integration and access to the learning environment; this could negatively impact upon a student's sense of belonging in the learning community and possibly delay academic progression (Kurth and Mellard, 2006; Sellers and van der Velden, 2003). Moreover, when formal academic support was not available at Northtown University it was often provided by inexperienced family and student peers. This intruded into and disrupted personal relationships. Furthermore, this was currently outside the remit and thus beyond the control of Northtown University.

Students placed particular emphasis on the need for informal personal support and peer networking in order for them to partake of out-of-classroom activities at Northtown University. Currently, teaching staff, ESWs, peers and family provided 'unseen' informal personal support for students that encouraged integration and facilitated student access to the wider learning environment. Student participants recommended that Northtown University take account of their 'individual' needs including, where necessary, their needs for support with peer networking. There is an emerging issue here – clearly, Northtown University's narrow conceptualisation of 'individual' need as 'formal' academic need is not the same as students' broader conceptualisation, which includes 'informal' personal need; this point will be revisited in chapter 8.

The findings from this current phase suggest that students with SCD have real and important needs beyond the strictly academic that may impact upon their experience. It is disturbing to note that these needs, far from being addressed, are largely met (or remain unmet) by chance, rather than through planned and evaluated activities of Northtown University. This is further discussed in chapter 8.

In total, these findings have added to previous literature in the area of student support networks. However, to further authenticate this research, these findings will be compared with findings from ESW interviews. This could add strength by clarifying the relative

importance of factors, such as the implications of formal academic and informal personal support to the retention and progression of students with SCD, to stimulate action in Disability Support services to instigate change (catalytic authenticity, see Ch.4, p.162).

Forthcoming chapter 8 will thus focus on an integrated discussion of the findings from ESW interviews, students' diaries and the literature to address research aim 3: 'Make recommendations of effective ways of supporting students with SCD with a view to providing access to the full range of social opportunities available within the HE environment'.

Chapter Eight – Discussion of the Findings

8.1 Preamble

This study set out to address the following research aims:

> 1. Explore how the current role of ESWs contributes to the establishment and maintenance of social support networks of students with SCD
>
> 2. Assess the contribution of formal academic support to students with SCDs' retention and progression
>
> 3. Make recommendations of effective ways of supporting students with SCD with a view to providing access to the full range of social opportunities available within the HE environment.

Preceding chapters 5 and 7 provided analyses of the findings from ESW interviews and student diaries. These findings are briefly summarised below. The concordance and disagreement between these findings is set out before the findings are integrated in discussion with the current literature. As such, the main findings from the present study are re-visited to show how key contributions were made to knowledge, methods and concepts. Innovative research techniques, alongside current literature, produced empirical findings that have paved the way for a unique insight into the area of student disability support and, as such, recommendations for additional/alternative support activities are made here. Hereafter, it is argued that by challenging existing conceptual frameworks, a 'new way' of perceiving and understanding disability can be envisioned – the 'fourth way': interdependency, which embodies concern for

another's well-being and responsiveness to others on their terms. Finally, a chapter summary is provided.

8.2 Summary of the Key Empirical Findings

Key findings from the present study indicated that ESWs and students felt that appropriate accommodations generally allowed students to integrate into the formal university setting. Appropriate academic accommodations, such as assignment extensions and extra time in examinations, or those undertaken by ESWs, such as note-taking and mentoring, 'levelled the academic playing field' by allowing students to access the formal learning environment and achieve their full academic potential.

However, when this was not in place, the absence of formal academic support could have detrimental outcomes for appropriate integration. In these circumstances, it will be argued that absence of formal academic support, particularly at crucial times, such as the transition period from further to higher education, may impact negatively on students' academic attainment and personal relationships.

In addition, ESWs and students made strong reference to 'real' and important needs beyond the strictly academic that may impact upon educational experience, such as informal personal support. Lack of

informal personal support, such as peer mediation, in the form of interpretation of communication and social interaction to enable students to network with their student peers, could impact negatively on student personal adjustment and relationships, thus hindering their access to the learning community. It is often difficult for students with SCD to access typical channels of communications; some may use non-verbal communication such as British Sign Language, others may find it difficult to initiate and sustain communication, all of which can impact on their ability to express themselves and interact with others (O'Neil, 2008). Thus, it is often difficult for them to share resources with their peers in those activities which require interdependent student learning in informal circumstances, such as groups/pairs. Therefore, their wider social support networks may be enhanced or limited by this. Consequently, this could negatively impact upon student academic achievement by limiting opportunity to develop critical thinking skills, and their affective experience by increasing feelings of isolation and lowering self-esteem.

Currently, student need for peer mediation may, or may not be fulfilled by ESWs. Although ESWs and students with SCD agree that students should have access to this type of support where there is a clear identified need, there is, nevertheless, some disagreement here as to who should provide it. Indeed, recommendations are made here that provision of a more comprehensive informal academic support system, such as a 'study buddy' scheme or social networking

site, would not simply improve their educational experience and attainment but achieve the betterment of their well-being. This is argued to be vital for improvement in the social integration of students with SCD.

It will therefore be argued below that support for these students could be improved by taking more account of their broader academic, personal and social needs in the wider university context. Yet, it will be further argued that responsibility for this does not entirely lie with the university.

8.3 Key Contributions to Knowledge: The Needs of Students as Perceived by Students and their ESWs

What follows is comparison between the two different data sources (ESW online interviews and student web-based diaries), which leads into discussion of the main findings from the present study with respect to the relevant literature. As such, issues are discussed here that concern the needs of students, and to a lesser extent, the needs of ESWs. Whilst there is no desire (or need) to generalise any of these findings, it is possible that the views of the participants in the present study, and the student support practices of universities, may correspond with the views and practices of others in similar situations.

For clarity and ease of reading, the aforementioned issues have been collated under the following headings; in relation to formal academic support issues, 'levelling the academic playing field' and 'the absence of formal academic support'; in relation to informal personal support issues, 'limiting access to network capital', 'looking beyond the strictly academic to meet students' wider personal and social needs' and 'building and maintaining wider social support networks for students with SCD'. Subsequently, reflection on the contribution to methodology is provided before existing conceptual frameworks are challenged.

8.3.1 Formal Academic Support

8.3.1.1 Levelling the academic playing field

The majority of ESWs and students with SCD agreed that appropriate academic accommodations facilitated student integration into the formal university setting and 'levelled the academic playing field'. However, only a small minority felt otherwise. Although ESWs did not explicitly mention this, they did appear to support the claim that appropriate accommodations 'levelled the academic playing':

> Personally I feel that as long as the student is satisfied with their academic work and feels they are achieving the best they can, that is what higher education should be about (Fiona, with 4 years' mentoring experience)

> I often feel their academic success is a moral victory – it puts right what is wrong – not with them but with the world (Eric, with 3 months' note-taking experience)

Cassandra, a 2nd year direct entry student made reference to a similar point here but explicitly pointed out that when appropriate support was in place this allowed her to achieve equally as well as her student peers:

> I was feeling positive because I was able to do the exam on the computer, and have 25% extra time. For the first time ever I felt totally satisfied with my exam because I had plenty of time to check it over and remember the things that I had learned…it has given me the confidence to think that I can do well and I can get just as good marks as anyone else

Alan, a 2nd year returnee to learning, agreed that appropriate accommodations not only 'levelled the academic playing field' but raised his confidence too:

> I had a mentoring session which I always enjoy...and again later in the day I had 20 reading sessions which I always come out of feeling refreshed and confident

However, there was agreement between a small number of ESWs and students with SCD in that sometimes formal academic support presented barriers to students' learning. In particular, there were concerns as to whether or not students with SCD gleaned the same or similar educational experience to that of their peers:

> I think it's the uncertainty that is brought about by being in between the student and their learning experiences - am I getting across to the student what the lecturer intends, am I doing enough to provide the student with a comparable experience of the lecture or seminar that other students have. I worry that doing what I do in some way prevents the student from engaging with the experience like their peers (Eric, with 3 months' note-taking and campus assistance experience)

It's not always easy to judge how useful the help you provide is, particularly when it is something like note-taking. Generally, you give the students the notes at the end of the class and that's the last you know about it (Dennis, with 5 years' mentoring experience)

However, it is important to note that barriers to students' development of peer support networks were generally a consequence of practicalities, such as examination arrangements and the ever present ESW, rather than ESW incompetence:

What bothered me today is being alone for the exam rather than being with the others I had spent time with to prepare for it (Phil, a 3rd year returnee to learning)

Well just being there I'm kind of in the way; like a barrier between them and their peers, rather than someone who facilitates interaction (Eric, with 3 months' note-taking and campus assistance experience)

Therefore, formal academic support is perceived by both ESWs and students as a worthwhile and necessary provision, yet interestingly it can also cause problems by not providing an inclusive environment. When students receive appropriate accommodations it is unknown whether this provides them with a comparable academic experience to their peers and could, in certain circumstances, impact on their development of peer support networks. This, in part, supports the findings of Kurth and Mellard (2006) were one student participant stressed that his sense of belongingness at university was disrupted due to having examinations in a separate location from his peers. Nevertheless, on balance formal academic support was positively

regarded by both ESWs and students with SCD, and this is consistent with a vast amount of existing literature.

It is argued here that many of the positive aspects around 'levelling the academic playing field' identified by participants in the present study are similar to those identified in the literature. Empirical findings from the present qualitative study, student web-based diaries and ESW online interviews, indicate that formal academic support, when appropriately delivered and sufficiently individualised, worked well enough to encourage students to achieve their full potential. Formal academic support 'levels the academic playing field' for students with SCD by facilitating their integration into the campus-based formal academic environment (classrooms, lectures, group work, studying in the library, work-based placements). This gives students adequate access to the learning environment (see Ch.5, p.221 and Ch.7, p.292).

These findings support those reported in previous, mainly quantitative, research studies. The effectiveness of formal academic support undertaken by ESWs (note-taking, mentoring, BSL, interpretation, campus/library support) is well documented in the literature (Cremer, 1991; Bertocci et al., 1992; Weiner, 1999; Stewart-Brown et al., 2000; Grant, 2002; Lowe and Cook, 2003; Avramidis and Skidmore, 2004; Wright, 2005; Heiman, 2006; Kurth and Mellard, 2006).

However, many previous quantitative studies have used 'yes/no' answers. For example, Bertocci et al. (1992) claim that formal academic support brings improvement in student concentration, assignment completion and time management skills, but it is difficult to determine from yes/no answers the extent to which the students experienced these benefits. In relation to these issues, the qualitative findings from the present study suggest that the extent to which these students benefit from formal academic support is reliant upon two main factors: appropriate delivery that gives access to the learning environment, and individualised support programmes.

Findings from the present study further allow insight into the implications of these factors in terms of students' academic attainment with the potential for the improvement of their grades (see Ch.7, p.294). For example, wide ranging academic, personal and social benefits can accrue when appropriate formal academic support is in place because it can foster a positive learning environment. As such, a positive learning environment may lead to a sense of satisfaction and achievement for students (see Ch.5, p.221) and ultimately, to a sense that the 'academic playing field' has been levelled and a social inequality mitigated. This, in turn, is argued to facilitate student academic retention and progression (see Ch.7, p.293). This supports the view that qualitative findings can provide meaningful insights into previous quantitative findings. Meaningful insights can be achieved by elaborating on how formal academic

support is important for students' concentration, assignment completion and time management skills. This can show why formal academic support is important in terms of academic attainment and the factors that contribute to this, such as appropriate delivery of support and individualised learning programmes.

To this point, the findings from the present study are consistent with those of Weiner and Wiener (1996) who used both surveys and interviews, illustrating how formal academic support is important for retention and progression because it allows students to improve both their academic (studying effectively, essay writing, class presentations and exam preparation) and social skills (develop close friendships, asking for student peer assistance, joining extracurricular activities). Weiner and Weiner's (1996) interview techniques were used to elaborate on survey answers that revealed areas of concern (high anxiety, career direction and self-esteem) to show how formal academic support contributed to skills that students perceived as lacking. These skills, similarly identified by participants in the present study, were a combination of both academic and social skills. The types of support identified and viewed as valuable by students in the present study included peer and staff support, practical and personal support but above all else, they wanted a sense of belonging, an environment where they felt safe and comfortable, where they could be themselves. The use of qualitative methodology therefore

provides more depth and more detailed insights into wider participant experience.

In sum, there is broad consensus, both within the findings in the present study and from the literature, that formal academic support can, and does, 'level the academic playing field' for students with SCD. Therefore, it is reasonable to suggest that it is more likely to be the case that those students in receipt of this support, who find it helpful, are more likely to be retained and thus more likely to progress successfully with their studies.

However, for various reasons, formal academic support was sometimes not in place. The implications of this are discussed below.

8.3.1.2 The absence of formal academic support

ESWs and students with SCD were in concordance that any absence of formal academic support for students with SCD could have disadvantageous outcomes for appropriate integration. A good example of this is provided by Cassandra, a 2nd year direct entry student. Cassandra explained the wide ranging difficulties she experienced when she did not have any academic support in place whilst on full time placement and how this lack of academic support impinged on her availability to socialise with her student peers. Peer socialisation was importance to her academic success:

My work placement is exhausting in itself because straining to hear all the time is very tiring, to then have to come home and start writing all evening is beginning to take its toll as I am becoming irritable and tired all the time. I feel that I am at a disadvantage and feel unsupported at this moment...I have no time for socialising [*with student peers*] which I feel is important because it is a break from studying and a chance to recharge my batteries so that I can work effectively...

Fiona, with 4 years' mentoring experience agreed that students need time with their peers to facilitate integration into the learning environment:

...having friends around may prevent feelings of isolation and alleviate the inevitable stress of meeting deadlines and forthcoming exams. Having someone to talk to can help students feel cared about

However, ESWs may not fully realise the role of student peers when there is an absence of formal academic support. Joshua felt that in the absence of formal academic support student peers played a vital role in his academic success:

They help me with absolutely everything, keeping track of my work and my social life and without them I doubt I would manage at Uni. I really need help all the time not just in lectures as I am so slow at everything I get left behind so easily and I can't catch up. I wish I could explain to people how important friends are and how by helping me to be independent and to stay in Uni they are saving me from being treated like a child at home. That is so important to me right now

This illustrates, very poignantly, the close relationship between formal academic and informal personal support, with informal personal support becoming ever more important in the absence of formal academic support.

Typically, Cassandra explained that students tend to rely on untrained student peers and family to make up any shortfall in academic support, which caused feelings of guilt and unnecessary confrontations:

> Because I often depend on other people to check my work for me I feel guilty because I know Joanne [*course peer*] is also very busy trying to do her own work and me and my mum sometimes have arguments because she feels that I am asking her about things that she has no knowledge

As such, ESWs and students with SCD were in agreement that formal academic support should only be provided by trained ESWs "Things would have been better if my work could have been proof read [*by an ESW rather than a student peer or family member*]" (Cassandra). This is essential because not only are ESWs able to individualise their support practice but they are also able to recognise when it may be beneficial for the student to seek professional support elsewhere:

> I see my role as being able to recognise support needs for each individual student and trying to fulfil those as much as I am able within my role and knowing when to bring in other professionals when I can't do anything (Brenda, with 4 years' mentoring experience)

Therefore, the relationship between formal and informal support is important for students with SCD. Informal support provided by peers and family members goes some way in addressing the shortfall of formal academic support; it nevertheless appears to be a poor substitute to that provided by trained and experienced ESWs. Parker (1999), and more recently, Richmond and Ross (2008) are in agreement here; informal support provided by family and peers can be inappropriate due to the negativity students, family and peers may experience with regard to issues concerning social obligation.

When there is an absence of formal academic support for students with SCD, there is some incongruence between the findings from the present study and the literature regarding the appropriateness of family and peers acting as substitutes for ESWs. This tension is set out below.

If formal academic support was not yet in place or not appropriately applied, it was often performed by family and peers. A number of studies gained students' views on this matter. Parker (1999) argues that although family are often more "flexible, comforting, supportive, and cheaper" than professional assistance (p.493), students often considered this support inappropriate because it was fulfilled through obligation, rather than choice. To this point, Sullivan (1998) asserted that students considered that voluntary support provided within peer friendships was more genuine and supportive than the obligatory

nature of family support. Nevertheless, Chelser and Chelser (2002) and McCauley and Van Velsor (2004) cast doubt on this interpretation because students, in their studies, viewed peer support as problematic because their peers have little, if any, experience in providing support for students with disabilities.

In sum, the evidence shows that formal academic support provided by family members is seen as inappropriate if provided under a sense of obligation. However, research is ambivalent on the aspect of peer support as a substitute in the absence of formal academic support. There is tension here as to whether peer support provides a positive or negative experience for students with SCD and the impact that may have on the student. As set out below, findings from the present study begin to resolve this disagreement.

Students in the present study were able to provide some clarity on these points. They felt that when formal academic support was not in place they had no option but to seek support elsewhere, often from family and peers. For example, this type of support was often undertaken by inexperienced family and peers who had no formal training in providing such support for students with SCD (see Ch.7, p.315). Although in agreement with Chelser and Chelser (2002) and McCauley and Van Velsor (2004) that it was problematic, according to these students, this was not just about inexperience in providing formal academic support but also related to the potential disruption to

personal relationships, exemplified as tension and upset due to arguments. Students in the present study recognised there could be uncomfortable outcomes when support or advice was considered by either the provider or the recipient as unreliable, putting immense strain on their relationships through heated discussions and subsequent feelings of guilt. As such, these students felt that it should be the responsibility of the University to ensure that formal academic support was in place. However, this in itself is not so straightforward.

Sometimes, it can prove difficult for universities to establish who these students are because they do not always disclose disabilities at the outset of their studies - this was the case for at least one participant in the present study (see Ch.7, p.296). Nevertheless, there are a number of students that Northtown University is aware of that are not in receipt of support because they are awaiting disability assessments. During the transition period from further to higher education, students find that their disability statements are obsolete and thus need renewing. This can be quite a lengthy process, which places constraint on the Disability Support Office preventing them from allocating support until the reassessment process is complete.

Often, this leaves students with no formal academic support provision until the latter part of the first academic year, or worse still, the beginning of the second year. This comes at a time when

students with a disability are at their most vulnerable due to the disruption of familial support. Wilcox et al. (2005) argue: "When students enter university, feeling lonely and homesick is a common experience" (p.713). As such, this can exacerbate student difficulties and place them under additional stress.

Taken together, this would lend support for the view that when there is an absence of formal academic support, it is undertaken nevertheless by persons unknown to the university and without its knowledge. On balance, this can be unhelpful because these persons have no formal training and when instances of inappropriate support occur this can have confrontational and upsetting consequences for those involved. Hence, it is argued here that formal academic support should only be provided by trained and experienced ESWs.

With this in mind, it is suggested here that in the current climate where universities are expected to be anticipatory of all student needs (Disability Equality Duty, 2006[24]) it should be possible for universities to recognise that under certain circumstances when support is not in place that support goes on unnoticed. Individuals will intentionally seek support for their needs (from family members and peers if necessary) when waiting for assessments to be processed. Yet, this type of *ad hoc* support may not be appropriate because it

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[24] See Disability Rights Commission, 2007b – renamed Equality and Human Rights Commission in October 2007.

can disrupt otherwise good relationships. One potential solution here is that an interim support service, undertaken by trained ESWs, could be made available. The availability of this service could be made known to all students in receipt of, or who are expected to be in receipt of, Disabled Student Allowance (DSA) to enable those without support to come forward and access provision. Expenses could then be subsequently reclaimed from the student's DSA.

The above sections focussed on formal academic support issues; 'levelling the academic playing field' and absence of formal academic support. What follows is based upon informal personal support issues[25]. Indeed the next section, 'limiting access to network capital', supports the extant literature. This is briefly revisited to facilitate understanding of the general consensus for providing informal personal support to enable student access to network capital. This is followed by a tension between the perceptions of ESW and student participants in the present study with regard to who should provide this type of support. As such, this primes the reader to aspects other than formal academic support, such as broader personal and social needs in the wider university context, which are set out in the forthcoming sections, 'looking beyond the strictly academic to meet wider personal and social needs' and 'building and maintaining wider social support networks for students with SCD'. It is subsequently argued that these aspects, alongside those of formal academic

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[25] Informal personal support is defined here as helping students to build supportive relationships, giving relationship advice, peer mediation and/or facilitating integration into the wider learning environment.

support, need to be considered by universities and those involved in the DSA process.

8.3.2 Informal Personal Support

8.3.2.1 Limiting access to network capital

There was vast amount of agreement between ESWs and students with SCD that informal personal support, particularly peer mediation, should be provided to facilitate student integration and lessen the danger of poor academic performance:

> In some cases it is clearly not enough to give just academic support or even academic plus general personal support. If physical support or other problems are likely to cut a student off from others socially, then his/her experience of university may not be a happy one, and in addition his/her academic work may suffer as a result (Dennis, with 5 years' mentoring experience)

> It was not just in structured [*formal academic*] sessions that the student needed my support. For example, the student's peers often met informally to discuss academic work but the student I supported was not confident communicating with their peers unsupported (Fiona, with 4 years' mentoring experience)

> In lectures and such like I could be more of a mediator, help with communication beyond the academic and try to integrate these students more into the whole group – get the other students to be more aware of the difficulties of living and working with communication difficulties and helping them to become more involved and supportive. Beyond that, I could support friendships by facilitating communication for both students with and without communication difficulties (Eric, with 3 months' note-taking and campus support experience)

Some mentors are highly trained and will suggest strategies for SCD students to encourage integration with their peers, which is an essential part of both social and academic university life (e.g. working in teams) (Glenda with 6 years' mentoring experience and co-ordination of student support services)

…we also need to ensure the students holistic needs, at the same time are met. This may mean the personal needs may have to be met in an attempt to meet the academic needs (Christine, with 9 years' mentoring experience and co-ordinating/training of mentors)

If we get along I go to lunch with them, where I provide additional advice often of a personal nature such as, emotional support with relationships, family, friends and student peers (Ian, with 3 years' mentoring experience)

Although students with SCD did not refer as directly to informal personal support as ESWs, they did allude to the importance of peer mediation indirectly "It [*support*] should be more than just her taking notes for me (Alan, a 2nd year returnee to learning):

...I have so few friends and everyone needs someone to talk to otherwise it becomes harder to carry on, to stay involved with Uni. Sometimes it's easier to cut all the social stuff out and just do the work but that's only having half the experience I think (Dean, a 2nd year returnee to learning)

I need support wherever I need to be and whatever I'm doing not just in classrooms and that is just not going to happen it seems. That makes me worried about my relationship with other students and my grades and I don't need to be worrying about this when I have enough trouble coping as it is (Joshua, a 2nd year direct entry student)

This is important because lack of informal personal support, such as peer mediation may hinder student access to the learning community and limit their access to network capital (resources that are flexible, efficient and effective Plickert et al., 2007):

> I explained to my support worker what we were doing and asked her to come with me and just note down what I observed, instead of helping me with other work so that I was not asking her to do extra. I just assumed this would be ok but to my surprise she refused saying it wasn't her job to help off the University premises…It was too late to re-arrange things with the group so I got left out (Joshua, 2nd year direct entry student)

Therefore, even though ESWs appear to be in favour of informal support (this issue is addressed later in this section) they are reluctant to undertake this role. Most refuse to carry out informal support even when faced with concrete situations where they could provide it. Thus, ESWs, although in favour of providing informal support in principle, may in practice draw back from it.

As demonstrated in the above extract, it is often difficult for students with SCD to share resources with their peers in activities which require interdependent student learning in informal circumstances, such as groups/pairs. Christine, with 9 years' experience supporting students with disabilities was in full agreement with this:

> I believe support for students with any disability should be provided outside of lectures to encourage development of social support networks, especially in the early days at university when social networks are fragile as I believe its difficult making the transition to university and even harder still with a disability

Moreover, Eric, with 3 months' note-taking and campus assistance experience was also in agreement here stressing that students' wider social support networks may be enhanced or limited by informal personal support:

> I think support shouldn't end at the classroom door so to speak. If students feel isolated and are prepared to admit it, then that is a need that is a consequence of the way we structure academic experience and we should address it

Therefore, ESWs express concerns that students are anxious and frustrated that they do not have access to informal support, compared to the provision of formal support. Typically, ESWs appear to have insight into the fragility of students' relationships and their tenuous hold on university life.

Informal personal aspects of disability support are well documented in the literature:

> …personal factors concern the extent to which students with disabilities require support and interventions in negotiating relationships within the university, with family and friends, with peers and with external agencies where necessary
>
> (NCIHE, 1997b: 5.9)

If the above is impeded this can have a negative impact on students' access to network capital. Network capital is "social capital that is embedded in interpersonal relations that can provide custom-tailored helpful resources that are flexible, efficient and effective" (Plickert et al., 2007: 406). For example, through contact with others in their social networks, students can exchange academic materials, plan essays, research a topic area together or share information and resources. They can also provide each other with companionship and emotional support such as empathy, understanding and compassion. If this is limited because students need informal personal support to make this happen, this can have detrimental consequences for students with SCD. This is similarly identified by participants in the present study and many others in the literature (see McGee et al., 1992; Garrison-Harrell and Kamps, 1997; Kamps et al., 1997; Kersting, 1997; Foster et al., 1999; Morrison et al., 2001; Blamires and Gee, 2002; Larose et al., 2005; Mesibov et al., 2005).

However, there is a tension here, as most ESWs in this study think they should not be providing informal personal support as a way to enhance student access to network capital, but the majority of students think they should. To add more fuel to the fire, the literature is split between the two views. The consensus and disagreement around these issues is discussed below.

Currently, student need for peer mediation may, or may not be fulfilled by ESWs:

> If they needed me to mediate between them and their peers through interpretation of both verbal and/or non-verbal communication, I could be 'on hand' (Fiona, with 4 years' mentoring experience)

> I think it is a good idea but I'm not sure how much help they would be happy with. They would want to have time to be just with other students but I think they need to learn how to include people who can't communicate with them into a conversation more… but they might on the other hand be stressed and unable to do this, if they are unable then they need the networking support (Anne, with 2 years' note-taking experience)

Interestingly, although some ESWs are clearly willing to provide informal personal support, who should undertake this informal personal support appears to be the only disagreement in the findings between ESWs and students with SCD. Anne suggests in the above extract that one good reason for not providing informal support is that students may not welcome this as it may intrude on their relationships with their peers. Nevertheless, some students with SCD feel that ESWs, or at least someone provided by the university, should provide this informal support to ease their peer relationship and academic anxieties:

> I need support wherever I need to be and whatever I'm doing not just in classrooms and that is just not going to happen it seems. That makes me worried about my relationship with other students and my grades and I don't need to be worrying about this when I have enough trouble coping as it is (Joshua, also a 2nd year direct entry student)

> My previous support workers have been inflexible and sort of rule bound…this can cause a bit of friction between us as it has in the past with other support workers who just have a routine and won't think beyond it. I am an individual with individual needs not just some label or some problem that can be solved by applying predetermined solutions (Dean, a 2nd year returnee to learning)

Although, ESWs were supportive of peer networking for students with SCD, they were adamant that it should not be them that fulfil this role because of professional boundaries and the potential to intrude on personal relationships "I think it would be difficult for an academic support worker to fulfil this role because of the blurring of boundaries" (Glenda, 6 years' mentoring experience and co-ordination of student support services). Pertinent to this point is that ESWs are not allowed to include themselves in student peer relations because "it crosses professional boundaries, intruding into student personal lives" (Janet, with 1 years' note-taking experience).

Therefore, ESWs reluctance to perform informal support appears to be related to the professional boundaries set out by the University. However, when ESWs do step outside of these imposed support boundaries they nevertheless have increased opportunity to play an important role in the establishment of student support networks. Students claim this is essential to their academic success.

Generally, formal academic support, provided by trained and experienced ESWs worked well. However, according to Goode (2007), student problems relate to personal and social issues within the wider university environment, as well as academic ones. These problems, as identified by students in Goode's (2007) study, include personal adjustments to university life, difficulties with disclosure of disability, in accessing learning and teaching, 'fitting in', feeling included and gaining independence from family. Blamires and Gee (2002: 20), based on evidence from a longitudinal project, make a similar point arguing that for university students with SCD:

> The greatest difficulty was creating social networks. Many students use this to share difficulties and this might not be open to this group of students

To this point, there is a growing body of qualitative literature that identifies a need for informal personal support that facilitates the construction of social support networks during the transition period to university and beyond. Student social support networks are important because they can alleviate some of the personal and social issues identified above in Goode's (2007) study, by facilitating students' access to network capital (Plickert et al., 2007). In particular, these networks can facilitate academic tasks, provide appreciation of opinions (Hobfoll, 1998), emotional support and social companionship (Walker et al., 1994). Above all, McKinney (2002) argues that access to network capital allows students to feel integrated in the university setting.

Therefore, it is important that communication channels for student peer discussions remain open because if students do not have access to network capital they may find themselves at a disadvantage (Palloff and Pratt, 1999). For Fink (2003), this may manifest in limited opportunities for conversation, development of critical thinking skills and the sharing of resources. Wood and Smith (2005) claim the above are necessary to sustain an effective learning community.

In sum, the general consensus in this emergent literature is that some students with SCD find it difficult to access typical channels of communication and thus have limited opportunities to meet peers in the wider university context. This is argued to limit their access to network capital. Taken together, there is broad consensus here that students need positive interactions with their peers, both in the formal and informal university setting. This is said to lessen the danger of isolation, improve a sense of well-being and facilitate their academic studies. According to the current literature, when students do not feel they have a legitimate place in the learning community this can put them in danger of low self-esteem (Goodenow, 2006), increased stress and anxiety (Saenz et al., 1999) and a tendency toward depression (Sargent et al., 2002).

On balance, it is more likely to be the case that these particular students, at times, need support other than the strictly formal academic kind. As such, they may find it helpful if informal personal support (help to build supportive relationships through giving relationship advice and providing peer mediation) is provided to facilitate the development and maintenance of wider social support networks.

In a parallel way, most ESWs in the present study also recognised the need for other forms of support for students, including supporting their social networks. Yet, like the participants in Blamires and Gee's (2002) project who felt: "There is a limit and staff did not want to intervene as it was seen as off limits" (p.20), those ESWs in the present study with a lower-level of training and experience, such as note-takers, did not feel able to provide this support (see Ch.5, p.227). There are, however, some diverse views here.

ESWs in the present study who were more experienced and had a higher-level of training, such as mentoring skills, generally did, albeit reluctantly, begin to work in the area beyond formal academic support. For example, some ESWs would provide informal personal support in terms of helping students to build and maintain relationships with their student peers and in accessing extracurricular activities; this, they claim, helped students to develop and maintain wider social support networks. This meant that these ESWs stepped

into a role that was invisible to Northtown University quality systems, namely, informal personal support, which was practiced both on and off campus, as and when they saw fit, during the academic day (see Ch.5, pp.230-232). Nevertheless, according to these ESWs, the advantages of providing such support are that it can help students and their peers to relax and develop social skills that enable them to communicate effectively with each other.

This further lends support for many findings in the literature. Muller et al. (2008), for example, found that students with SCD can thrive on social connectedness through activities based on shared interests. Similarly, Stinson and Whitmore (1992), Kluwin and Stinson (1993) and Stinson and Kluwin (1996) take the view that students are more likely to participate in extracurricular activities when ESWs provide mediation between them and their peers. For some student participants in the present study this, however, was not to be the case. Some students experienced great difficulties accessing extracurricular activities because some ESWs were not prepared to provide any type of support, formal academic or informal personal, outside of the university premises (see Ch.7, p.318). Thus, tension exists here because some ESWs are adamant that they should not be supporting students off campus.

Principally, ESWs in the present study claim this was because the University does not provide insurance for off-campus activities other than student work-based placements. Furthermore, according to these ESWs, this was also because those who did undertake this informal role found it uncomfortable for at least two well-founded reasons. In part, this was because it crossed professional boundaries and was also partly due to the large age gaps often present between ESWs and students. At present, the latter issue concerning age gaps does not appear to have been identified in the extant literature.

With regard to the view that ESWs tend to be older than the students they support, according to ESWs in the present study, age gaps appeared to be more of an issue, or possibly an excuse, when they supported students meeting their peers in informal, rather than formal settings, because of the heightened potential for power imbalances (see Ch.5, p.237). Informal personal support could evoke unequal power relations because students may feel less powerful, less intelligent or confident with older people. According to these ESWs, this could have a negative impact, both on the academic environment and on the person. It could make educational situations awkward and the student may experience an increase in dependency, lack of autonomy and peer isolation. As such, students and their peers may alter their behaviour and not act in typical student ways. Students in the present study did not comment on any of the aforementioned reasons identified by ESWs for not getting involved in informal

personal support. However, some did argue that ESWs should be more flexible and undertake informal personal support activities.

With regard to the view that provision of informal personal support crossed professional boundaries, this is argued to be one constraint of ESW basic training that arises from a need for professionalism. For example, ESWs are given specific instructions to be friendly but not friends with students; they must not go for coffee breaks/lunch with students, and must not provide off-campus support as there is currently no insurance for this type of activity. Thus, when some ESWs cross the professional boundaries set by Northtown University into the realm of informal personal support and start to do things that they are not trained to do, they are not merely going against University requirements; in some instances, ESWs in the present study feel this could also do more harm than good. For example, if ESWs cross professional boundaries it may then become difficult for them to 'step back' into their formal academic roles. Moreover, ESWs in the present study feel that it could interfere with student peer relationships because peers may channel their communication through ESWs, rather than attempting to communicate directly with students with SCD. Thus, ESWs in the present study argue that they are not trained in providing this type of support, and more importantly, do not think they should be; they felt that informal personal support should not be part of the educational support they provide.

Taken together, there is disagreement on who should undertake informal personal support. ESWs in the present study, like those in Blamires and Gee's (2002) study clearly think they should not, whilst some students in the present study clearly think ESWs, or at least someone, should. If this issue is not resolved, the broader implications here are that students with SCD still may not be getting the student experience they are seeking, such as peer friendships that can provide network capital. Students in the present study and others, following more than a decade of research (see for example, Walker et al., 1994; Hobfoll, 1998; McKinney, 2002; Fink, 2003; Wood and Smith, 2005; Goode, 2007; Plickert, et al., 2007), felt that without this type of support they were placed at risk of not being able to access the 'whole' university experience. A 'gap' has clearly been identified here, the provision of additional support for students' growing, or underdeveloped, social support networks.

A plausible forecast is that the tension between ESWs and students will not be overcome until universities focus more attention on those aspects of support that are not directly related to the student's formal academic experience. On balance, not all student problems can be regarded as of the formal academic variety; some derive from personal and social issues, such as the need for additional assistance with building and maintaining wider social support networks. It is suggested below that it is not entirely the Universities' responsibility for their perception of student need in the narrowest

form of formal academic support, to the neglect of student wider social relations. This aspect is discussed below before making suggestions for improvements to student disability support.

8.3.2.2 Looking beyond the strictly academic to meet students' wider personal and social needs

Thus far, it is reasonable to suggest that the aforementioned arguments indicate the need for a framework of support that can facilitate access to network capital. This should take account of both formal academic and informal personal support in the wider university context. This issue will now be discussed further.

ESWs and student participants in the present study vastly agree that students have support needs beyond those that are currently considered at university:

> ...there is a lot of social activity between students that I don't support, well really I can't support because that's not what I'm there for...Academic support – going beyond that is discouraged, well more than that actually…I just want to emphasise the unfairness of the situation I suppose, I'm there to help but in the sense of helping with friendships and social support I am not allowed (Eric, with 3 months' note-taking and campus assistance experience)

> It was not just in structured [*formal academic*] sessions that the student needed my support. For example, the student's peers often met informally to discuss academic work but the student I supported was not confident communicating with their peers unsupported. Therefore the student did not attend these informal sessions and may have possibly missed out on support students provide each other with (Fiona, with 4 years' mentoring experience)

> With these students the problems or issues are quite often social and to my mind they do not engage fully in uni life… (Brenda, with 4 years' mentoring experience)

> ...encouraging integration with their peers, is an essential part of both social and academic university life (Glenda with 6 years' mentoring experience and co-ordination of student support services)

> …we also need to ensure the students holistic needs, at the same time are met. This may mean the personal needs may have to be met in an attempt to meet the academic needs (Christine, with 9 years' mentoring experience and co-ordinating/training of mentors)

> In some cases it is clearly not enough to give just academic support or even academic plus general personal support. If physical support or other problems are likely to cut a student off from others socially, then his/her experience of university may not be a happy one, and in addition his/her academic work may suffer as a result (Dennis, with 5 years' mentoring experience)

Therefore, according to ESWs informal personal support is an essential part of university life, socially as well as academically, because it facilitates peer integration through access to social and academic activities. Peer integration can lessen the danger of student isolation, which can negatively impact on academic performance.

Although students with SCD did not specifically refer to informal personal support, they did provide good examples that show general agreement with ESWs that students have support needs beyond those that are currently considered at university:

What bothered me today is being alone for the exam rather than being with the others I had spent time with to prepare for it…It felt like I was being isolated from my friends and treated differently, which I don't like. All my friends are so supportive it feels bad not to be with them...It's easy to feel like you don't belong at Uni with more able bodied people...(Phil, a 3rd year returnee to learning)

My support worker and I don't have much time to spend together discussing everyday things, because of this we have struggled to build a friendship. It should be more than just her taking notes for me... (Alan, a 2nd year returnee to learning)

Some people may not need support outside the Uni [*formal classroom setting*] but I do - why can't I have it? (Joshua, a 2nd year direct entry student)

Thus, ESWs and students alike, argue this necessitates consideration of all issues relating to student experience whilst attending university, and that wherever possible, support should consider informal as well as formal academic issues. However, student needs can conflict with the prevailing 'audit culture', which strives for economic efficiency (see Riddell et al., 2007). To be economic with effort, time and finance it is the case that students with SCD may typically be allocated interpreters, note-takers and mentors only, rather than the informal personal support that students assert they need. As such, current support does not offer vital assistance with the creation and maintenance of support networks within the wider university context. As discussed in the previous section, the need for this type of support has been consistently identified by both participants in the present study and the existing literature. To neglect this support is to the detriment of students' opportunities to

access a range of social and wider academic opportunities available in the university setting.

At first glance, this may appear to follow new-managerial principles that hold that 'impersonal' outcome measures should be based on rationality, bureaucracy and economic efficiency (for an overview, see Reed and Deem, 2002 and the present study Ch.2, p.60). Basically, these outcome-based measures require administrative audit and assessment through group categorisation, counting and accountability. Riddell et al's. (2007) longitudinal project illustrates a good example of this. This project aimed to explore four different institutional responses to the demands of the 'audit culture' in relation to accommodating students with disabilities. These authors found evidence to support the view that individual universities' key priorities in relation to students with disabilities were to increase recruitment and retention through institutional barrier removal. Barrier removal places emphasis upon adapting the environment to make it more accessible for students by installing lifts, ramps, hearing aid loops and providing formal academic support. The incentive for this is financial. It is driven by HEFCE who provide a financial incentive to universities by allocating premium funding to be paid on the basis of the number of students claiming DSA. Thus, many universities are generally in the same situation as Northtown University due to HEFCE and DSA processes; they are encouraged implicitly to adopt

practices that offer little priority to consideration of informal academic support.

Yet, funding is twofold; it is also channelled at individual student level in the form of DSA. The DSA assessment process (for more details see Ch.4, p.165) claims to be based on strategies to facilitate participation in all aspects of mainstream higher education (National Network of Assessment Centres, 2008). However, the view taken here is that the DSA assessment process itself also deflects attention away from informal personal support. For example, if DSA assessors[26] fail to recognise and acknowledge informal personal support needs in their reports and thus make no recommendations to the LEA and university, there is no impetus for the LEA to sanction informal personal support and significantly here, for the university to provide it.

Thus, support is profoundly influenced by the DSA process. For example, the majority of students with SCD at Northtown University currently have access to interpreters, note-takers and mentors, but not 'study buddies' (see Ch.4, p.167), who can be employed to offer support with difficulties that students may be experiencing academically, personally and socially (Blamires and Gee, 2002). Zellers et al. (2008) in the United States of America, Blamires and

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[26] Assessors are qualified professionals employed to assess student study needs, such as educational psychologists and occupational therapists that have "experience and knowledge of the equipment and support that students with disabilities need to study successfully at university" (National Network of Assessment Centres, 2008: no page number).

Gee (2002) and more recently McGowan et al. (2009) in the UK context, consistently describe 'study buddy' schemes as positive for the students involved.

Although assessors may be aware of the types of support that exist, including 'study buddy' schemes (see Ch.4, p.167), they appear only to recommend this support when it is specifically requested by the student (see Ch.4, p.168). However, if students are not fully informed about what types of support are available, they are effectively denied the opportunity to request them and thus receive them. From this, it would be reasonable to suggest that it should be the responsibility of both universities and assessors to ensure students are fully informed of all available support services during the DSA process. Informing students of all available types of support, academic, personal and social, can place them in a better position to negotiate support with assessors and the university to meet their perceived needs.

The key point here is that each student receives a personal DSA allowance to cater for their support needs, yet the DSA system itself encourages universities to provide students with support that takes little account of wider academic, personal and social need. The danger here is that universities may well increase recruitment of students with a disability based on HEFCE incentives, but retention and progression may decrease due to inappropriate recommendations from the DSA assessment process. Indeed, at

Northtown University there has been a general increase in students with SCD since 2000 but the University, on average, has only successfully retained those on short-term, particularly one year courses (see Ch.4, p.165). It is argued here that assessors need to look beyond formal support needs to meet students' wider academic, personal and social needs at university.

It is essential to recognise that student participants in the present study feel that Northtown University is not meeting their wider support needs and that deficit lies not with the University *per se* but with a combination of influences from HEFCE policy and the DSA assessment process. On balance, there is good evidence in the present study and growing support in the extant literature that what is needed is an approach to disability support that can incorporate personal and social need, as well as academic.

One potential solution is in the form of Direct Payments (see Office of Public Sector Information, 1996 and the present study Ch.2, p.67), but again, not all students with SCD feel confident, able or want to take full responsibility for employing and managing their own support provision (see Carmichael and Brown, 2002). Thus, it is reiterated that assessors need to ensure students are aware of the types of support available and need to reconsider support provision in negotiation with students that takes account of student need to align not only academic, but also personal and social needs of disability.

This may, in turn, facilitate student building and maintenance of wider social support networks that may give access to network capital, as discussed below.

8.3.2.3 Building and maintaining wider social support networks

From the above, it is argued that there is a clear demand for some kind of additional support activity at universities to incorporate students' personal and social needs. In order for this to be actualised, firstly, this needs to be recommended by assessors and sanctioned by LEAs. Once these recommendations and sanctions are in place, it follows that it would be reasonable for universities who receive these recommendations to consider a supplementary mode of support. This additional support would be one that aligns with student need to foster effective academic and social support networks in the wider university context, whilst at the same time respecting ESWs in that this should not be part of their support role.

Potentially then, this additional support can be fulfilled in one of two ways. Firstly, a person, or persons not yet identified, could be trained as paid professionals to undertake this informal type of building and maintaining of social support networks for students with SCD. Secondly, given the right circumstances, students with SCD could perform this for themselves. Each of these will now be considered in turn.

There is potential to employ postgraduate students to primarily undertake this informal role as 'study buddies'. It is suggested here that postgraduates, being students themselves, are possibly better suited than ESWs to this informal role because they are still embedded within the student culture, and possibly 'fit in' more readily with other students as they are not entirely bound by professional formal academic role constraints. This may go some way to equalising potential power imbalances. Thus, by separating out the formal academic ('the public') and informal personal ('the private') aspects of student disability support, universities could both relieve the pressure on ESWs and meet the needs of students with SCD. Allocating informal personal support duties to employed postgraduates could enable ESWs to concentrate on their formal academic duties. Postgraduate employees could then concentrate on providing support with personal and social issues for those students who feel they need it. As Zellers et al. (2008: 563) argue, this notion of dual (formal academic and informal personal) support can encourage students to draw upon a range of people for specific reasons:

> One mentor is no longer adequate to meet the full complement of another's technical and personal needs in the context of modern society. Dynamic organisational change, increased specialisation, and innovation, and the acceleration of technological advances prescribe a new mentoring paradigm in which mentoring relationships are pluralistic and reciprocal

On balance, some students and ESWs in the present study clearly identified a need for additional support not currently provided at Northtown University. Similarly, there is a growing body of research evidence in the literature that suggests suitably maintained 'study buddy' schemes can facilitate students in the wider university context; academically, personally and socially. From this, it is reasonable to suggest that in part, universities with similar practices should assume at least some responsibility here by using a portion of students' DSA allowance to employ suitable individuals as 'study buddies' for those that require this service.

Secondly, it is argued here that if there was a means to do so, students in part, could build and maintain wider social support networks for themselves. Students with SCD prefer technological means of communication, as do many other students without SCD (Markett et al., 2006; Harley, 2007; Churchill, 2009). These aspects will be considered in turn.

Hinchcliffe and Gavin (2008; 2009) argue that 'new' communicative technology, such as mobile telephone text and the Internet can bridge time-space separations when students find themselves distanced by course structures, differing timetables and independent study. Yet, for those who prefer to communicate at a distance, technology has its advantages too. Those with SCD wanting to develop or maintain social networks can utilise 'new' communicative

technology to their advantage because it can support alternative forms of communication, such as text-based and/or visual forms of communication. The majority of student participants in the present study echoed what many had asserted in their DSA reports; that they preferred to communicate at a distance rather than face-to-face, particularly via mobile telephone text and email. Equally, O'Neil (2008) argues technology is a useful means for people with SCD to communicate as they "can thrive on the Internet and exchange much needed support without having to engage in the face-to-face contact that sometimes exhausts them" (p.792).

In particular, technology such as the Internet can be a useful platform in which academic, personal and social support can be exchanged to facilitate student membership in the learning community, sharing of resources and distribution of intelligence (see Harley et al., 2007). Valentine et al. (2006) argue that the Internet has great potential for people with SCD because it can provide access, to among other things, network capital:

- Easier access to information resources and services, which enhance personal information
- Computer-mediated communication may enable people with SCD to communicate more easily with others
- Provides a platform for others without SCD to access information about and develop ways of communicating with people with SCD

Therefore, if there was technological provision in place, such as an Internet-based social networking site for students with SCD, they would quite readily maintain their own social support networks through this technology. This would integrate them with students without SCD because, being primarily text-based, each would find it easier to communicate, share information and resources, offer and receive advice, emotional support and companionship.

Taken together, there is good evidence from both the present study and the literature to support the view that technology is a useful form of mediation for those who prefer text-based communication at a distance (see the present study, Ch.4, p.201, this chapter, p.363; O'Neil, 2008; Hinchcliffe, 2009). However, in the HE environment it is currently underused with students with SCD and students more generally. On balance, it is reasonable to suggest here that this could be made more available and become part of a framework of support. Funds for this could be taken from HEFCE premium funding.

In sum, there are two particular points to be made here; firstly, there is a clear need arising out of the student body that is not fulfilled by current support and that is to maintain or initiate wider social support networks for students with SCD. There is potential here for 'study buddies' to fulfil this role funded through DSA by providing students with help to build supportive relationships, giving relationship advice, peer mediation and/or facilitating integration into the wider learning

environment. Secondly, technology could be used more effectively to provide social support, funded through HEFCE. In the broadest sense, communicative technology is available but Northtown University is not making full use of it, particularly in light of the issue that technology offers a form of text-based, rather than verbal-based communication, which these students and others prefer, as evidenced empirically in both the present study (see Ch.4, p.201) and the literature (see Stone, 2004; Harley et al., 2007; O'Neil, 2008; Hinchcliffe, 2009).

The implications of these findings as discussed above have provided new insight into student disability support and a 'fresh' platform from which existing concepts of disability can now be challenged, as set out below. Firstly, though, is a reflection on methodological contribution.

8.4 Key Contributions to Methods and Concepts

8.4.1 Methodological Contribution

Previous literature (see Ch.3, p.121; Ch.4, p.185 and Ch.6, pp.262-264) and empirical evidence from the present study (see Ch.4, p.201 and this chapter, p.363) support the notion that if students with a disability are to be empowered and their points of view put forward in a way that they feel comfortable with, clearly, the technology that

they want to use has to be acknowledged and used by researchers (see also O'Neil, 2008; Hinchcliffe, 2009). Students need to be able to speak for themselves through a method that they find comfortable and then, if this is done, this may give access to what they 'really' think and feel. By doing this, it is argued their needs will become apparent.

This research utilised 'new' communicative technology, in particular synchronous online interviewing techniques and web-based diaries, to gain the perspectives of ESWs and students in the area of student social support. Using 'new' communicative technology that corresponded with participants communicative preferences[27] went some way toward filling the 'gap' of paucity of qualitative research that gained the 'voice' of these participants. As O'Neil (2008: 787) asserts:

> Instead of ignoring or silencing them it is time to lend them our ears. Who better to ask, after all, about what ASD really is than someone who lives with it every day?

Indeed, these communicative technologies facilitated access to unique insights in the area of student support that were largely unsubstantiated in the literature and consequently provided several contributions to knowledge.

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[27] Participants with SCD felt more comfortable using textual, rather than verbal communication.

Following a short evaluation survey (see Appendix 9, p.485), student participants' views were gathered, both positive and negative, about their experience of web-based research diaries. These experiences, followed by researcher responses to the challenges posed by using web-based diaries as a tool for data collection, are set out below.

8.4.1.1 Participant's reflections: the positive experience of taking part in web-based diary research

Alan, keeping a diary for the first time, enthusiastically commented that:

> I always wanted to keep a diary, but I had been put off in the past due to being dyslexic [*reading and writing difficulties*]. I enjoyed the whole experience and wouldn't hesitate to be a diary participant again. The interface was easy to use, it took no time at all to complete the diary and it was compatible with my speech recognition software[28]. The diary stimulated and maintained a good level of interest and brought issues to the fore that I had unconsciously suppressed

Matthew, also keeping a diary for the first time, felt that the web-based diary was a stress free way for him to participate:

> The web-based diary was great, easy to use, and pleasant to look at with no distracting visual stimuli which can prevent me concentrating on the task and the instructions were easy to follow. I prefer to communicate at a distance rather than face-to-face due to my condition, its less stressful for me, I would not have taken part otherwise

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[28] Computer software package that converts dictated speech-to-text and vice versa (see British Dyslexia Association, 2009).

Moreover, Matthew found that to his benefit the diary was compatible with his Blackberry wireless device[29], which he used a great deal to communicate:

> Computers are my thing, I use them every day so I immediately sent the diary link to my Blackberry wireless device and set up a daily reminder. I always had the diary with me but it remained invisible to others. Wherever I was I could complete an entry, doing so was not unlike someone answering or sending a text or email. This suited me well because I tend to forget to do things or I put them off until later and never get things done

For Matthew, having the diary web-based eased his worries about losing things and increased anonymity:

> …worse still I misplace things, but with the web-based diary there are no bits of paper to fill in and the danger of me leaving them around and other people reading them is eliminated, it is a lot more private this way. It felt secure and I felt able to write what I really wanted to with no comeback

Maria felt that the physical isolation or separation from the context enabled autonomy; she could limit the extent to which others could see or touch her and felt control over her environment:

> I get so paranoid that people may be able to see straight through me or worse still that they may even touch me. If I want I can just shut off the computer, it's easy to walk away

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[29] Combines the facilities of a mobile telephone, text messaging and emails, with the added benefit of being able to open and view attachments (integrates up to ten accounts), delivered automatically to the handset. The keyboard technology has a QWERTY style layout. The service currently supports formats such as Microsoft Word, Excel, PowerPoint, WordPerfect, Adobe PDF, zip archives, HTML and ASII documents. The device has an organiser, which includes a calendar, email, tasks and memos, allowing the user to keep on track and a browser for quick Internet access (see Blackberry.com, 2009).

Maria further commented that she preferred (computer mediated) text-based to verbal-based communication:

> I like it because I can just type what comes to mind and not have to worry about it as much. I can type my feelings better than I can voice them. However, I found myself thinking a lot more about what is the right way to say something, I was trying to make sense of and interpret my mood or attitude in addition to the words I was using – not just what I wanted to say but how I wanted to say it so that there was no misunderstanding

Maria echoed what many diarists felt, that examining and editing their words before sending them gave them the feeling of control over what others see, read and therefore know about them:

> I can read through my entries carefully and edit before I send them and even choose to include non-verbals such as smiley faces☺, this allows me to confidently show what I want others to see how I feel

8.4.1.2 Participant's reflections: the negative experience of taking part in web-based diaries

Despite the aforementioned positive experiences, it is important to note that using web-based diaries also engendered some concerns for participants. In contrast to online interviews with ESWs where communication was two-way, web-based diary communication was one-way and participant initiated. Matthew, for example, had concerns that:

> Even though I set myself reminders I just could not get started, I kept putting it off because I had trouble getting the information down

As a response to the above, the researcher suggested timely strategies by email correspondence that prompted participants into beginning their diary submissions:

> Just start from the beginning of the event by describing the setting (Researcher)

Participants such as Matthew found this technique helpful:

> I welcomed early encouragement from the researcher who prompted me to start the entries and thanked me when each entry was received. Keeping these communication channels open was vital to my continued participation

However, using web-based diaries posed a number of challenges for the researcher. These are set out below.

Monitoring each diary on a daily basis was time-consuming but when weighed against having little travel and no transcription, this accumulated a considerable overall saving in terms of time and potential transcription errors.

One significant challenge occurred when participants, 2 in this case, used speech recognition software to verbally record their entries. When speech recognition software such as Dragon Naturally Speaking (see Dyslexia.com, 2006) was used to convert verbal communication into text, diarists' accounts were not always easy to comprehend. Sometimes, due to the speaker's accent, the software would type words incorrectly. In addition, Dragon Naturally Speaking

does not enter punctuation or define paragraphing in the text. To limit loss of data when participants use speech recognition software it is imperative that the researcher encourages participants to check for and correct any word recognition errors and dictate all punctuation and new paragraphs in their diary entries prior to submission.

Across the sample, the online diarists were sufficiently engaged with the web-based interface. They were more open, more eloquent, and more confident with their accounts, compared to face-to-face interviews the researcher had previously conducted. Although these diary accounts had fewer words compared to conventional verbal interviews, qualitative approaches do after all strive for quality, not quantity. It has been shown here that diaries can access difficult-to-reach groups who prefer alternative means of communication. Moreover, they are analogous with qualitative approaches because they collect meaningful and considered accounts but without large amounts of data in which analysts can feel overwhelmed, which is a major drawback of these approaches (Symon, 2004). Being succinct, web-based diaries offer a way to control data flow without the need for data reduction at the analytical level, which can be problematic as there is always a chance that what is reduced could be vital to the study.

8.4.2 Challenging Existing Conceptual Frameworks

There is little doubt that the current conceptual framework based around the social model of disability, which has recast disability away from an individual (disability as a psychological or physiological incapacity) to a social problem, has contributed to positive changes in the lives of people with a disability. For many, it has allowed the potential for the removal of institutional and social barriers, oppressive practices and discriminatory attitudes:

> Writings and research in this paradigm focus on the disabling environment – the physical and social barriers which exclude disabled people and render them powerless and voiceless. It presents a material analysis...documents the barriers to equal participation and opportunity in education, health service provision, employment, housing, transport, the built environment, leisure and social activities
>
> (Watson, 2004: 103)

However, the social model of disability is argued to be driven by political motives and dominated by the 'voices' of male, physically impaired activists who disregard the diversity and complexity of the lived experience of impairment. Indeed, this model is charged with excluding various groups, such as women and those with sight or hearing impairment (Finkelstein, 1981), as well as learning difficulties (Holford, 2007):

> Dominated by wheelchair users, perhaps because
> many had previously been able bodied, and had been
> involved with other political movements (Finkelstein,
> 2001: 4). Some activists remember it as being sexist
> (Campbell and Oliver, 1996: 52), and as dominated by
> a typically masculine form of politics, which was hard,
> ideological and combative (Campbell and Oliver, 1996:
> 67)
>
> <div align="right">(Shakespeare, 2006: 13)</div>

The medical/individual model of disability has also been advantageous for people with a disability. For many, through medical intervention and treatment, it has provided the potential for the reduction of biological and physiological impairments, such as sensory, learning and mobility difficulties that can manifest as pain and discomfort and for many, a shorter life expectation. Where treatment is successful, the ensuing psychological burdens that can follow, such as stress, anxiety and depression can be reduced (Harris, 2005). Yet, this model is criticised for its emphasis on the individual, the body, rehabilitation, professional power and for its oppressive potential (Söder, 2009).

Although very different models (one focuses on social attitudes and practices, the other on physiological impairments), there is a conceptual similarity between the two. Each model can be argued, at least in one respect, to be striving for a similar goal. This goal is primarily to seek to remove disabling barriers, whether they are caused through social oppression or individual impairment, to enable the person to live their life as free as possible from disability. In the context of this thesis, these models suggest that once institutional or

personal barriers are removed the student can be active in their learning, *independent*; an autonomous and self-governing citizen.

It is, however, argued here that this common goal is based upon the notion of the person as a self-contained entity, which can be understood using the concept of individualism (see Triandis, 1988). Individualism atomizes the person by separating them out as an individual player in pursuit of satisfying their own needs, wishes and desires, without taking the interests of society into account. Society is merely a collection of separate, isolated individuals who remain unchanged by any social relations. According to Wolgast (1987: 189), social atomism is the:

> ...commonly accepted view that society is a simple collection of separate individuals, each having its own interests, motivation, and autonomy, following their separate interests...people are conceived as basically similar, just as molecules are. This helps to guarantee that any contract they enter into will yield equality of status and basic rights

The person in this view is essentially equal, rational and self-contained, a 'social atom'. This notion derives from deontology, based on the work of Kant (1959), a theory of ethical duties inspired by the concept of autonomy (independency) and the principle of respect for autonomy - actions fulfilling duties are morally right regardless of the consequences. As such, those that are dependent are at risk of being devalued and perceived as morally inadequate (for critique of Kant's concept of autonomy see Secker, 1999). Thus,

providing peer mediation may be considered the right thing to do even if it produces some unwanted consequences, for instance, the potential for unequal power relations, if it follows the rule that 'one should do unto others as they would have done unto them'. Indeed, this is so even if the person who provides the mediation lacks virtue and has an immoral intention in doing the act.

The crux of this approach "seeks to understand how separate individuals can develop and sustain connections and still be separate; how they engage in relationships and still remain free" (Hirschmann, 1997: 170). Yet, although this individualist view has served well to argue for 'rights' to freedom of self-expression and lifestyle for people with a disability, helping to undermine the authority of one person over another, particularly where professional 'expert' opinion is concerned, this view nevertheless is problematic.

It is argued here that in practice, rather than living in an atomistic way, people live out their lives through *interdependency*, which can increase their participation in communities (White et al., 2010). Moreover, the person is not simply a self-contained individual; in their constitution they are already social. Interdependency is similarly theorised in a number of perspectives that privilege social relations and perceive people as products of relationships. For example, the social constructionist Gergen (1997) argues that interdependency is not just about helping people out. All human beings are

interdependent. Networks of people are interrelated, they are already a part of each other, and thus interdependency constitutes social life itself. Thus in this view, interdependency is not the result of individual action or reaction, but a result of human coordination of action, as Shotter (1995) claims, 'joint action'. To this point, Gergen (2009: 242-243, *original emphasis*) asserts:

> If raised in social isolation, what would an individual think about? There would be no capacity to think about science, literature, or art; no deliberation on good or evil; no concern with family, community, or global well-being. These "objects of thought" all develop through our relationships with others...*the primary aim of education is to enhance the potentials for participating in relational processes-from the local to the global*. The aim then, is not that of producing independent, autonomous thinkers-mythological creatures at best-but of facilitating relational processes that can ultimately contribute to the continuing and expanding flow of relationships within the world more broadly

Similarly, Wolgast (1987), and more recently Sevenhuijsen (2000), using feminist self-in-relationship theory, flesh out the argument that people are what they are only by virtue of relationships. With an emphasis on caring, these authors propose that people are interdependent, rather than independent; through moral concern for others' well-being and responsiveness, people help each other:

> As is argued by a great number of authors, the care framework is inherently characterized by a relational ontology: individuals can only exist because they are members of various networks of care and responsibility, for good or for bad. The self can only exist through and with others and vice versa (Gilligan, 1987; Tronto, 1993; Griffith, 1995; Clement, 1996; Hirschmann and DiStefano, 1997; Sevenhuijsen, 1998)

> (Sevenhuijsen, 2000: 9)

The concept of interdependency in this perspective relies on the notion of social connectedness and aims to capture how people are helped by various others throughout their life. Here, support is a central part of humanity, built on moral responsiveness where people have concern for others' well-being as well as their own:

> ...normally parents take care of their children, and children their elderly parents, while we help elderly people and give them our seats and give contributions for the poor and the sick. In short, we don't behave atomistically....nurse and doctors and teachers and social workers have a motivation for their professions which atomism cannot account for, that we can have a concern for unborn generations and people we have never seen, that we strive for a society that is simply just and act from pity and kindliness without a string of reasons generated from our personal sensations or desires. People help one another spontaneously, answer questions when asked, give directions and so on
>
> (Wolgast, 1987: 196)

Participants in the present study provide examples of interdependency that are consistent with a growing body of feminist self-in-relationship theory that challenges notions of independency (see for example, Tronto, 1993; Morris, 1996; Sevenhuijsen, 1998, 2000; Corker and French, 1999; Williams, 1999; Thomas, 2001; Diprose, 2002; Fisher, 2007). Participants in the present study like those in Müller et al's. (2008) study, tend to suggest that effective social supports and strategies for improving social connectedness and access to network capital may constitute a morality of care, rather than 'rights'. Regardless of the serious social challenges they face, such as isolation and problems with communication, students

with SCD long for intimacy, social connectedness and have desires to make a contribution to the well-being of others (both at an individual and community level). For example, participants' recommendations include social supports (activities based on shared interests, highly structured activities and small groups), communication supports (alternative modes of communication, such as Internet-based social networking sites), and personal support through self-initiated strategies for handling anxiety (physical activity, and time alone).

On balance, it is reasonable to suggest here that an individualist perspective, based on reason and justice, is remote from the needs and interests of students with SCD. Walker (1998) asserts that a morality of care is always embodied, situated and created through relations with others. Gilligan (1987: 24) provided a framework for a feminist ethics of care based upon a morality of care, rather than a morality of 'rights':

> ...care is grounded in the assumption that self and other are interdependent, an assumption reflected in a view of action as responsive and, therefore, as arising in relationship rather than the view of action as emanating from within the self, and, therefore, 'self-governed'

For Gilligan (1988a), the connected self is responsive to others on their terms and has a concern for others' well-being or alleviation of hurt and suffering, both physical and psychological. These relationships are mediated through the activity of care to maintain

caring and connection with others and grounded in interdependence, which occurs from recognition of the interconnectedness of people. The focus here is openness to others; Diprose (2002) explains this as embodied generosity, responding to the needs of others and relationship building:

> While the moral subject in the discourse of individual rights looks at situations of moral dilemma from the stance of the 'highest principles' and takes rights and obligations as a means of establishing relationships, the moral subject in the discourse of care always already lives in a network of relationships, in which s/he has to find balances between different forms of responsibility (for the self, for others and for the relationships between them)
>
> (Sevenhuijsen, 2000: 10)

Taken together, the current conceptual framework based around the social model of disability is argued to promote individualism. To deal with the problem of disability by instituting 'rights' and removing environmental barriers only addresses these issues if the student with a disability is perceived in an atomistic way; as essentially not connected with or dependent upon interrelationships with family, peers, ESWs, teaching staff or the Disability Support Office. Connections between people are thus "a sign of dependence, negatively valued and considered as a source of limitation" (Gilligan, 1988b: p.xiv). Concentrating solely on facilitating the student to be independent, autonomous and self-governing, with a focus on providing resources alone, rather than facilitating relationships, overlooks the social aspects of disability that are essential for student social support. As identified by both participants in the present study

and the existing literature, providing additional informal personal support is not necessarily inequitous. Social connections between those with shared interests can be lost without appropriate support measures in place, such as ones that can facilitate the development and maintenance of student positive social support networks.

As such, the kinds of ways that disability is thought about are affected. By solely concentrating on a social model of disability, Shakespeare (2006) argues that researchers lose sight of social interaction and student need because the focus is exclusively on removing negative social attitudes and practices (also see Ch.2, p.95). As evidenced earlier in this chapter, not all student problems are formal academic ones; some are social and derive from interrelationships, responsibilities and roles.

8.4.2.1 Interdependence the 'Fourth Way': A Conceptual Model for a Better Understanding of Disability

Current disability policy aligns with the social model perspective and is thus set within a self-determination paradigm[30] (see Patrick et al., 2007 and the present study, Ch.2, p.72). Through the British disability movement (see Longmore, 2003), it is argued that this perspective has had a political influence in the form of new-

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[30] The rational student has a capacity for self-determination by assuming a competent course of action that most effectively, with minimal cost and maximum benefit, fulfils their need for academic achievement and increases their employability status.

managerialism (see Ch.2, p.61 and Ch.3, p.122). Legislation, such as the Disability Equality Duty (2006 see Disability Rights Commission, 2007b), constructs people with disabilities as agents, as independent as those without disabilities, recognising them as capable of rational thinking and forming their own interpretations and views on how they should be treated.

Alongside this runs new-managerialist practice. This operates around the idea of reducing social exclusion through policy and practice that encourages self-regulating, responsible citizens to take charge of their learning to improve their individual employment opportunities (see Davies et al., 2000 and the present study, Ch.2, p.61). Yet, like the social model of disability, new-managerialism promotes individualism through its denial of interdependency and social connectedness and its maintenance of social atomism – separateness and self-interest. As a driver of activity it does not look at a person's wider academic, personal and social needs; instead, it looks at encouraging independence for self-gratification.

The social model of disability and new-managerialism have in common the aspect of discouraging people from looking at wider social need, such as relationships. As evidenced in the present study, this is at a time when the students are anxious for their wider academic and social needs to be catered for, and social atomism is pushing disability practice in the opposite direction (see Ch.7, p.332).

Thus far, there have been 'three ways' that address particular social values of the time, such as education, employment and social exclusion, and, as such, each 'way' contained different policies of governmental commitments and programmes (see Armitage et al., 2003). Each saw the introduction of policies that have been argued to have constituted minimal interventions in HE practice for students with SCD (see Ch.2, p.49).

The 'first way' (1944-1979) was set within the medical/individual backdrop of welfare consensus, student *dependency* and professional autonomy. During this period, people with SCD were categorised through school medical examination as 'seriously disabled'. This meant that they were removed from segregated medical institutions and placed into 'special' segregated education. Borsay (2005) argues that claims to professional expertise underwrote the expansion of segregated education from which students emerged with below-average qualifications.

The 'second way' (1979-1997) was also set amidst the medical/individual backdrop but moved toward de-professionalism and the beginnings of market-oriented managerialism, which brought with it the rise of social atomism and social disconnection. During this period, the issue of appropriate education for students with disabilities had little impact upon further and higher education. Many disabilities were at best unrecognised, at worst stigmatised.

Legislation, through the Disability Discrimination Act (DDA, 1995b), addressed discrimination against people with a disability in employment and in the provision of goods and services but not in education. Consequently, people with SCD were denied educational opportunities, both in terms of access and attainment.

The 'third way' (1997-present) emphasises *independence* through self-regulation and new-managerialist strategies. This encourages self-governing citizens, who through volition, actively and responsibly shape their own lives and employability status in pursuit of becoming part of a civil society (Rose, 1999; Davies et al., 2000). This has been argued to be problematic for students with a disability because it loses sight of the importance of social interaction between people with and without disabilities and their interdependency (Sevenhuijsen, 2000; Cummins and Lau, 2003; Fisher, 2007; Shakespeare, 2006; Müller et al., 2008; White et al., 2010). The person always already lives in a network of relationships; the self is constituted inter-subjectively. Thus the self, in all its aspects including academic achievement, is threatened if social relationships are encumbered; it becomes difficult to be a person when what constitutes as being a person derives from their connectedness with others (Sevenhuijsen, 2000). Williams (2001) argues this powerful employment ethic has weakened social and community networks for vulnerable people and those already at a disadvantage, such as

people with disabilities, because they are at a disadvantage in the employment market.

Throughout these periods it is argued that the shift of power from medical and associated professionals to managers, over perception and treatment of people with a disability may have merely served to transfer inequality from remedy to bureaucracy and to the pursuit of economic efficiency.

On balance, a limited view of student disability support is apparent because the importance of social connections has been ignored in pursuit of student independence (Levett-Jones and Lathlean, 2007). From this, it follows that it would be reasonable to suggest an alternative view here that posits a more integrative model, the potential 'fourth way'. The 'fourth way' model would have the potential to perceive people as interconnected, as parts of social networks that support each other interdependently through concern for another's well-being, and a responsiveness to others on their terms. Disabled or not, people are not isolated entities but relational beings that generally work 'better' interdependently with others. In this respect, people with disabilities are no different from people without disabilities; at times, they need more or less support depending on their circumstances:

There is no overarching recognition by the state that we all have needs and are in need of different types of care and support at different stages in our lives. Nor of the ways in which needs are contested and renegotiated between individuals within the context and the course of ongoing lives. Creating only certain individuals and groups of individuals as needy eclipses the way in which everybody is needy. Eclipsed too, are considerations of how we are all anticipating our future needs, even if 'in private', and the presuppositions of the positions of others, the contingencies and interdependencies that this will inevitably involve

(Watson, et al., 2004: 344)

Yet, participants in the present study and evidence in the literature (see for example, O'Neil, 2008), suggests that people with SCD are perhaps more at risk of isolation than those without SCD because of the difficulties they can experience in initiating and sustaining communication.

Watson et al. (2004) draw on the work of Fraser (1989) on needs and Fraser and Gordon (1994) on interdependency to develop a conceptual framework of care described in terms of 'needscape', which recognises that needs are responsive to others and have a concern for others' well-being. Watson et al. (2004) argue that this emancipatory model can mediate between disability studies notions of independency developed from: "political roots" (p.339), which aim to break "the link between disability and dependency" (p.335) and feminist perspectives of care based around the notion that "the giving and receiving of care is imperative to human existence" (p.333).

To this point, an alternative framework for disability may be able to reconcile medical/individual (dependency) and social model (independency) conceptualisations of disability to build an alternative framework for discussion of what constitutes appropriate support provision. Such an approach, based on notions of interdependency, equally points to an understanding that personal autonomy is essential but does not negate the social connectedness of people. This approach owes much to feminist authors (Wolgast, 1987; Gilligan, 1988a; Tronto, 1993; Morris, 1996; Sevenhuijsen, 1998, 2000; Corker and French, 1999; Williams, 1999; Thomas, 2001; Diprose, 2002) who have challenged notions of independency, and criticised individualist approaches to care that socially atomise the person. Thus, this framework can be understood in terms of seeking and valuing care, built upon notions of care where people are responsive to others on their terms and have a concern to safeguard others' physical and psychological well-being.

To summarise briefly, there is a clear dichotomy between British medical/individual and social models of disability and the shortcomings of each - the former instils notions of dependency by focussing on the individual and impairment effects, the latter instils notions of independency by focussing on social and structural effects. Nevertheless, each has been argued to be based on the same core value, that of individualism, which manifests in social atomism. Following the work of Watson et al. (2004), this disregard

for social connectedness can be offset by interdependency. This has the potential to perceive people as interconnected, as parts of social networks that support each other interdependently through concern and responsiveness to others.

The present study thus builds on social constructionist (see Gergen, 1994, 2009; Shotter, 1993; 1995) and feminist self-in-relationship theory (Wolgast, 1987; Sevenhuijsen, 2000) that privileges social relations and perceives people as products of relationships. The self in all its aspects, including academic attainment, is jeopardised if social relationships are undermined; it becomes hard to be a person to the extent that it is not possible to be a person without connection with others. The potential 'fourth way' thus has an emphasis on caring and values care that is morally responsive to others on their terms and safeguards others' well-being; this in itself can promote personal autonomy and social connectedness. Personal autonomy comes out of interdependency through consultation with students about what is 'best' for them; this is achieved in negotiation with others. Recognising and responding to student needs on their terms by facilitating the building and maintenance of wider social support networks are important factors that contribute to the development of student social relationships and connectedness in the learning environment. This, in turn, can enhance access to network capital.

These findings have important implications for HE policy and practice, disability support management and future research practice. These issues will be returned to in the forthcoming concluding chapter 9 as a set of principles to guide HE disability policy and practice are presented.

8.5 Chapter Eight Summary

A number of issues were raised and their implications noted that are argued here to impact on the likelihood of formal academic support improving students with SCDs' retention and progression, and the contribution of ESWs to the establishment and maintenance of students' social support networks.

ESWs and students each considered formal academic support, when it was appropriately delivered, to contribute positively to student retention and progression. However, an absence of formal academic support meant that sometimes untrained and inexperienced family and student peers would undertake this type of support. Largely, this had negative outcomes, particularly for students' personal and social relationships. Empirical evidence from the present study aligns with the extant literature that formal academic support should only be provided by trained and experienced ESWs. To this point, an interim support service may prove useful for those waiting for support to be allocated.

Evidence from the present study indicates that rather than being student-centred, resources for disability support are institutionally focused and take little account of informal personal support need. The current conceptual framework, based around the social model of disability, having a political influence in the form of a new-managerialist 'audit culture' and situated within a morality of 'rights', was considered in practice to atomise the person and overlook wider social aspects of disability that can be located within a morality of care. Social connections in terms of interdependency, understood here as responsiveness to others on their terms and a desire to safeguard others' well-being, have been somewhat overlooked. This is reminiscent of both social constructionist (see Gergen, 1997) and feminist self-in-relation theory (Wolgast, 1987; Sevenhuijsen, 2000) where it is suggested that people are what they are only by virtue of relationships.

HEFCE and DSA processes encourage universities to provide support in its narrowest form with a focus on formal academic support resources. These findings indicate that an individualist approach forestalls student access to wider academic, personal and social opportunities. Students with SCD are potentially more at risk of social isolation than their peers because of difficulties initiating and sustaining communication, essential for the development of student peer friendships and access to network capital. It is suggested here that account is taken of their academic, personal and social issues in

the wider learning environment. As such, professionals need to work in negotiation with students; this is considered to be crucial and will be suggested as a core principle for disability policy and practice in forthcoming chapter 9. Moreover, as part of a framework of support, the employment of study buddies and/or the introduction and use of 'new' technology are viable options to bridge the 'gap' here and foster membership in the learning community, which can have positive outcomes for student retention and progression.

Concluding chapter 9 addresses the implications of the findings and provides a set of principles to guide HE disability policy and practice.

Chapter Nine – Conclusion: Implications of the Findings for HE Disability Policy and Practice

9.1 Preamble

This chapter will conclude by addressing the significance of the research to disability policy and practice, and outlining further areas for future scholarship. It will be suggested below that universities and disability assessors, influenced by HEFCE and DSA processes to provide formal academic support alone, should take responsibility and facilitate opportunities for students with SCD to be included as active participants in the wider university setting. Difference should be celebrated; it is arguably a part of being a unique and interesting human being. Anticipating and responding to students' need in their terms should therefore be paramount. Decision-making concerning inclusion of students with disabilities needs to ensure that students' academic, personal and social requirements are met. At an institutional level, the Quality Assurance Agency for Higher Education general principles (1999: 6) embody this notion of inclusive practice for the student with a disability, yet currently, the present study and extant literature illustrates that this appears to be somewhat absent from practice:

> Institutions should ensure that in all their policies, procedures and activities, including strategic planning and resource allocation, consideration is given to the means of enabling disabled students' participation in all aspects of the academic and social life of the institution

A set of principles for HE disability policy and practice are thus derived based on 'fourth way' concepts of interdependency and social connectedness.

9.2 Implications of the Findings for HE Disability Policy and Practice

9.2.1 Critique of Existing Disability Policy

There are problems with disability policy both theoretically and practically. Theoretically, a large part of disability policy is influenced by social model assumptions and 'third way' new-managerialism that encourages student independence and self-governance. Thus, in practice disability policy aligns with a morality of 'rights' and the notion of addressing social structure and negative attitudes, rather than a morality of care that gives priority to interdependency and responsiveness to others on their terms. In the latter view, the person is always embedded in social relationships. A 'fourth way' perspective based on notions of interdependency would acknowledge that people are socially connected and morally responsive to others' needs for educational 'success'. As such, some improvements can be made to existing disability policies, as suggested below.

Many disability policies are situated within a morality of 'rights' rather than a morality of care where consideration is given to students' social relationship. This has been evidenced both in the present study and the existing literature as important for student overall achievement. Typically, policies suggests that the 'rights' of all students should be protected; this terminology suggests that students are dependent on others, and has an emphasis on weaknesses, rather than strengths. Thus, students are at risk of being devalued and perceived as inadequate. Within a morality of care, this could be replaced with discourse that aligns with notions of personal autonomy arising out of being responsive to others on their terms, such as promoting the well-being of all students.

Moreover, disability policies commonly stress that reasonable adjustments should be made to ensure those with disabilities are able to engage as fully as reasonably possible in the life of the university. 'Reasonable' is suggested here to be much more aligned with negotiation and informed decision-making than is suggested in current policy. For example, 'reasonable' may mean going further than ensuring engagement in university life by providing students with enough information to enable them to negotiate their academic, personal and social needs. To this point, guidance should be provided for students on what support is available and this should include 'listening' to students and recognising personal and social, as well as academic need.

As the participants in the present study indicated making students feel welcome and their subsequent feelings of well-being rely on positive social networking. Thus, rather than an inclusive ethos based upon ontological separateness, as typical disability policies suggest, understanding of what inclusive means should embody notions of social connectedness to encourage the development and maintenance of positive social support networks. Once again, the notion of involvement and participation should include 'listening' to students and taking their views on board. Encouraging involvement and participation of students with a disability can be undertaken by ensuring mechanisms are in place that have regard to their views.

In terms of typical disability policies, the challenge for universities and disability assessors is the re-alignment of social model and new-managerialist activity. This challenge can be met with a 'new' kind of activity to inform disability policies; that is, if the person is looked at as social connected to others in relationships. Policy is designed to inform practice, as such critique of existing practice, as influenced by current disability policies is summarised below.

9.2.2 Critique of Existing Disability Practice

As evidenced by participants in the present study, student-centred recommendations have been influenced by HEFCE financial incentives and the DSA assessment process that shifts emphasis away from personal and social need. In practice, this does not take into account informal personal support activities, argued by participants in the present study as crucial for the full university experience.

Empirical evidence from the present study indicates that current policies are effectively translated into practice. This is problematic because the issues raised in the present study are symptomatic of this and suggest that policies and subsequent practice need to change. Practically, looking at and sourcing formal academic need, rather than tailoring support to student academic, personal and social need, has culminated in a lack of support in certain areas for students with SCD, such as their social relationships.

Thus, if policies change, practice will change too, as the focus will be on alternative ways to support these students. Deriving principles for disability support are set out below bearing in mind the suggested improvements to policy.

9.3 The 'Fourth Way': Principles for Disability Support

> Principles are abstract rules intended to guide decision-makers in making normative judgements in domains like the law, politics, and ethics…[*They can*] govern human behaviour and inform reasoning and decision-making
>
> (McLaren, 2003: 145-146)

From critique of existing policies and practice, and what has been learned from the present study, a set of principles are derived for disability support that captures the 'fourth way' - interdependency. These include universities and disability assessors looking beyond the current artificial boundaries of disability support to recognise the student as a relational being in the wider social context:

1. Be morally responsive to students on their terms
2. Take all reasonable steps to ensure opportunities for all students' informed views to be heard
3. Provide students with sufficient information to allow them to participate in the decision-making with regard to their support
4. Negotiate with students programmes of support based on interdependency and social connectedness
5. Respect students' capacity for personal autonomy through interdependency
6. Endeavour to help develop and maintain students' social support networks
7. Facilitate opportunities for students' access to campus-wide activities
8. Encourage students' engagement in both the academic and social life of the University
9. Promote positive relations between professionals, students, peers and family

Guided by the above principles, recommendations for practice might include:

- An interim service for those waiting for support to be allocated
- Support negotiated with students, which can include provision of both formal academic and informal personal support for those who would benefit
- Utilising technology to create greater opportunity for students to obtain network capital. For example, possible use of Harvard-style lecture theatres to accommodate 'new' communicative technology. Harvard-style lecture theatres incorporate individual seating and a large U-shaped seating plan to allow for a more interactive style of lecture. A full technology package would be available, which includes video cameras, a ceiling mounted projector and speakers. Power points would be located underneath the bench style desks for student laptops and electronic equipment. The use of laptops during lectures would facilitate communication between students, their peers and teaching staff. Particularly for those who prefer text-based communication as they may find it easier to participate, ask and answer questions
- Development and maintenance of student social networking sites and web-based diaries to facilitate ease of transition to university. For example, student participants in the present study pointed out that they benefited from writing their support experiences in the daily support diaries. It would be great for university Disability Officers to implement these web-based diaries, particularly at the onset of support, to enable them to monitor support activity

To summarise, following critique of current disability policies and practice, the alternative principles derived above are based on a relational approach that can incorporate a broader understanding of disability support. Mediated by a moral imperative, this approach re-conceptualises students with a disability as interdependent, both in their capacity for personal autonomy, and their social need through relationships. The findings thus illustrate the interdependent nature of

student relationships with professionals, student peers and family. As such, they highlight the importance of the provision of information about the availability of support services for students with SCD and respecting their views.

Thus, bearing in mind the suggested improvements, as set out above (see this chapter, pp.407-411), there was room for improvement to be made to existing HE disability policies and their translation into practice that aligned with the 'fourth way' and the notion of interdependency.

9.4 Progressing Research in the Area of Student Disability Support

The following topics may provide additional insight into the nature of the phenomenon that is students with SCDs' social support whilst attending university:

- People who were part of an ethnic or racial minority were absent in the present study. The issue of culture and how it impacts on disability support may be important and thus may require further research
- To gain a fuller picture of students' social support networks, interviews could be undertaken with student peers, family members, disability officers and teaching staff on related issues. These could be areas to be explored in the future
- A systematic comparison could be carried out between students with SCD using direct payments and those using university disability support services. This may provide a deeper understanding at a practical level in relation to the viability of different systems of support

- At a theoretical level, issues with different social communication conditions such as dysphasia, aphasia, cerebral palsy and the impact of student disability support on student experience could be explored
- It would be interesting to explore disability support practice for students with SCD in other countries, where socio-political systems and models of support may be different. Through such research, a number of interesting findings could be shared to develop disability policy and practice locally, nationally and internationally

9.4.1 Unique Contribution

The present study was unique in focus because it aimed to compliment a Disability Equality Scheme action plan target for 2010, set at Northtown University, by actively seeking ways of supporting students with SCD that provide appropriate integration and access to the full range of opportunities provided within the learning environment. It was unique methodologically as well. For the first time, the present study has utilised multiple qualitative methods and incorporated the use of 'innovative' communicative technology to gather the experiences of both ESWs and students concerning university students with SCDs' social support networks.

This communicative technology, online interviewing and web-based diaries, used Internet text-based communication platforms, and, as such, was primarily participants' preferred means of communication. This meant that by utilising user-friendly technology the present study gave 'voice' to participants that otherwise tend to go 'unheard' in

research of this kind. This empowered participants to put their points of view forward in a way that they felt comfortable.

Moreover, the analysis of ESW online interviews and student web-based diaries provided original and valuable insight into their views of students with SCDs' social support networks. The 'fusion' of theory and data provided in-depth understanding, rather than mere description, and furnished a critical account of student disability support. This has revealed a number of areas of concern within student disability support processes, that without redress, may result in justifiable criticisms should students with SCDs' social support networks be compromised. Whilst there is no aspiration to generalise any of these findings, nevertheless, student support practices at other universities may correspond with Northtown University's practices.

As such, an opportunity exists here to move the disability agenda away from one based on individualism to one based on social connectedness. This may go some way in influencing the reconstruction of current university disability policy, practice and provision. In turn, this may encourage professionals to work in negotiation with students, and adds to the knowledge base by allowing university disability support services and disability assessors to understand students with SCDs' experience of student disability

support. Thus, appropriate plans can be put in place to meet their wider academic, personal and social needs:

- An interim support service
- Support negotiated with students
- Provision of both formal academic and informal personal support
- Utilising technology to create greater opportunity for students to obtain network capital
- Development and maintenance of student social networking sites and web-based diaries to facilitate ease of transition to university

9.4.2 Conclusion

This study reinforces the value of interdependency and self-in-relationship research that aims to explore the experience of disability support. The findings of the present study have provided unique insights into the phenomena of disability support in higher education. The challenge for universities and disability assessors is one of recognising that students with SCD are interdependent, and are relational beings who may be more at risk of isolation than those without SCD due to communication difficulties. The challenge is met by incorporating personal and social support, as well as formal academic support, into student disability policy and practice.

References

Affleck, G., Zautra, A., Tennen, H., Armeli, S. (1999). Multilevel Daily Process Designs for Consulting and Clinical Psychology: A Preface for the Perplexed. *Journal of Consulting and Clinical Psychology*. Vol. 67, pp.746-754.

Agneessens, F., Waege, H., Lievens, J. (2006). Diversity in Social Support by Role Relations: A Typology. *Social Networks*. Vol. 28, (4), pp.427-441.

Albrecht, G. L. (1992). *The Disability Business: Rehabilitation in America*. Newbury Park: Sage.

Allan, G. (1993). Social Structure and Relationships. In S. Duck. (Ed). *Social Context and Relationships: Understanding Relationship Processes Series Volume 3*. Newbury Park, California: Sage. Pp.13-20.

Allan, G. (2001). Personal Relationships in Late Modernity. *Personal Relationships*. Vol. 8, (3), pp.325-339.

Allport, G. (1942). *The Use of Personal Documents in Psychological Science*. New York: Social Science Research Council.

Altman D. (1988). Legitimation through Disaster: AIDS and the Gay Movement. In E. Fee, D. M. Fox. (Eds.). *AIDS: The Burdens of History.* Berkeley: University of California Press. Pp.301-315.

American Psychiatric Association. (1994). *Diagnostic and Statistical Manual of Mental Disorders IV*. Washington, DC: American Psychiatric Association.

Antia, S. D., Stinson, M. S., Gaustad, M. G. (2002). Developing Membership in the Education of Deaf and Hard of Hearing Students in Inclusive Settings. *Journal of Deaf Studies and Deaf Education. Vol.* 7, (3), pp.214-229.

Archer, M. S. (1990). Human Agency and Social Structure: A Critique of Giddens. In J. Clark., C. Modgil., F. Modgil. (Eds.). *Anthony Giddens: Consensus and Controversy.* Brighton: Falmer Press. Pp.73-84.

Aries, P. (1962). *Centuries of Childhood*. Harmondsworth: Penguin.

Armitage, A., Bryant, R., Dunnill, R., Hayes, D., Hudson, A., Kent, J., Lawes, S., Renwick. (2003). *Teaching and Training in Post-Compulsory Education*. 2nd Edn. Buckingham: Open University Press.

Armstrong, F., Barton, L. (Eds.). (1999). *Disability, Human Rights and Education: Cross Cultural Perspectives.* Buckingham: Open University Press.

Arthur, D. (2005). *Recruiting, Interviewing, Selecting and Orienting New Employees.* 4th Edn. Saranac Lake, NY, USA: AMACOM.

Austin, J. L. (1962). *How to Do Things with Words.* Oxford: Oxford University Press.

Avis, J., Bathmaker, A., Parsons, J. (2002). Communities of Practice and the Construction of Learners in Post-Compulsory Education and Training. *Journal of Vocational Education and Training.* Vol. 54, (1), pp.27-50.

Avramidis, E., Norwich, B. (2002). Teachers' Attitudes Towards Integration/Inclusion: A Review of the Literature. *European Journal of Special Needs Education.* Vol. 17, (2), pp.129-147.

Avramidis, E., Skidmore, D. (2004). Reappraising Learning Support in Higher Education. *Research in Post-Compulsory Education.* Vol. 9, (1), pp.63-82.

Baddeley, A. A. (2007). Using a Tablet PC Has Given My Academic Writing a New Lease of Life. *British Journal of Educational Technology.* Vol. 38, (1), pp.164-166.

Baker, C., Padden, C. (1978). *American Sign Language: A Look at its Story Structure and Community.* Silver Spring, MD: T. J. Publishers Inc.

Barnes, B. (1977). *Interests and the Growth of Knowledge.* London: Routledge and Kegan Paul.

Barnes, C. (1991). *Disabled People in Britain and Discrimination.* London: Hurst and Co.

Barnes, C. (1997). A Legacy of Oppression: A History of Disability in Western Culture. In L. Barton and M. Oliver (Eds.). *Disability Studies: Past, Present and Future.* Leeds: The Disability Press. Pp.3-24.

Barnes, C. (2008). *The Disability Archive UK: About the Archive.* [Online].
Available: <http://www.leeds.ac.uk/disability-studies/archiveuk/>
[Accessed 31 January 2008].

Barnes, C., Mercer, G. (Eds.). (1997). *Doing Disability Research.* Leeds: The Disability Press.

Barnes, C., Mercer, G. (2003). *Disability.* Cambridge: Polity.

Barnes, C., Mercer, G. (Eds.) (2004). *Implementing the Social Model of Disability: Theory and Research*. Leeds: The Disability Press.

Barnes, C., Mercer, G. (2006). Independent Futures: Creating User-Led Disability Services in a Disabling Society. *Scandinavian Journal of Disability Research*. Vol. 8, (4), pp.317-320.

Barnes, C., Mercer, G., Shakespeare, T. (1999). *Exploring Disability: A Sociological Introduction*. Cambridge: Polity Press.

Barnes, C., Oliver, M., Barton, L. (Eds.). (2002). *Disability Studies Today*. Cambridge: Polity.

Barthes, R. (1972). *Mythologies*. London: Paladin.

Barton, L. (Ed). (1996). *Disability and Society: Emerging Issues and Insights*. London: Longman.

Bass, B. L., Linney, K. D., Butler, A. B., Grzywacz, G. (2007). Evaluating PDAs for Data Collection in Family Research with Non-Professional Couples. *Community, Work and Family*. Vol. 10, (1), pp.57-74.

Baxter, L. A. (1991). Content Analysis. In B. M. Montgomery and S. Duck (Eds.). *Studying Interpersonal Interaction*. New York: The Guilford Press. Pp.239-254.

Begley, C. M. (1996). Triangulation of Communication Skills in Qualitative Research Instruments. *Journal of Advanced Nursing*. Vol. 24, pp.688-693.

Berg, B. L. (2007). *Qualitative Research Methods for the Social Sciences*. 6th Edn. Boston, MA: Pearson Education.

Berger, P., Luckmann, T. (1966). *The Social Construction of Reality*. Garden City, NY: Doubleday.

Berger, R. J. (2008). Agency, Structure, and the Transition to Disability: A Case Study with Implications for Life History Research. *The Sociological Quarterly*. Vol. 49, (2), pp.309-333.

Bertocci, D., Hirsch, E., Sommer, W., Williams, A. (1992). Student Mental Health Needs: Survey Results and Implications for Service. *Journal of American College Health*. Vol. 41, pp.3–10.

Billig, M. (1995). *Banal Nationalism*. London: Sage.

Blackberry.com. (2009). *What is BlackBerry*? Research in Motion Limited. [Online].
Available: <http://eu.blackberry.com/eng/ataglance/blackberry.jsp> [Accessed 6 March 2009].

Blamires, M., Gee, S. (2002). *Raising Aspirations: Increasing the Participation of Students with Autistic Spectrum Disorders (Social Communication Difficulties) in Higher Education. Report of the HEFCE Strand Two Disability ASPIHE Project.* Christ Church University College. [Online].
Available:<http://education.cant.ac.uk/xplanatory/assets/documents/a spihereportv041.DOC> [Accessed 7 October 2007].

Bond, C. F. (1982). Social Facilitation: A Self-Presentational View. *Journal of Personality and Social Psychology.* Vol. 42, pp.1042-1050.

Borsay, A. (2005). *Disability and Social Policy in Britain since 1750: A History of Exclusion.* Hampshire: Palgrave Macmillan.

Boulos, M. N. K., Wheelert, S. (2007). The Emerging Web 2.0 Social Software: An Enabling Suite of Sociable Technologies in Health and Healthcare Education. *Health Information and Libraries Journal.* Vol. 24, (1), pp.2-23.

Bowker, N., Tuffin, K. (2003). Dicing with Deception: People with Disabilities' Strategies for Managing Safety and Identity. *Journal of Computer-Mediated Communication.* Vol. 8, (2). [Online].
Available: <http://jcmc.indiana.edu/vol8/issue2/> [Accessed 9 January 2007].

Boxall, K. (2007). Disability Rights and Wrongs. In A. Sheldon, R. Traustadottir, P. Beresford, K. Boxall, M. Oliver. Review Symposium: Disability Rights and Wrongs? *Disability and Society.* Vol. 22, (2), pp.224-229.

Boyatzis, R. E. (1998). *Transforming Qualitative Information: Thematic Analysis and Code Development.* London: Sage.

Branson, J. (2002). *Damned for Their Difference: The Cultural Construction of Deaf People as Disabled: A Sociological History.* Washington, DC, USA: Gallaudet University Press.

Breakwell, G. (1990). *Interviewing: Problems in Practice.* London: The British Psychology Society and Routledge Ltd.

Breslow, L. (1972). A Quantitative Approach to the World Health Organisation Definition of Health: Physical, Mental and Social Well-Being. *International Journal of Epidemiology.* Vol. 1, (4), pp.347-355.

Brett, P. (2008). MeLAS: Mobiles Enhancing Learning and Support. JISC Final Report. [Online].
Available:<http://jisc.ac.uk/media/documents/programmes/elearningi nnovation/melasfinalreport.pdf> [Accessed 11 August 2009].

Brewer, J., Hunter, A. (2006). *Foundations of Multimethod Research: Synthesizing Styles*. London: Sage.

British Dyslexia Association. (2009). *About Dyslexia*. Bracknell: The British Dyslexia Association. [Online].
Available: <http://www.bdadyslexia.org.uk/aboutdyslexia.html> [Accessed 6 March 2009].

British Psychology Society. (2007). *Conducting Research on the Internet: Guidelines for Ethical Practice in Psychological Research Online*.   [Online].   Available:<http://www.bps.org.uk/document-download-area/document-download$.cfm?file_uuid=2B3429B3-1143-DFD0-7E5A-4BE3FDD763CC&ext=pdf> [Accessed 25 April 2008].

British Sociological Association. (2002). *Statement of Ethical Practice for the British Sociological Association*. [Online].
Available:<http://www.britsoc.co.uk/NR/rdonlyres/468F236C-FFD9-4791-A0BD-4DF73F10BA43/0/StatementofEthicalPractice.doc> [Accessed 25 April 2008].

Bronfenbrenner, U. (1974). The Origins of Alienation. *Scientific American*. Vol. 232, pp.53-61.

Brooke, C., Oliver, R. (2003). Online Learning Communities: Investigating a Design Framework. *Australasian Journal of Educational Technology*. Vol. 19, (2), pp.139-160.

Brown, P., Lauder, H. (2000). Human Capital, Social Capital, and Collective Intelligence. In S. Baron, J. Field and T. Schuller. (Eds.) *Social Capital, Critical Perspectives*. Oxford: Oxford University Press. Pp. 226-242.

Bruce, T. J., Saeed, S. A. (1999). Social Anxiety Disorder: A Common Underrecognised Mental Disorder. *American Family Physician*. Vol. 60, (8), pp.2311-2322.

Bruner, J. S. (1990). *Acts of Meaning*. Cambridge, MA: Harvard University Press.

Bryman, A. (2004*). Social Research Methods*. 2nd Edn. Oxford: Oxford University Press.

Burr, V. (2003). *Social Constructionism*. 2nd Edn. London: Routledge.

Bury, M. (1996). Defining and Researching Disability: Challenges and Responses. In C. Barnes and G. Mercer. (Eds.). *Exploring the Divide: Illness and Disability*. Leeds: The Disability Press. Pp.31-53.

Campbell, J. Oliver, M. (1996). *Disability Politics: Understanding our Past, Changing Our Future*. London: Routledge., quoted in Shakespeare, T. (2006). *Disability Rights and Wrongs*. Oxon: Routledge. P.13.

Carmichael, A., Brown, L. (2002). The Future Challenge for Direct Payments. *Disability and Society*. Vol. 17, (7), pp.797-808.

Case, J. M., Marshall, D. (2008). The 'No Problem' Discourse Model: Exploring an Alternative Way of Researching Student Learning. *International Journal of Educational Research*. Vol. 47, (3), pp.200-207.

Cassell, C. Symon. G. (Eds). (2004). *Essential Guide to Qualitative Methods in Organizational Research*. London: Sage.

Centre for Studies on Inclusive Education. (1996). *Summary of the Report of the Further Education Funding Council Learning Difficulties and/or Disabilities Committee*. [Online].
Available: <http://www.csie.org.uk/publications/tomlinson-96.pdf > [Accessed 22 February 2008].

Chadwick, B. A., Bahr, H. M., Albrecht, S. L. (1984). Social Science Research Methods. Englewood Cliffs, NJ: Prentice Hall., cited in B. L. Berg. (2007). *Qualitative Research Methods for the Social Sciences*. 6th Edn. Boston, MA: Pearson Education. Pp.105-106.

Chandler, D. (2002). *Semiotics: The Basics*. London: Routledge.

Cheek, J. (2007). Qualitative Inquiry, Ethics, and Politics of Evidence: Working Within These Spaces Rather Than Being Worked Over by Them. *Qualitative Inquiry*. Vol. 13, (8), pp.1051-1059. [Online].
Available: <http://qix.sagepub.com/cgi/content/abstratct/13/8/1051> [Accessed 13 May 2008].

Chelser, M., Chelser, N. (2002). Gender-Informed Mentoring Strategies for Women Engineering Scholars: On Establishing a Caring Community. *Journal of Engineering Education*. Vol. 91, pp.49-55.

Christie, H. (2004). Leaving University Early: Exploring the Differences between Continuing and Non-Continuing Students. *Studies in Higher Education*. Vol. 29, (5), pp.617-636.

Churchill, D., Wong, W., Law, N., Salter, D., Tai, B. (2009). Social Bookmarking–Repository–Networking: Possibilities for Support of Teaching and Learning in Higher Education. *Serials Review* 2009. Article in Press. [Online].
Available from: Science Direct <http://www.sciencedirect.com> [Accessed 11 August 2009].

Clarke, P. (2000). *The Internet as a Medium for Qualitative Research.* Paper presented at the 2nd Annual Conference on World-Wide Web Applications*.* [Online].
Available:<http://generalupdate.rau.ac.za/infosci/conf/Wednesday/Clarke.htm> [Accessed 6 May 2007].

Clement, G. (1996). *Care, Autonomy and Justice. Feminism and the Ethics of Care*. Boulder: Westview.

Coates, J. (1988). Gossip Revisited: Language in All-Female Groups. In J. Coates and D. Carnepon (Eds.). *Women in their Speech Communities: New Perspectives on Language and Sex.* London: Longman.

Cohn, D. (1978). *Transparent Minds: Narrative Modes for Presenting Consciousness in Fiction*. New Jersey: Princeton University Press.

Cole, M. (2009). Using Wiki Technology to Support Student Engagement: Lessons from the Trenches. *Computers and Education*. Vol. 52, (1), pp.141-146.

Coleridge, P. (1993). *Disability, Liberation and Development*. Oxford: Oxfam.

Coleman, J. S. (1990). *Foundations of Social Theory*. Cambridge: Belknap.

Coomber, R. (1997). Using the Internet for Survey Research. *Sociological Research Online*. Vol. 2, (2). [Online].
Available: <http://www.socresonline.org.uk/2/2/coomber.htm> [Accessed 6 May 2007].

Corbin J., Strauss, A. (2008). *Basics of Qualitative Research*. 3rd Edn. London: Sage.

Corker, M., French, S. (1999). Reclaiming Discourse in Disability Studies. In M. Corker, S. French (Eds.). *Disability Discourse*. Buckingham, UK: Open University Press. Pp.1-12.

Cregan, K. (2006). *The Sociology of the Body: Mapping the Extraction of Embodiment*. London: Sage.

Cremer, I. (1991). Support Services for Hearing Impaired Students. In K. Schulte, I. Cremer (Eds.). *Developing Structures to Serve Hearing-Impaired Students in Higher Education*. Heidelberg, Germany: Research Centre of Applied Linguistics for the Rehabilitation of the Disabled.

Crichton, S., Kinash, S. (2003). Virtual Ethnography: Interactive Interviewing Online as Method. *Canadian Journal of Learning and Technology*. Vol. 29, (2). [Online].
Available:<http://www.cjlt.ca/index.php/cjlt/article/view/40/37>
[Accessed 4 April 2009].

Crotty, M. (1998). *The Foundations of Social Research*. London: Sage.

Crow, L. (1996). Including All Our Lives: Renewing the Social Model of Disability. In C. Barnes and G. Mercer (Eds.). *Exploring the Divide: Illness and Disability*. Leeds: The Disability Press. Pp.55-73.

Cummins, R. A., Lau, A. L. (2003). Community Integration or Community Exposure? A Review and Discussion in Relation to People with an Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities*. Vol. 16, pp.145-157.

Dagel, D., Dowaliby, F. (1989). Third-Week Prediction of Incoming Postsecondary Deaf Student Probation/Suspension. *Journal of the American Deafness and Rehabilitation Association. Vol.* 22, pp.53-56.

Darwin, A. (2000). Critical Reflections on Mentoring in Work Settings. *Adult Education Quarterly*. (May). Vol. 50, (3), pp.197-211.

Davies, H. T. O., Nutley, S. M., Smith, P. C. (2000). *What Works? Evidence Based Policy and Practice in Public Services*. Bristol: Policy Press.

Davis, M. (2004). Reflecting on the experience of Interviewing Online: Perspectives from the Internet and HIV Study in London. *Aids Care-Psychological and Socio-Medical Aspects of Aids/HIV*. Vol. 16, (8), pp.944-952.

Dawson, K., Wall, P. (1969). *Society and Industry in the 19th Century: A Documentary Approach*. London: Oxford University Press.

Dawson, S. (2006). A Study of the Relationship between Student Communication Interaction and Sense of Community. *The Internet and Higher Education*. Vol. 9, (3), pp.153-162.

Dawson, S. (2008). A Study of the Relationship between Student Social Networks and Sense of Community. *Educational Technology and Society.* Vol. 11, (3), pp.224-238.

Degenne, A., Forse, M. (1999). *Introducing Social Networks.* London: Sage.

Denzin, N. K. (1989). *The Research Act: A Theoretical Introduction to Sociological Methods.* Prentice Hall: Englewood Cliffs.

Denzin, N. K., Lincoln, Y. S. (2003). Introduction: The Discipline and Practice of Qualitative Research. In N.K. Denzin, Y.S. Lincoln (Eds.). *Strategies of Qualitative Inquiry.* 2nd Edn. London Sage. Pp.1-45.

Department for Education and Skills. (2005). *Departmental Report 2005: Presented to Parliament by the Secretary of State for Education and Skills and the Chief Secretary to the Treasury by Command of Her Majesty June 2005.* Norwich: HMSO. [Online]. Available:<http://www.official-documents.gov.uk/document/cm65/6522/6522.pdf> [Accessed 25 March 2010].

Department of Health. (2000). *Health and Social Care Act 2001: Explanatory Notes.* Department of Health. [Online]. Available: <http://www.christie.com/documents/7.pdf> [Accessed 16 June 2009].

Derrida, J. (1976). *Of Grammatology.* Baltimore, MD: John Hopkins University Press.

DiFilippo, J. M., Overholser, J. C. (2000). Suicidal Ideation in Adolescent Psychiatric Inpatients as Associated with Depression and Attachment Relationships. *Journal of Clinical Child Psychology.* Vol. 29, pp.155-166.

Diprose, R. (2002). *Corporeal Generosity.* New York: State University of New York Press.

Disability Discrimination Act. (1995a). *Chapter 50, Part 1, Disability: Sect.1 Meaning of Disability and Disabled Person.* Office of Public Sector Information. [Online]. Available:<http://www.opsi.gov.uk/acts/acts1995/ukpga_19950050_en_5#pt4-l1g29> [Accessed 22 February 2008].

Disability Discrimination Act. (1995b). *Part III Discrimination in Other Areas: Goods, Facilities and Services.* Office of Public Sector Information.[Online]. Available:<http://www.opsi.gov.uk/acts/acts1995/ukpga_19950050_en_4#pt3> [Accessed 14 January 2008].

Disability Discrimination Act. (1995c). *Chapter 50, Part IV Education*. Office of Public Sector Information. [Online]. Available:<http://www.opsi.gov.uk/acts/acts1995/ukpga_19950050_en_5#pt4-l1g29> [Accessed 22 February 2008].

Disability Discrimination Act. (1995d) *as amended by SENDA, 2001: Part IV Education*. Her Majesty's Stationery Office. [Online]. Available:<http://www.opsi.gov.uk/acts/acts1995/Ukpga_19950050_en_1.htm> [Accessed 1 March 2008].

Disability Rights Commission. (2002). *Education for All: Getting In, Getting On or Getting Nowhere?* [Online]. Available: <http://www.drc-gb.org/newsroom/newsdetails.asp?id=204&section=2> [Accessed 24 October 2005].

Disability Rights Commission. (2006). *Legislation, Codes, Regulations and Guidance: DDA Chronology*. [Online]. Available:<http://83.137.212.42/sitearchive/DRC/the_law/legislation__codes__regulation/dda_chronology.html> [Accessed 14 March 2008].

Disability Rights Commission. [Equality and Human Rights Commission]. (2007a). *Evaluating the Impact of the Disability Rights Commission: Summary Report*. [Online]. Available:<http://www.leeds.ac.uk/disability-studies/archiveuk/DRC/Evaluating%20the%20impact%20of%20the%20Disability%20Rights%20Commission%20--%20EXECUTIVE%20SUMMARY.pdf> [Accessed 31 January 2008].

Disability Rights Commission. [Equality and Human Rights Commission]. (2007b). *Making the Duty Work: A Guide to the Disability Equality Duty for Disabled People and their Organisations*. [Online]. Available:<http://www.equalityhumanrights.com/Documents/Disability/Public%20sector/Disability%20equality%20duty/General%20information/Making%20the%20duty%20work%20A%20guide%20to%20the%20Disability%20Equality%20Duty%20for%20disabled%20people%20and%20their%20organisations.pdf> [Accessed 6 December 2007].

Disability Rights Commission. [Equality and Human Rights Commission]. (2007c). *Learning Lessons: Defining, Representing and Measuring Disability*. [Online]. Available:<http://www.leeds.ac.uk/disability-studies/archiveuk/DRC/Learning%20lessons%20--%20defining%20measuring%20and%20classifying%20disability.pdf> [Accessed 2 February 2008].

Dowaliby, F. J., Lang, H. G. (1999). Adjunct Aids in Instructional prose: A Multimedia Study with Deaf College Students. *Journal of Deaf Studies and Deaf Education*. Vol. 4, pp.270-282.

Dyslexia.com. (2006). *Speech Recognition, Dyslexia and Disabilities*. [Online]. Available: <http://www.dyslexic.com/dictcomp> [Accessed 9 January 2009].

Duck, S. (1991). *Friends, for Life: The Psychology of Personal Relationships*. 2nd Edn. London: Harvester Wheatsheaf.

Eby, L. T., Allen, T. D. (2002). Further Investigation of Protégés Negative Mentoring Experiences. *Group and Organisational Management*. Vol. 27, (4), pp.456-479.

Economic and Social Research Council. (2006). *Research Ethics Framework. Section 3: Governance, Ethics and Ethical Principles*. [Online].
Available:<http://www.esrcsocietytoday.ac.uk/ESRCInfoCentre/Imag es/ESRC_Re_Ethics_Frame_tcm6-11291.pdf>   [Accessed   23 September 2008].

Elias, M. J. (2006). The Connection Between Academic and Social-Emotional Learning. In M. J. Elias, H. Arnold (Eds.). *The Educator's Guide to Emotional Intelligence and Academic Achievement*. Thousand Oaks, CA: Corwin Press. Pp. 4-14.

Elliott, H. (1997). The Use of Diaries in Sociological Research on Health Experience. Sociological Research Online. [Online].
Available:<www.socresonline.org.uk/socresonline/2/2/7.html> [Accessed 4 October 2008].

Elo, S., Kyngäs, H. (2008). The Qualitative Content Analysis Process. *Journal of Advanced Nursing*. Vol. 62, (1), pp.107-115.

Eminovic, N., Wyatt, J. C., Tarpey, A. M., Murray, G., Ingrams, G. J. (2004). First evaluation of the NHS Direct Online Clinical Enquiry Service: A Nurse-led Web Chat Triage Service for the Public. *Journal of Medical Internet Research*. Vol. 6, (2), e17. [Online].
Available: <http://www.jmir.org/2004/2/e17/> [Accessed 1 May 2007].

Faraone, S. V., Sergeant, J., Gillberg, C., Biederman, J. (2003). The Worldwide Prevalence of ADHD: Is it an American Condition? *World Psychiatry*. Vol. 2, (2), pp.104-113. [Online].
Available:<http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid =1525089> [Accessed 6 January 2009].

Feyerabend, P. K. (1976). *Against Method*. New York: Humanities Press.

Field, S., Sarver, M., Shaw, S. (2003). Self Determination: A Key to Success in Postsecondary Education for Students with Learning Disabilities. *Remedial and Special Education*. Vol.24, (6), pp.339-349.

Fielding, J. (2008). Coding and Managing Data. In Gilbert, N (Ed.). *Researching Social Life*. 3rd Edn. Pp. 323-352.

Fink, L. D. (2003). *Creating Significant Learning Experiences: An Integrated Approach to Designing College Courses*. San Francisco, CA: Jossey-Bass.

Finkelstein, V. (1980). *Attitudes and Disabled People*. New York: World Rehabilitation Fund, Inc. [Online]. Available:<http://www.leeds.ac.uk/disability-studies/archiveuk/finkelstein/attitudes.pdf> [Accessed 5 February 2008].

Finkelstein, V. (1981). Disability and the Helper/Helped Relationship. An Historical View. In A. Brechin, P. Liddiard, J. Swain (Eds.). *Handicap in a Social World*. London: Hodder and Stoughton. Pp.1-5.

Finkelstein, V. (2001). *A Personal Journey into Disability Politics*. Leeds: University of Leeds, Centre for Disability Studies.

Fisher, P. (2007). Experiential Knowledge Challenges 'Normality' and Individualised Citizenship: Towards 'Another Way of Being. *Disability and Society*. Vol. 22, (3), pp.283-298.

Fisher, R. P., Geiselman, R. E. (1992). *Memory-Enhancing Techniques for Investigative Interviewing: The Cognitive Interview*. Springfield, IL: Charles C. Thomas.

Flick, U. (1998). *An Introduction to Qualitative Research: Theory, Method and Applications*. London: Sage.

Flick, U. (2006). *An Introduction to Qualitative Research*. 3rd Edn. London: Sage.

Flick, U., von Kardorff, E., Steinke, I. (Eds.). (2004). What is Qualitative Research? An Introduction to the Field. In U. Flick, E. von Kardorff, I. Steinke (Eds.). *A Companion to Qualitative Research*. London: Sage. Pp.3-11.

Flynn, N. (2004). *Instant Messaging Rules: A Business Guide to Managing Policies, Security, and Legal Issues for Safe IM Communication*. Saranac Lake, NY, USA: AMACOM.

Foster, S. (2001). Examining the Fit between Deafness and Disability. *Research in Social Sciences and Disability*. Vol. 2, pp101-123.

Foster, S., Long, G., Snell, K. (1999). Inclusive Instruction and Learning for Deaf Students in Postsecondary Education. *Journal of Deaf Studies and Deaf Education.* Vol. 4, pp.225-235.

Foucault, M. (1972). *The Archaeology of Knowledge*. London: Tavistock.

Fraser, N. (1989). *Unruly Practices: Power, Discourses and gender in Contemporary Social theory*. Cambridge: Polity Press.

Fraser, N., Gordon, L. (1994). Dependency Demystified: Inscriptions of Power in a Keyword of the Welfare State. *International Studies in Gender, State and Society*. Vol. 1, (1), pp.4-31.

French, S. (1993). Disability Impairment or Something in Between? In J. Swain, V. Finkelstein, S. French and M. Oliver (Eds.). *Disabling Barriers – Enabling Environments*. London: Sage. Pp.17-25.

French, S. (1996). The Attitudes of Health Professionals towards Disabled People. In G. Hales (Ed.). *Beyond Disability: Towards an Enabling Society.* London: Sage. Pp. 145-160.

Frith, U. (2003). *Autism: Explaining the Enigma*. 2nd Edn. Oxford: Blackwell.

Further and Higher Education Act. (1992). *Chapter 13: Part 1 Further Education: Responsibility for Further Education, Sect. 4 Persons with Learning Difficulties*. Office of Public Sector Information. [Online]. Available:<http://www.opsi.gov.uk/acts/acts1992/ukpga_19920013_en_2#pt1-ch1-pb2-l1g4> [Accessed 22 February, 2008].

Ganz, J. B., Kaylor, M., Bourgeois, B., Hadden, K. (2008). The Impact of Social Scripts and Visual clues on Verbal Communication in Three Children with Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities*. Vol. 23, (2), pp.79-94.

Garfinkel, H. (1967). *Studies in Ethnomethodology*. Englewood Cliffs, NJ: Prentice-Hall.

Garrison, D. R., Anderson, T. (2003). *E-learning in the 21st Century*. London: RoutledgeFalmer.

Garrison-Harrell, L., Kamps, D. (1997). The Effects of Peer Networks on Social-Communicative Behaviours for Students with Autism. *Focus on Autism and Other Developmental Disabilities*. Vol.12, pp.241-255.

Gaustad, M. G. (1999). Including the Kids Across the Hall: Collaborative Instruction of Hearing, Deaf, and had of Hearing Students. *Journal of Deaf Studies and Deaf Education*. Vol. 4, (3), pp.176-190.

Geertz, C. (1973). Thick Description: Towards and Interpretive Theory of Culture. In C. Geertz (Ed.). *The Interpretation of Cultures*. New York: Basic Books.

George, L. K. (1993). Sociological Perspectives on Life Transitions. *Annual Review of Sociology*. Vol. 19, pp.353-373.

Gergen, K. J. (1985). The Social Constructionist Movement in Modern Psychology. *American Psychologist*. Vol. 40, (3), pp.266-275.

Gergen, K. J. (1994). *Realities and Relationships: Soundings in Social Constructionism*. Cambridge, Mass; London: Harvard University Press.

Gergen, K. J. (1997). *Realities and Relationships: Soundings in Social Constructionism*. London: Harvard University Press.

Gergen, K. J. (2001). *Social Constructionism in Context*. London: Sage.

Gergen, K. J. (2009). *Relational Being: Beyond Self and Community*. Oxford, New York: Oxford University Press.

Germonprez, M., Zigurs, I. (2009). Task, Technology, and Tailoring in Communicative Action: An In-depth Analysis of Group Communication. *Information and Organisation*. Vol. 19, (1), pp.22-46. [Online].
Available from: Science Direct <http://www.sciencedirect.com> [Accessed 14 August 2009].

Gilligan, C. (1987). Moral Orientation and Moral Development. In E. Feder Kittay, D. T. Meyers (Eds.). *Women and Moral Theory*. Totowa: Rowman and Littlefield. Pp.19-33.

Gilligan, C. (1988a). Remapping the Moral Domain: New Images of Self in Relationship. In C. Gilligan, J. D. Ward, J. M. Taylor, B, Bardige (Eds*.). Mapping the Moral Domain*. Cambridge, Mass: Harvard University Press. Pp.3-20.

Gilligan, C. (1988b). Preface. In C. Gilligan, J. D. Ward, J. M. Taylor, B, Bardige (Eds*.). Mapping the Moral Domain*. Cambridge, Mass: Harvard University Press. Pp.i-vi.

Goode, J. (2007). Managing Disability: Early Experiences of University Students with Disabilities. *Disability and Society.* Vol. 22, (1), pp.35-48.

Goodenow, C. (2006). The Psychological Sense of School Membership Among Adolescents: Scale Development and Educational Correlates. *Psychology in the Schools.* Vol. 30, (1), pp.79-90.

Gooding, L. Locke, A., Brown, S. D. (2007). Social Networking Technology: Place and Identity in Mediated Communities. *Journal of Community Applied Social Psychology.* Vol. 17, (6), pp.463-476.

Goodman, J. (2003). Reflections on Researching an Archive of Disability: Sandlebridge, 1902-1935. *Educational Review.* Vol. 55, (1), pp.47-54.

Goodwin, M. S. (2008). Enhancing and Accelerating the Pace of Autism Research and Treatment: The Promise of Developing innovating Technology. *Focus on Autism and Other Developmental Disabilities.* Vol. 23, (2), pp.125-128.

Gorard, S., Smith, E., May, H., Thomas, L., Adnett, N., Slack, K. (2006). *Review of Widening Participation Research: Addressing the Barriers to Participation in Higher Education: A report to HEFCE by the University of York, Higher Education Academy and Institute for Access Studies.* [Online]. Available:<http://www.hefce.ac.uk/pubs/rdreports/2006/rd13_06/barri ers.doc> [Accessed 1 May 2007].

Gould, S. J. (1984). *The Mismeasure of Man.* London: Penguin.

Granello, P. F. (1999). College Students Wellness as a Function of Social Support and Empathic Ability. *Journal of College Counselling.* Vol. 2, (2), pp.110-120.

Granovetter, M. (1973). The Strength of Weak Ties. *American Journal of Sociology.* Vol. 78, (6), pp.1360-1380.

Grant, A. (2002). Identifying Students' Concerns: Taking a Whole Institutional Approach. In N. Stanley and J. Manthorpe (Eds.). *Student Mental Health Needs: Problems and Responses.* London: Jessica Kingsley. Pp.51-64.

Graves, P., Tracy, J. (1998). Personal Viewpoint: Education for Children with Disabilities the Rational for Inclusion. *Journal of Paediatric Child Health.* Vol. 34, pp.220-225.

Griffen, M. (1997). Student Activities in Middle School: What Do They Contribute? *NAASP Bulletin.* Vol. 7, pp.87-92.

Griffith, M. (1995). *Feminisms and the Self: The Web of Identity*. London: Routledge.

Guba, E. G., Lincoln, Y. S. (1989). *Fourth Generation Evaluation*. Newbury Park, CA: Sage.

Gunter, B. (2002). Online Versus Offline Research: Implications for Evaluating Digital Media. *Aslib Proceedings*. Vol. 54, (4), pp.229-239.

Habermas, J. (1984). *Reason and the Rationalisation of Society: The Theory of Communicative Action.* (Vol.1). Boston: Beacon Press. English translation by Thomas McCarthy.

Habermas, J. (1987). *Lifeworlds and System: A Critique of Functionalist Reason: The Theory of Communicative Action.* (Vol.2). Boston: Beacon Press. English translation by Thomas McCarthy.

Hahn, H. (2001). Adjudication or Empowerment: Contrasting experiences with a Social Model of Disability. In L. Barton (Ed.). *Disability, Politics and the Struggle for Change*. London: David Fulton Publishers. Pp.59-78.

Harley, D., Winn, S., Pemberton, S., Wilcox, P. (2007). Using Texting to Support Students' Transition to University'. *Innovations in Education and Teaching International*. Vol. 44, (3), pp.229-241.

Harris, J. (2000). Is there a Coherent Social Conception of Disability? *Journal of Medical Ethics*. Vol. 26, (2), pp.95-100.

Harris, J. (2005). Enhancements are a Moral Obligation. *Welcome Science.* October, 1, pp.16-17. London: Wellcome Trust. [Online]. Available:<http://www.wellcome.ac.uk/stellent/groups/corporatesite/ @msh_publishing_group/documents/web_document/wtd019376.pdf > [Accessed 13 March 2008].

Harris, M. (1976). History and Significance of the Emic/Etic Distinction. *Annual Review of Anthropology*. Vol. 5, pp.329-350.

Haslam, N., Rothschild, L., Ernst, D. (2002). Are Essentialist Beliefs Associated With Prejudice? *British Journal of Social Psychology*. Vol. 41, pp.87-100.

Hayes, D. (2003). Managerialism and Professionalism in Post-Compulsory Education. In J. Lea, D. Hayes, A. Armitage, L. Lomas, S. Markless (Eds.). *Working in Post-Compulsory Education*. Maidenhead: Open University Press. Pp.88-100.

Heelas, P., Lock, A. (Eds.). (1981). *Indigenous Psychologies: The Anthropology of the Self*. London: Academic Press.

Heiman, T. (2006). Social Support Networks, Stress, Sense of Coherence and Academic Success of University Students with Learning Difficulties. *Social Psychology of Education*. Vol. 9, 4), pp.461-478.

Her Majesty's Stationery Office. (1910). Annual Report for 1912 of the Chief Medical Officer of the Board of Education., cited in Warnock Report. (1978). *Special Educational Needs: Report of the Committee of Enquiry into the Education of Handicapped Children and Young People.* London. Her Majesty's Stationery Office. [Online]. Available:<http://www.educationengland.org.uk/documents/warnock/index.html> [Accessed 8 June 2010]. P.14.

Her Majesty's Stationery Office. (1985). *The Curriculum from 5 to 16: HMI Series: Curriculum Matters No 2*. London: Her Majesty's Stationery Office. [Online].
Available:<http://www.educationengland.org.uk/documents/hmi-8to12/index.html> [Accessed 8 June 2010].

Higher Education Funding Council for England. (1996). *Survey into the Operation of the Disabled Students' Allowance.* Bristol: HEFCE.

Higher Education Funding Council for England. (2006). *Policy Development. Annex B Disability Equality Scheme*. [Online].
Available:<http://www.hefce.ac.uk/pubs/hefce/2006/06_28/>
[Accessed 11 September 2009].

Higher Education Statistics Agency (2010). *Statistics: View Statistics Online: Students and Qualifiers Data Tables: Disability, 2006/07; 2007/08; 2008/09*. [Online].
Available:<http://www.hesa.ac.uk/index.php?option=com_datatables&Itemid=121&task=show_category&catdex=3> [Accessed 31 March 2010].

Hinchcliffe, V. (2009). Internet Mediated Research: The Viability of Synchronous Online Interviewing and Web-Based Diaries for Data Collection with Participants with Social Communication Difficulties. *The International Journal of Interdisciplinary Social Sciences*. Vol. 4, (1), pp.181-198. [Online].
Available:<http://iji.cg.publisher.com/product/pub.88/prod.725>
[Accessed 22 June 2009].

Hinchcliffe, V., Gavin H. (2008). Internet Mediated Research: A Critical Reflection upon the Practice of Using Instant Messenger for Higher Educational Research Interviewing. *Psychology and Society.* Vol 1, (1), pp.91-104. [Online].
Available:<http://www.psychologyandsociety.sps.cam.ac.uk/previousissues/?id=11> [Accessed 30 November 2008].

Hinchcliffe, V., Gavin H. (2009). Social and Virtual Networks: Evaluating Synchronous Online Interviewing using Instant Messenger. *The Qualitative Report.* Vol. 14, (2), pp.318-340. [Online].
Available: <http://www.nova.edu/ssss/QR/> [Accessed 3 June 2009].

Hine, C. (2008). The Internet and Research Methods. In N. Gilbert (Ed.). *Researching Social Life.* 3rd Edn. London: Sage. Pp.304-320.

Hirschmann, N. (1997). Revisioning Freedom: Relationship, Context and the Politics of Empowerment. In N. Hirschmann and C. DiStefano (Eds.). *Revisioning the Political. Feminist Reconsideration of Traditional Concepts in Western Political Theory.* Boulder: Westview Press. Pp.157-180.

Hirschmann, N., DiStefano, C. (Eds.) (1997) *Revisioning the Political: Feminist Reconsideration of Traditional Concepts in Western Political Theory.* Boulder: Westview Press.

Hirst, M., Baldwin, S. (1994). *Unequal Opportunities: Growing up Disabled.* Social Policy Research Unit. London: HMSO.

Hobfoll, S. E. (1998). *Stress, Culture and Community: The Psychology and Philosophy of Stress.* New York: Plenum Press.

Hodgson, K. W. (1953). The Deaf and Their Problems: A Study in Special Education. London: Watts & Co.

Holford, P. (2007). *Mental Health Project: What are Dyslexia and Dyspraxia.* [Online].
Available:<http://www.mentalhealthproject.com/content.asp?id_Content=1021> [Accessed 9 May 2007].

Homans, G. (1974). *Social Behaviour: Its Elementary Forms.* New York: Harcourt Brace Jovanovich.

Hookway, N. (2008). Entering the Blogosphere: Some Strategies for Using Blogs in Social Research. *Qualitative Research.* Vol. 8, (1), pp.91-113.

House, J. S. (1981). *Work, Stress and Social Support.* Reading, MA: Addison-Wesley.

Hughes, B., Paterson, K. (1997). The Social Model of Disability and the Disappearing Body: Towards a Sociology of Impairment. *Disability and Society.* Vol. 12, (3), pp.325-340.

Hunt, P. A. (1996). Critical Condition. In P. A. Hunt (Ed.). *The Experience of Disability*. London: Geoffrey Chapman. Chapter 12. [Online].
Available:<http://www.leeds.ac.uk/disability-studies/archiveuk/Hunt/a%20critical%20condition.pdf> [Accessed 5 February 2008].

Hurst, A. (1999). The Dearing Report and Students with Disabilities and Learning Difficulties. *Disability and Society*. Vol. 14, (1), pp.65-83.

James, N. (2006). Credibility, Authenticity and Voice: Dilemmas in Online Interviewing. *Qualitative Research*. Vol. 6, (3), pp.403-420.

Jamison, R.N., Raymond, S. A., Levine, J. G., Slawsby, E. A., Nedeljkovic, S. S., Katz, N. P. (2001). Electronic Diaries for Monitoring Chronic Pain: 1-Year Validation Study. *Pain*. Vol. 91, pp.277-285.

Johnson, P., Buehring, A., Cassell, C., Symon, G. (2006). Evaluating Qualitative Management Research: Towards a Contingent Criteriology. *International Journal of Management Reviews*. Vol. 8, (3), pp.131-156.

Jones, G. M., Edwards, G. (2009). Time to Engage? Texting to Support and Enhance First Year Undergraduate Learning. *International Journal of Mobile Technologies*. Vol. 3, (2), pp.6–11.

Jones, K. (1998). *Mental Health and Social Policy 1845-1959*. London: Routledge.

Jones, N., Blackey, H., Fitzgibbon, K., Chew, E. (2009). Get Out of MySpace!. *Computers and Education*. Article in Press. [Online].
Available from: Science Direct <http://www.sciencedirect.com> [Accessed 18 August 2009].

Jordan, B. (2001). Tough Love: Social Work, Social Exclusion and the Third Way. *British Journal of Social Work*. Vol. 31, (4), pp. 527-546.

Kamps, D., Potucek, J., Lopez, A., Kravits, T., Kemmerer, K. (1997). The Use of Peer Networks across Multiple Settings to Improve Social Interaction for Students with Autism. *Journal of Behavioural Education*. Vol. 7, pp.335-357.

Kant, I. (1959). *Foundations of the Metaphysics of Morals*. L. W. Beck (trans.). Indianapolis: The Bobbs-Merrill Company.

Kenny, D. A., Bolger, N., Kashy, D. A. (2002). Traditional Methods for Estimating Multilevel Models. In D. S. Moskowitz, S. L. Hershberger (Eds.). *Modelling Intra-individual Variability with Repeated Measures data: Methods and Applications*. Mahwah, NJ: Lawrence Erlbaum. Pp.1-24.

Kersting, S. A. (1997). Balancing Between Deaf and Hearing Worlds: Reflections of Mainstreamed College Students on Relationships and Social Interactions. *Journal of Deaf Studies and Deaf Education.* Vol. 2, pp.252-263.

King, E. (1998b). The Use of Self in Qualitative Research. In J. E. Richardson (Ed.). *Handbook of Qualitative Research Methods for Psychology and the Social Sciences*. Leicester: British psychology Society Books. Pp.119-130.

King, N. (1998a). Template Analysis. In G. Symon, C. Cassell. (Eds.). *Qualitative Methods and Analysis in Organizational Research: A Practical Guide*. London: Sage. Pp.118-134.

King, N. (2004). Using Templates in the Thematic Analysis of Text. In C. Cassell, G. Symon. (Eds.). *Essential Guide to Qualitative Methods in Organizational Research*. London: Sage. Pp.256-270.

King, N. (2006). *Template Analysis: What is Template Analysis: Philosophical Position.* [Online]. Available:<http://www.hud.ac.uk/hhs/research/template_analysis/index.htm> [Accessed 27 March 2007].

Kluwin, T., Stinson, M. S. (1993). *Deaf Students in Local Public High Schools: Background, Experiences, and Outcomes*. Springfield: Charles. C. Thomas.

Knox, H., Savage, M., Harvey, P. (2006). Social Networks and the Study of Relations: Networks as Method, Metaphor and Form. *Economy and Society*. Vol. 35, pp.113-140.

Korinek, L., Walther-Thomas, C., McLaughlin, V. L., Williams, B. T. (1999). Creating Classroom Communities and Networks for Student Support. *Intervention in School and Clinic. Vol.* 35, (1), pp.3-8.

Krippendorff, K. (1980). *Content Analysis: An Introduction to its Methodology*. Beverly Hills, CA: Sage.

Krippendorff, K. (2004). *Content Analysis: An Introduction to its Methodology*. 2nd Edn. London: Sage.

Kuehnast, K. (2004). *Better a Hundred Friends than a Hundred Rubles?: Social Networks in Transition - The Kyrgyz Republic*. Washington, DC, USA: World Bank Publications.

Kuhn, T. S. (1970). *The Structure of Scientific Revolutions*. 2nd Edn. Chicago: University of Chicago Press.

Kurth, N. K., Mellard, D. F. (2006). Student Perceptions of the Accommodations Process in Postsecondary Education. *Journal of Postsecondary Education and Disability.* Vol. 19, (1), pp. 69-82. [Online].
Available:<http://www.ahead.org/uploads/docs/jped/journals/JPEDVo l19No1.rtf> [Accessed 17 September 2009].

Kvale, S. (1996). *Interviews: An Introduction to Qualitative Research Interviewing*. London: Sage.

Ladd, P. (2002). *Understanding Deaf Culture: In Search of Deaf hood.* Clevedon: Multilingual Matters Limited.

Lane, H. (1992). *The Mask of Benevolence: Disabling the Deaf Community*. New York: Knopf.

Lang, H. G. (2002). Higher Education for Deaf Students: Research Priorities in the New Millennium. *Journal of Deaf Studies and Deaf Education.* Vol. 7, (4), pp.267-280.

Lang, H. G., Stinson, M. S., Kavanagh, F., Liu, Y., Basile, M. (1998). Learning Styles of Deaf College Students and teaching Behaviours of their Instructors. *Journal of Deaf Studies and Deaf Education*. Vol. 4, pp.16-27.

Larose, S., Tarabulsy, G., Cyrenne, D. (2005). Perceived Autonomy and Relatedness as Moderating the Impact of Teacher-Student Mentoring Relationships on Student Academic Adjustment. *The Journal of Primary Prevention*. Vol. 26, (2), pp.111-128.

Larsen. K. (2005). *Stephen Hawking: A Biography*. Westport, CT: Greenwood Press.

Latour, B. (2005). *Reassembling the Social: An Introduction to Actor-Network Theory*. Oxford: Oxford University Press.

Lave, J., Wenger, E. (1991). *Situated Learning: Legitimate Peripheral Participation*. Cambridge: Cambridge University Press.

Levett-Jones, T., Lathlean, J. (2007). Belongingness: A Prerequisite for Nursing Students' Clinical Learning. *Nurse Education in Practice*. Article in Press, Corrected Proof. [Online].
Available from: <http://www.sciencedirect.com> [Accessed 7 June 2007].

Lev-Wiesel, R., Nuttman-Shwartz, O., Sternberg, R. (2006). Peer Rejection during Adolescence: Psychological Long-Term Effects – A Brief Report. *Journal of Loss and Trauma*. Vol. 11, pp.131-142.

Lincoln, Y. S., Guba, E. G. (1985). *Naturalistic Inquiry*. London: Sage.

Longmore, P. K. (2003). *Why I Burned My Book and Other Essays on Disability.* Philadelphia, PA, USA: Temple University Press.

Longmore, P. K., Umansky, L. (2001). *The New Disability History*. New York: New York University Press.

Lowe, H., Cook, A. (2003). Mind the Gap: Are Students Prepared for Higher Education'. *Journal of Further and Higher Education*. Vol. 27, (1), pp.53-76.

Mackenzie, D. (1976). Eugenics in Britain. *Social Studies of Science*. Vol. 6, (3/4), pp.499-532.

Mahony, P., Hextall, I. (2000). *Reconstructing Teaching: Standards, Performance and Accountability*. London: Routledge.

Mannheim, K. (1951). *Ideology and Utopia*. New York: Harcourt Brace. Originally published in 1929.

Markett, C., Sanchez, A., Weber, S., Tangney, B. (2006). Using Short Message Service to Encourage Interactivity in the Classroom. *Computers and Education*. Vol. 46, pp.280-293.

Marsh, I. (Ed.). (2000). *Sociology: Making Sense of Society*. 2nd Edn. Harlow: Prentice Hall.

Martin, A. J., Dowson, M. (2009). Interpersonal Relationships, Motivation, Engagement, and Achievement: Yields for Theory, Current Issues, and Educational Practice. *Review of Educational Research*. Vol. 79, 1, pp.327-365.

Mason, J. (1998). *Qualitative Researching*. London: Sage.

Maxted, P. (1999). *Understanding Barriers to Learning*. London: Campaign for Learning.

May, T. (2004). Reflexivity and Social Science: A Contradiction in Terms? In B. Carter, C. New. (Eds.). *Making Realism Work: Realist Social Theory and Empirical Research*. London: Routledge. Pp.171-189.

McCauley, C. D., Van Velsor, E. (Eds.). (2004). *The Centre for Creative Leadership Handbook of Leadership Development.* 2nd Edn. San Francisco, CA: Jossey-Bass.

McGee, G. G., Almeida, M. C., Sulzer-Azaroff, B., Feldman, R. S. (1992). Promoting Reciprocal Interactions via Peer Incidental Teaching. *Journal of Applied Behaviour Analysis.* Vol. 25, pp.117-126.

McGowan, B., Saintas, P., Gill, K. (2009). On Mentoring, Social Mentoring and Befriending. *AI and Society.* Vol. 23, (4), pp.613-630.

McKinney, K. J. (2002). Students with Chronic Illness: The Construction of Self in the College Environment. *Dissertation Abstracts International Section A: Humanities and Social Sciences.* Vol. 62, (12-A), pp.4089. US: Uni Microfilms International.

McLaren, B. M. (2003). Extensionally Defining Principles and Cases in Ethics: An AI Model. *Artificial Intelligence.* Vol. 150, (1-2), pp.145-181.

McLean, M. (2001). Can we Relate Conceptions of Learning to Student Academic Achievement? *Teaching in Higher Education.* Vol. 6, (3), pp. 399-413.

McQueen, R., Knussen, C. (2002). *Research Methods for Social Science: A Practical Introduction.* Harlow: Pearson Education Limited.

Mechanic, D. (1989). Theory, Method and Substance. *Journal of Health and Social Behaviour.* Vol. 30, pp.147-160.

Melia, K. M. (1989). *Everyday Nursing Ethics.* Basingstoke: Macmillan Education.

Mesibov, G., Howley, M. (2003). *Accessing the Curriculum for Pupils with Autistic Spectrum Disorders: Using the TEACCH Programme to Help Inclusion.* London: David Fulton Publishers.

Mesibov, G. B., Shea, V., Schopler, E. (2005). *The TEACCH Approach to Autistic Spectrum Disorders.* New York: Plenum Press.

Middleton, L. (1996). *Making a Difference: Social Work with Disabled Children.* Birmingham: Venture Press.

Milligan, C., Bingley, A., Gatrell, A. (2005). Digging Deep: Using Diary Techniques to Explore the Place of Health and Well-Being Amongst Older People. *Social Science and Medicine.* Vol. 61, pp.1882-1892.

Mishler, E. (1995). Models of Narrative Analysis: A Typology. *Journal of Narrative and Life History*. Vol. 5, pp. 87-123.

Mollenhorst, Volker, B., Flap, H. (2008). Social Context and Personal Relationship: The Effect of Meeting Opportunities on Similarity for Relationships of Different Strength. *Social Networks*. Vol. 30, pp.60-68.

Moran-Ellis, J., Alexander, V. D., Cronin, A., Dickinson, M., Fielding J., Sleney, J., Thomas, H. (2006). Triangulation and Integration: Processes, Claims and Implications. *Qualitative Research*. Vol. 6, (1), pp.45-59.

Morgan, S. J., Symon, G. (2004). Electronic Interviews in Organisational Research. In C. Cassell, G. Symon. (Eds.). *Essential Guide to Qualitative Methods in Organizational Research*. London: Sage. Pp.23-33.

Morris, J. (1991). *Pride Against Prejudice*. London: Women's Press.

Morris, J. (Ed.). (1996). *Encounters with Strangers: Feminism and Disability*. London: The Women's Press.

Morrison, L., Kamps, D., Garcia, J., Parker, D. (2001). Peer Mediation and Monitoring Strategies to Improve Initiations and Social Skills for Students with Autism. *Journal of Positive Behaviour Interventions*. Vol. 3, pp.237-250.

Moustakas, C. E. (1994). *Phenomenological Research Methods*. Thousand Oaks, Calif: Sage

Müller, E., Schuler, A., Yates, G. B. (2008). Social Challenges and Support from the Perspective of Individuals with Asperger Syndrome and Other Autism Spectrum Disabilities. *Autism*. Vol. 12, (2), pp.173-190.

Murray, M. M. (2001). *Beyond the Myths and Magic of Mentoring: How to Facilitate an Effective Mentoring Process*. San Francisco, CA: Jossey-Bass.

National Network of Assessment Centres (2008). *Information about the Study Aids and Study Strategies Assessment ("Needs Assessment")*. [Online].
Available: <http://www.nnac.org/students/sassa.php> [Accessed 5 January 2009].

National Autistic Society. (2007). *Diagnosis of Autistic Spectrum Disorders - A Brief Guide for Health Professionals.* [Online].
Available:<http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=1419&a=2224> [Accessed 4 October 2007].

National Committee of Inquiry into Higher Education [NCIHE]. (1997a). *Report of the National Committee: Chapter 7, Widening Participation in Higher Education.* [Online]. Available: <http://www.leeds.ac.uk/educol/ncihe/> [Accessed 22 February 2008].

National Committee of Inquiry into Higher Education [NCIHE]. (1997b). *Report 6: Widening Participation in Higher Education for Lower Socio-Economic Groups and Students with Disabilities: Section 5, Recommendations for Policy on Access for Students with Disabilities.* [Online].
Available:<http://www.leeds.ac.uk/educol/ncihe/> [Accessed 22 February 2008].

National Dissemination Centre for Children with Disabilities (NICHCY). (2004). *Disability Fact Sheet – No.3: Deafness and Hearing Loss.* [Online].
Available:<http://www.nichcy.org/pubs/factshe/fs3txt.htm> [Accessed 4 October 2007].

Nelson, C., Treichler, P. A., Grossberg, L. (1992). Cultural Studies: An Introduction. In L. Grossberg, C. Nelson, P. A. Treichler (Eds.).*Cultural Studies.* New York: Routledge. Pp.1-16.

Nelson, J. L., Berens, B. S. (1997). Spoken Daggers, Deaf Ears and Silent Mouths. In L. J. Davis (Ed.). *The Disability Studies Reader.* London: Routledge. Pp. 52–74.

Ng, S. H., Brooke, M., Dunne, M. (1995). Interruption and Influence in Discussion Groups. *Journal of Language and Social Psychology.* Vol. 14, pp. 369-381.

O'Connell, P. (2005). 'A Better Future?': *Young Adults with Complex Physical and Commutation Needs in Mainstream Education.* Paper Developed for the Final Report of the RITE Research Project. Brighton: The DARE Foundation. [Online].
Available:<http://www.leeds.ac.uk/disability-studies/archiveuk/o'connell/oconnellp%20a%20better%20future%20bera%202005.pdf> [Accessed 24 August 2009].

Office of Public Sector Information. (1996). *Community Care [Direct Payments] Act 1996: Ch.30, Sect 3: Consequential Amendments.* [Online].
Available:<http://www.opsi.gov.uk/acts/acts1996/ukpga_19960030_en_1#pb1-l1g3> [Accessed 15 June 2009].

Office of Public Sector Information. (1998). *Data Protection Act 1998: Ch.29, Part 1: Schedule 2; Preventing Disclosure of Sensitive Personal Data.* [Online].
Available:<http://www.opsi.gov.uk/Acts/Acts1998/ukpga_19980029_en_2#pt1> [Accessed 13 November 2008].

Office of Public Sector Information. (2008). *Health and Social Care Act 2001: Ch.15, Part 4: Sections 57 and 58.* [Online].
Available:
<http://www.opsi.gov.uk/Acts/acts2001/ukpga_20010015_en_1>
[Accessed 16 June 2009].

Oliver, M. (1990). *The Politics of Disablement.* London: Macmillan.

Oliver, M. (1996). *Understanding Disability: From Theory to Practice.* London: Macmillan.

Oliver, M. (2007). Disability Rights and Wrongs. In A. Sheldon, R. Traustadottir, P. Beresford, K. Boxall, M. Oliver. Review Symposium: Disability Rights and Wrongs? *Disability and Society.* Vol. 22, (2), pp.230-234.

O'Neil, S. (2008). The Meaning of Autism: Beyond Disorder. *Disability and Society.* Vol. 23, (7), pp.787-799.
Open University. (2003). *Survey into Creating Accessible Resources for Academic Staff.* [Online]. Available:<www.open.ac.uk/cater> [Accessed 21 October 2003].

Osterman K. F. (2000). Students' Need for Belonging in the School Community. *Review of Educational Research.* Vol. 70, (3), pp. 323-367.

Pahl, R., Pevalin, D. J. (2005). Between Family and Friends: A Longitudinal Study of Friendship. *British Journal of Sociology.* Vol. 56, (3), pp.433-50.

Palloff, R., Pratt, K. (1999). *Building Learning Communities in Cyberspace.* San Francisco, CA: Jossey-Bass.

Parker, V. (1999). Personal Assistance for Students with Disabilities in HE: The Experience of the University of East London. *Disability and Society.* Vol. 14, (4), pp.483-504.

Parr, S., Paterson, K., Pound, C. (2003). Time Please! Temporal Barriers in Aphasia. In S. Parr. (Ed.). *Aphasia Inside Out: Reflections on Communication Disability.* Berkshire: McGrawHill Education. Pp.127-144.

Parton, N. (2006). Changes in the form of Knowledge in Social Work: From the 'Social' to the 'Informational'? *British Journal of Social Work*. Advance Access: 27th October 2006, pp.1-17.

Patrick, H., Knee, C. R., Canevello, A., Lonsbary, C. (2007). The Role Fulfilment in Relationship Functioning and Well-Being: A Self-Determination Theory Perspective. *Journal of Personality and Social Psychology*. Vol. 92, (3), pp.434-457.

Patton, M. Q. (1990). *Qualitative Evaluation and Research Methods*. 2nd Edn. London: Sage.

Paulson, B. L., Everall, R. D. (2001). The Teen Suicide Research Project. *Alberta Journal of Educational Research*. Vol. 47, pp.91-94.

Pearce, F., Woodiwiss, A. (2001). Reading Foucault as a Realist. In j. Lopez, G. Potter. (Eds.). *After Postmodernism: An Introduction to Critical Realism*. London: Althone. Pp.51-62.

Peat, M., Dalziel, J., Grant, A. M. (2000). Enhancing the Transition to University by Facilitating Social and Study Networks: Results of a One-Day Workshop. *Innovations in Education and Training International. Vol.* 37, (4), pp.293-303.

Pescosolido, B. A. (2001). The Role of Social Networks in the Lives of People with Disabilities. In G. L. Albrecht, K.D. Seelman. (Eds.). *Handbook of Disability Studies*. Thousand Oaks, CA, US: Sage.

Piasecki, T. M., Hufford, M. R., Solhan, M., Trull, T. J. (2007). Assessing Clients in their Natural Environments with Electronic Diaries: Rationale, Benefits, Limitations, and Barriers. *Psychological Assessment*. Vol. 19, (1), pp.25-43.

Pietra, A. L., Makam, V., Tran, T. U. (2005). *Usable Accessibility at U.C. Berkeley: Designing with Accessibility in Mind*. SIMS Masters Project. [Online].
Available:<http://tutran.net/files/UsableAccessibility-Final.pdf>
[Accessed 4 April 2009].

Plickert, G., Rochelle, R., Côté, B. W. (2007). It's Not Who You Know, it's How You Know Them: Who Exchanges What With Whom? *Social Networks*. Vol. 29, pp.405-429.

Plummer, K. (2001). *Documents of life 2: An Invitation to a Critical Humanism*. London: Sage.

Pollard, W. C. (1866). Report for the Year 1865: Fortieth Report of the West of England Institution for the Instruction of Deaf and Dumb Children of the counties of Devon, Cornwall, Somerset and Dorset. Exeter., cited in Borsay, A. (2005). *Disability and Social Policy in Britain since 1750: A History of Exclusion*. Hampshire: Palgrave Macmillan. P.95.

Pontius, J. L., Harper, S. R. (2006). Principles for Good Practice in Graduate and Professional Student Engagement. In M. Guentzel, B. Elkins Nesheim. (Eds.). *Supporting Graduate and Professional Students: The Role of Student Affairs. New Directions for Student Services*. San Francisco: Jossey-Bass. Pp.47-58.

Potter, G. (2000). *The Philosophy of Social Science: New Perspectives*. Harlow: Pearson Educational.

Powney, J., Watts, M. (1987). *Interviewing in Educational Research*. London: Routledge.

Priestley, M. (1999). *Disability Politics and Community Care*. London: Jessica Kingsley.

Priestley, M., Jolly, D., Pearson, C., Riddell, S., Barnes, C., Mercer, G. (2006). Direct Payments and Disabled People in the UK: Supply, Demand and Devolution. *The British Journal of Social Work*. Vol. 37, (7), pp.1189-1204.

Pritchard, D. G. (1963). Education and the Handicapped 1760-1960., cited in Warnock Report. (1978). *Special Educational Needs: Report of the Committee of Enquiry into the Education of Handicapped Children and Young People.* London. Her Majesty's Stationery Office. [Online].
Available:<http://www.educationengland.org.uk/documents/warnock/index.html> [Accessed 8 June 2010]. P.10.

Procidano, M. E., Heller, M. (1983). Measures of Perceived Social Support from Friends and from Family: Three Validation Studies. *American Journal of Community Psychology*. Vol. 11, (1), pp.1-24.

Putnam, R. D. (2000). *Bowling Alone: The Collapse and Revival of American Community*. New York: Simon and Schuster.

Quality Assurance Agency for Higher Education. (1999). *Code of Practice for the Assurance of Academic Quality and Standards in Higher Education*: Section 3. *Students with Disabilities*. Gloucester: QAA.[Online].
Available:<http://www.qaa.ac.uk/academicinfrastructure/codeOfPractice/section3/COP_disab.pdf> [Accessed 6 December 2007].

Qualifications and Curriculum Authority. (2004). *An Evaluation of Entry Level Qualifications: A Joint Project by QCA, ACCAC, CCEA and LSC*. [Online]. Available:<http://www.qca.org.uk/libraryAssets/media/7550_elevel.pdf> [Accessed 14 March 2008].

Raab, L., Adam, A. J. (2005). The University College Model: A learning-Centred Approach to Retention and Remediation. *New Directions for Institutional Research*. Vol. 2005, Issue 125, pp.87-106.

Rafaeli, S., Ravid, G., Soroka, V. (2004). De-lurking in Virtual Communities: *A Social Communication Network Approach to Measuring the Effects of Social and Cultural Capital*. Paper Presented at the 37th Hawaii International Conference on System Sciences. [Online]. Available:<http://ieeexplore.ieee.org/xpl/freeabs_all.jsp?arnumber=1265478> [Accessed 20 August 2009].

Ragins, B. R., Cotton, J. L. (1999). Mentor Functions and Outcomes: A Comparison of Men and Women in Formal and Informal Mentoring Relationships. *Journal of Applied Psychology*. Vol. 84, (4), pp.529-550.

Reed, M., Deem, R. (2002). New Managerialism: The Manager-Academic and Technologies of Management in Universities – Looking Forward to Virtuality? In K. Robins, F. Webster (Eds.). *The Virtual University? Knowledge, Markets and Management*. New York: Oxford University Press. Pp.126-147.

Richmond, C. A. M., Ross, N. A. (2008). Social Support, Material Circumstance and Health Behaviour: Influences on Health in First Nation and Inuit Communities of Canada. *Social Science and Medicine*. Vol. 67, (9), pp.1423-1433.

Rickinson, B., Rutherford, D. (1995). Increasing Undergraduate Student Retention Rates. *British Journal of Guidance and Counselling*. Vol. 23, (2), pp.161-72.

Rickinson, B., Rutherford, D. (1996). Systematic Monitoring of the Adjustment to University of Undergraduates: A Strategy for Reducing Withdrawal Rates. *British Journal of Guidance and Counselling*. Vol. 24, (2), pp. 213-225.

Riddell, S. (1998). Chipping Away at the Mountain: Disabled Students' Experiences of Higher Education. *International Studies in Sociology of Education*. Vol. 8, pp.203-222.

Riddell, S., Tinklin, T., Wilson, A. (2005). *Disabled Students in Higher Education: Perspectives on Widening Access and Changing Policy.* London: Routledge.

Riddell, S., Weedon, E., Fuller, M., Healey, M., Hurst, A., Kelly, K., Piggott, L. (2007). Managerialism and Equalities: Tensions within Widening Access Policy and Practice for Disabled Students in UK Universities. *Higher Education.* Vol. 54, (4), pp.615-628.

Rieser, R. (2001). The Struggle for Inclusion: The Growth of a Movement. In L. Barton (Ed.). *Disability, Politics and the Struggle for Change.* London: David Fulton Publishers. Pp.132- 148.

Riessman, C. K. (1993). *Narrative Analysis.* Newbury Park, CA: Sage.

Robson, C. (2002). *Real World Research: A Resource for Social Scientists and Practitioners – Researchers.* 2nd Edn. Oxford: Blackwell.

Rogers, A. (2002). *Teaching Adults.* 3rd edn. Buckingham: Open University Press.

Rose, N. (1999). *Powers of Freedom: Reframing Political Thought.* Cambridge: Cambridge University Press.

Rosenblum, D. (2007). *Managing Organisational Security: What Anyone Can Know – The Privacy Risks of Social Networking Sites.* IEEE Security and Privacy. Harvard University.

Ruch, G. (2005). Relationship-Based Practice and Reflective Practice: Holistic Approaches to Contemporary Child Care Social Work. *Child and Family Social Work.* Vol. 10, (2), pp.111-123.

Russell, D. (2005). *Priorities for Success: Funding for Learning and Skills 2006-2008: Of Interest to all Providers Receiving LSC Funding Plus Partners and Stakeholders.* Coventry: Learning and Skills Council National Office. [Online].
Available:<http://readingroom.lsc.gov.uk/lsc/2005/funding/streams/fe-funding-allocations-2005-06-further-update-and-analysis.pdf>
[Accessed 11 September 2009].

Sacks, H. (1992). *Lectures on Conversation.* Volume 1. Oxford: Blackwell.

Saenz, T. Marcoulides, G. A., Junn, E., Young, R. (1999). The Relationship between College Experience and Academic Performance among Minority Students. *The International Journal of Educational Management*. Vol. 13, (4), pp.199-207. [Online]. Available:<http://www.emeraldinsight.com/Insight/ViewContentServlet;jsessionid=50987549113D5FD5DC5C639A64117B0A?Filename=Published/EmeraldFullTextArticle/Pdf/0600130405.pdf> [Accessed 18 September 2009].

Salend, S. J. (1999). Facilitating Friendships among Diverse Students. *Intervention in School and Clinic*. Vol. 35, (1), pp.9-15.

Sargent, J., Williams, R., Hagerty, B., Lynch-Sauer, J., Hole, K. (2002). Sense of Belonging as a Buffer against Depressive Symptoms. *Journal of the American Psychiatric Nurses Association*. Vol. 8, pp.120-129.

Schacter, D. L. (1996). *Searching for Memory: The Brain, the Mind and the Past*. New York: Basic Books.

Scott, J. (2000). *Social Network Analysis - A Handbook*. 2nd Edn. London: Sage.

Searle, G. R. (1976). *Eugenics and Politics in Britain, 1900-1914*. Leyden: Noordhoff International Publishing.

Secker, B. (1999). The Appearance of Kant's Deontology in Contemporary Kantianism: Concepts of Patient Autonomy in Bioethics. *Journal of Medicine and Philosophy*. Vol. 24, (1), pp.43-66.

Sellers, J., van der Velden, G. (2003). *Supporting Student Retention. York:* Learning and Teaching Support Network, LTSN Generic Centre.

Sevenhuijsen, S. (1998). *Citizenship and the Ethics of Care: Feminist Considerations on Justice, Morality and Politics*. London: Routledge.

Sevenhuijsen, S. (2000).Caring in the Third Way: The Relation between Obligation, Responsibility and Care in Third Way Discourse. *Critical Social Policy*. Vol. 20, (1), pp.5-37.

Shakespeare, T. (2005). Disability, Genetics and Global Justice. *Social Policy and Society*. Vol. 4 (1), pp.87-95.

Shakespeare, T. (2006). *Disability Rights and Wrongs*. Oxon: Routledge.

Shakespeare, T., Watson, N. (2001). The Social Model of Disability: An Outdated Ideology? *Research in Social Science and Disability*. Vol. 2, pp.9-28.

Shapiro, J. P. (1994). *No Pity: People with Disabilities Gorging a New Civil Rights Movement.* New York: Three Rivers Press.

Sheldon, A. (2007). Disability Rights and Wrongs. In A. Sheldon, R. Traustadottir, P. Beresford, K. Boxall, M. Oliver. Review Symposium: Disability Rights and Wrongs? *Disability and Society*. Vol. 22, (2), pp.209-213.

Shotter, J. (1993). *Conversational Realities: Constructing Life through Language.* London: Sage.

Shotter, J. (1995). Dialogical Psychology. In J. A Smith, R. Harré, L. V. Langenhove (Eds.). *Rethinking Psychology.* London: Sage. Pp. 160-178.

Silverman, D. (1996). *Telling it like it is: The Interview in the Interview Society*, paper presented to the Fourth International Conference of International Sociology Association, Essex, 1-5 July.

Silverman, D. (2001). *Interpretating Qualitative Data: Methods for Analysing Talk, Text, and Interaction.* 2nd Edn. London: Sage.

Silverman, D. (2005). *Doing Qualitative Research: A Practical Handbook.* 2nd Edn. London: Sage.

Skar, R. N. L. (2003). Peer and Adult Relationships of Adolescents with Disabilities. *Journal of Adolescence.* Vol. 26, (6), pp. 636-649.

Skinner, J. (2006). *A Guide for Tutors.* Learning Differences Centre, University of Southampton. [Online].
Available: <www.dyslexia.soton.ac.uk>
[Accessed 7 January 2007].

Smith, C. P. (1992). Reliability Issues. In C. P. Smith, J. W. Atkinson, D. C. McClelland, J. Veroff (Eds.). *Motivation and Personality: Handbook of Thematic Content Analysis.* New York: Cambridge University Press. Pp.393-400.

Smith, M. (2010). Lecturers Attitudes to Inclusive Teaching Practice at a UK University: Will Staff "Resistance" Hinder Implementation? *Tertiary Education and Management.* Vol. 16, (3), pp.211-227. [Online].
Available:<http://www.informaworld.com> [Accessed 20 October 2010].

So, H. J., Brush, T. (2008). Student Perceptions of Collaborative Learning, Social Presence and Satisfaction in a Blended Learning Environment: Relationships and Critical Factors. *Computers and Education.* Vol. 51, (1), pp.318-336.

Söder, M. (2009). Tensions, Perspectives and Themes in Disability Studies. *Scandinavian Journal of Disability Research*. Vol. 11, (2), pp.67-81. [Online].
Available:<http://pdfserve.informaworld.com> [Accessed 7 January 2009].

Stanley, H. (2003). The Journey to Becoming a Graduate Nurse: A Study of the Lived Experience of Part-Time Post-Registration Students. *Nurse Education in Practice*. Vol. 3, (2), pp.62-71.

Stanley, N., Manthorpe, J. (Eds.). (2002). *Student Mental Health Needs: Problems and Responses*. London: Jessica Kingsley.

Stanley, N, Ridley, J, Manthorpe, J, Harris, J, Hurst, A. (2007). *Disclosing Disability: Disabled Students and Practitioners in Social Work, Nursing and Teaching: A Research Study to Inform the Disability Rights Commissions Formal Investigation into Fitness Standards.* [Online].
Available:<http://www.leeds.ac.uk/disability-studies/archive/Hurst%20Alan/DiscolsingDisabilityReport07.pdf> [Accessed 20 October 2010].

Steele, R., Lauder, W., Caperchione, C., Anastasi, J. (2005). An Exploratory Study of the Concerns of Mature Access to Nursing Students and the Coping Strategies Used to Manage these Adverse Experiences. *Nurse Education Today*. Vol. 25, (7), pp.573-581.

Steier, F. (1991). *Research and Reflexivity*. London: Sage.

Steinfield, C., Ellison, N., Lampe, C. (2008). Online Social Network Use, Self-Esteem, and Social Capital: A Longitudinal Analysis. *Journal of Applied Developmental Psychology*. Article in Press, Uncorrected Proof. [Online].
Available from: Science Direct <http://www.sciencedirect.com> [Accessed 28 July 2008].

Stewart-Brown, S., Evans, J., Patterson, S., Doll, H., Balding, J., Regis, D. (2000). The Health of Students in Institutes of Higher Education: An Important and Neglected Public Health Problem? *Journal of Public Health Medicine*. Vol. 22 (4), pp.492-499.

Stinson, M. S., Kluwin, T. (1996). Social Orientation toward Deaf and hearing Peers among Deaf Adolescents in Local Public Schools. In P. Higgins, J. Nash (Eds.). *Understanding Deafness Socially.* Springfield: Charles, C. Thomas. Pp.191-202.

Stinson, M. S., Walter, G. G. (1992). Persistence in College. In S. B. Foster and G. G. Walter (Eds.). *Deaf Students in Postsecondary Education.* New York: Routledge. Pp.43-64.

Stinson, M. S., Whitmore, K. (1992). Students' Views of their Social relationships. In T. N. Kluwin, D. F. Moores, M. G. Gaustad (Eds.). *Towards Effective Public School Programs for Deaf Students: Context Process and Outcomes*. New York: Teachers College Press. Pp.149-174.

Stone, A. (2004). *Blended Learning, Mobility and Retention: Supporting First-Year University Students with Appropriate Technology. Proceedings of MLEARN 2004: Mobile Learning Anytime Everywhere*. London, UK: Learning and Skills Development Agency. Pp.183-186.

Stone, A. A., Shiffman, S. S., Schwartz, J. E., Broderick, J. B., Hufford, M. R. (2003). Patient Compliance with Paper and Electronic Diaries. *Controlled Clinical Trials*. Vol. 24, pp.182-199.
Stone, D. A. (1985). *The Disabled State*. Basingstoke: Macmillan.

Sullivan, A. (1998). *Love Undetectable: Notes on Friendship, Sex, and Survival*. New York: Alfred A. Knopf.

Swain, J., French, S., Barnes, C., Thomas, C. (Eds.). (2004). *Disabling Barriers – Enabling Environments*. London: Sage.

Swain, J., French, S., Cameron, C. (Eds.). (2003). *Controversial Issues in a Disabling Society*. Buckinghamshire: Open University Press.

Symon, G. (2004). Qualitative Research Diaries. In C. Cassell, G. Symon. (Eds.). *Essential Guide to Qualitative Methods in Organizational Research*. London: Sage. Pp.98-113.

Taylor, G. (1996). A Sense of Real Achievement? The Experience of Deaf Students in Social Work and Youth and Community Work Training. *Social Work Education*. Vol. 15, (1), pp.46-74. [Online]. Available:<http://docserver.ingentaconnect.com/deliver/connect/routl edg/02615479/v15n1/s5.pdf?expires=1253281986&id=52099173&titl eid=712&accname=University+of+Huddersfield&checksum=1D8A3F 1C4A12F963FBE7A31A50D61E28> [Accessed 18 September 2009].

Taylor, G., Palfreman-Kay, J. M. (2000). Helping Each Other: Relations Between Disabled and Non-disabled Students on Access Programmes. *Journal of Further and Higher Education*. Vol. 24, (1), pp.39-53.

Temple, B., Young, A. (2004). Qualitative Research and Translation. *Qualitative Research*. Vol. 4, (2), pp.161-178.

Thibaut, J. W., Kelley, H. H. (1959). *The Social Psychology of Groups*. New York: John Wiley and Sons.

Thomas, C. (1999). *Female Forms: Experiencing and Understanding Disability*. Buckingham: Open University Press.

Thomas, C. (2001). Feminism and Disability: The Theoretical and Political Significance of the Personal and the Experiential. In L. Barton (Ed.). *Disability Politics and the Struggle for Change*. London: David Fulton. Pp.48-58.

Thomas, C. (2004). How is Disability Understood? *Disability and Society*. Vol. 19, (6), pp.569-583.

Tinto, V. (1987). *Leaving College: Rethinking the Causes and Cures of Student Attrition*. Chicago: University of Chicago Press.

Tomlinson, S. (1982). *The Sociology of Special Education*. London: Routledge and Kegan Paul.

Triandis, H. C. (1988). Collectivism vs. Individualism: A Reconceptualization of a Basic Concept in Cross-Cultural Psychology. In G. Verma, C. Bagley (Eds.). *Cross-Cultural Studies of Personality, Attitudes and Cognition*. London: MacMillan. Pp.60-95.

Tronto, J. (1993) *Moral Boundaries: A Political Argument for an Ethic of Care*. London: Routledge.

Tweedal, C. B. (2000). *Retention in Accelerated Degree-Completion Program.* Long Beach, CA: Adult Higher Education Alliance.

Ueno, K. (2005). The Effects of Friendship Networks on Adolescent Depressive Symptoms. *Social Science Research*. Vol. 34, pp.484-510.

Union of the Physically Impaired Against Segregation. (1976). *Fundamental Principles of Disability*. London: Union of the Physically Impaired Against Segregation.

Valentine, G., Skelton, T., Levy, P. (2006). *The Role of the Internet in Deaf/deaf Peoples Inclusion in the Information Society*. Arts & Humanities Research Council. [Online].
Available:<http://www.geog.leeds.ac.uk/projects/deafweb/>
[Accessed 20 January 2008].

Välimäki T., Vehviläinen-Julkunen K., Pietilä A. M. (2007). Diaries as Research Data in a Study on Family Caregivers of People with Alzheimer's Disease: Methodological Issues. *Journal of Advanced Nursing.* Vol. 59, (1), pp. 68-76.

van de Ven, L. Post, M., de Witte, L., Heuvel, W. (2005). It Takes two to Tango: The Integration of People with Disabilities into Society. *Disability and Society*. Vol. 20, (3), pp.311-329.

Velikova, G., Wright, E. P., Smith, A. B., Cull, A., Gould, A., Forman, D. (1999). Automated Collection of Quality-of-Life data: A Comparison of Paper and Computer Touch-screen Questionnaires. *Journal of Clinical Oncology*. Vol. 17, pp.998-1007.

Verbrugge, L. M. (1980). Health Diaries. *Medical Care*. Vol. 18, pp.73-95.

Vislie, L. (2003). From Integration to Inclusion: Focusing Global Trends and Changes in the Western European Societies. *European Journal of Special Needs Education*. Vol. 18, (1), pp.17-35.

von Kardorff, E. (2004). Qualitative Evaluation Research. In U. Flick, E. von Kardorff, I. Steinke. (Eds.). *A Companion to Qualitative Research*. London: Sage. Pp.137-142.

Walker, M. E., Wasserman S., Wellman, B. (1994). Statistical Models for Social Support Networks. In S. Wasserman J. Galaskiewicz. (Eds.). *Advances in Social Network Analysis: Research in the Social and Behavioural Sciences*. London: Sage. Pp.53–78.

Walker, M. U. (1998). *Moral Understandings: A Feminist Study in Ethics*. New York: Routledge.

Walker, R., Cooke, M., McAllister, M. (2008). The Meaningful Experiences of Being an RN Buddy. *Nurse Education Today*. Vol. 28, (6), pp.760-767. [Online].
Available from: Science Direct <http://www.sciencedirect.com> [Accessed 20 August 2009].

Walther, J. B., D'Addario, K. P. (2001). The Impacts of Emoticons on Message Interpretation in Computer-Mediated Communication. *Social Science Computer Review*. Vol. 19, (3), pp.324-347. [Online].
Available:<http://ssc.sagepub.com/cgi/content/abstract/19/3/324> [Accessed 22 December 2008].

Warnock, M. (2005). *Special Educational Needs: A New Look*. London. Philosophy of Education Society of Great Britain.

Warnock Report. (1978). *Special Educational Needs: Report of the Committee of Enquiry into the Education of Handicapped Children and Young People.* London. Her Majesty's Stationery Office. [Online]. Available:<http://www.educationengland.org.uk/documents/warnock/index.html> [Accessed 8 June 2010].

Wasserman, S., Faust, K. (1994). *Social Network Analysis: Methods and Applications*. Cambridge: Cambridge University Press.

Watson, C. (2006). Unreliable Narrators? Inconsistency (and some inconstancy) in Interviews. *Qualitative Research*. Vol. 6, (3), pp.367-384.

Watson, N. (2004). The Dialectics of Disability: A Social Model for the 21st Century? In C. Barnes and G. Mercer (Eds.). *Implementing the Social Model of Disability: Theory and Research*. Leeds: The Disability Press. Pp. 101-117.

Watson, N., McKie, L., Hughes, B., Hopkins, D., Gregory, S. (2004). (Inter)Dependence, Needs and Care: The Potential for Disability and Feminist Theorists to Develop and Emancipatory Model. *Sociology*. Vol. 38, (2), pp.331-350. [Online].
Available:<http://soc.sagepub.com/cgi/content/abrstarct/38/2/331>
[Accessed 25 November 2009].

Watson, N., Shakespeare, T., Cunningham-Burley, S., Barnes, C., Corker, M., Davis, J., Priestley, M. (1999). *Life as a Disabled Child: A Qualitative Study of Young People's Experiences and Perspectives: Final Report to the ESRC*. University of Edinburgh Department of Nursing Studies.

Weiner, E. (1999). The Meaning of Education for University Students with a Psychiatric Disability: A Grounded Theory Analysis. *Psychiatric Rehabilitation Journal*. Vol. 22, (4), pp.403-409.

Weiner, E., Wiener, J. (1996). Concerns and Needs of University Students with Psychiatric Disabilities. *Journal of Postsecondary Education and Disability*. Vol. 12, (1), pp.1-24.

Wetherell, M., Potter, J. (1992). *Mapping the Language of Racism: Discourse and the Legitimation of Exploitation*. Hemel Hempstead: Harvester Wheatsheaf.

White, G. W., Simpson, J. L., Gonda, C., Ravesloot, C., Coble, Z. (2010). Moving from Independence to Interdependence: A Conceptual Model for Better Understanding Community Participation of Centres for Independent Living. *Journal of Disability Policy Studies*. Vol. 20, (4), pp.233-240.

Wilcox, P., Winn, S., Fyvie-Gauld, M. (2005). It was Nothing to do with the University, it was Just the People: The Role of Social Support in the First-Year Experience of Higher Education. *Studies in Higher Education*. Vol. 30, (6), pp.707-722.

Williams, F. (1999). Good Enough Principles for Welfare. *Journal of Social Policy*. Vol. 28, (4), pp.667-687.

Williams, F. (2001). In and Beyond New Labour: Towards a New Political Ethics of Care. *Critical Social Policy*. Vol. 21, (4), pp.467-493.

Wilson, M. (1997). Community in the Abstract: A Political and Ethical Dilemma. In Holmes, D. (Ed.). *Virtual Politics Identity and Community in Cyberspace*. London: Sage.

Wing, L. (1988). *Aspects of Autism-Biological Research*. London: Gaskell/National Constable.

Wittgenstein, L. (1963). *Philosophical Investigations*. (G. E. M. Anscombe. Trans.). New York: Macmillan Press.

Wolfensberger, W. (1972). *The Principle of Normalisation in Human Services*. Toronto: National Institute on Mental Retardation.

Wolgast, E. H. (1987). *The Grammar of Justice*. Ithaca, N.Y: Cornell University Press.

Wood, A., Smith, M. (2005). *Online Communication: Linking Technology, Identity and Culture*. 2nd Edn. London: Lawrence Erlbaum Associates.

Wood, P. (1981). *International Classification of Impairments, Disabilities and Handicaps*. Geneva: World Health Organisation.

Woolgar, S. (1988). *Knowledge and Reflexivity*. Newbury Park, Calif.: Sage.

World Health Organisation (Quality of Life Group). (1993). *Measuring Quality of Life: The Development of the World Health Organisation's Quality of Life Instrument*. Geneva: World Health Organisation.

World Health Organisation. (2002). *Towards a Common Language for Functioning, Disability and Health ICF*: The International Classification of Functioning, Disability and Health. Geneva: World Health Organisation. [Online].
Available:<http://www.who.int/classifications/icf/site/beginners/bg.pdf > [Accessed 12 January 2008].

Wormald, J., Wormald, S. (1914). *A Guide to the Mental Deficiency Act, 1913*. London: P. S. King and Son.

Wright, B. C. (2005). Accommodating Disability in Higher Education: A Closer Look at the Evidence for a Mainstream Framework of Learning Support. *Research in Post-Compulsory Education*. Vol. 10, (1), pp.121-144.

Wright, D. L., Aquilino, W. S., Supple, A. J. (1998). A Comparison of Computerised and Paper-and-Pencil Self-Administered Questionnaires in a Survey on Smoking, Alcohol, and Drug Use. *Public Opinion Quarterly*. Vol. 62, pp.331-353.

Yee, G. (Ed.). (2006). *Privacy Protection for E-Services.* Hershey, PA, USA: Idea Group Publishing.

Zellers, D. F., Howard, V., Barcic, M. A. (2008). Faculty Mentoring Programs: Reenvisioning Rather Than Reinventing the Wheel. *Review of Educational Research*. Vol. 78, (3), pp.552-588.

Appendices

Appendix 1: ESW Recruitment Letter, Information Sheet and Consent Form

Recruitment Letter

Dear Support Worker

I am currently engaged in research funded by the Economic and Social Research Council that examines the social support networks of students with social communication difficulties.

Students with social communication difficulties are those students who receive your support and may experience problems when communicating with others, for example students with deafness/hearing impairments and/or autistic spectrum disorder. As a support worker you have a 'key' role in the support and social support networks of students with social communication difficulties, and therefore, your experience with any of the following is vital to this research; teaching for the Deaf, BSL communication, note-taking, study mentoring, library/campus support, dyslexia tuition.

To gain access to your experience I would like to undertake an interview with you (face-to-face or online over the Internet) within the next three weeks, to ask about the issues involved in supporting students with social communication difficulties. The interview is ethically approved by the University ▮▮▮▮▮▮▮▮ and will be carried out in accordance with Economic and Social Research Council guidelines.

I would be grateful if you would respond to my request, initially via email at <v.hinchcliffe@hud.ac.uk>. Subsequently, if you are agreeable, I will arrange a mutually convenient time for the interview to take place.

Yours Sincerely

Vanessa Hinchcliffe

(BSc, PGCE, MSc, MIfL)

Interview Information Sheet

Thank you very much for agreeing to take part in the interview. I am a PhD research student in the Department of Social Work at the University of Huddersfield, researching the subject of student social support networks. The aim of the interview is to gain an understanding of your experience as a non-medical support worker. I will ask you to freely describe issues you consider being an important part of your provision of support for students with social communication difficulties. You have already received a copy of the interview schedule in advance. Participation in the interview is voluntary; you have the right not to answer specific questions and to freely withdraw from the study at any stage of the research process, without giving a reason and without difficulty.

The interview is ethically approved by the University and will be carried out in accordance with Economic and Social Research Council guidelines (as set out below). The interview will be conducted online (over the Internet), saved and stored. Transcripts will be erased on completion of the study. You will not be asked to reveal your name or to identify yourself in any way and any potentially identifying information spontaneously provided will be deleted from the transcripts. Steps have been taken to ensure security but privacy cannot be totally guaranteed over a public network and you need to take responsibility in guarding your own privacy and that of family and friends by not revealing personal information unrelated to the study over the Internet.

In line with the Research Governance Framework (DOH 2001, 2003), findings will be made available to all participants and disseminated to University disability support staff and teaching staff were applicable.

The thesis will be on display in the University of Huddersfield library and may include conference papers, journal publications and reports from staff development.

Thank you very much again for your time.

Vanessa Hinchcliffe (BSc, PGCE, MSc, MIfL)
Email: <v.hinchcliffe@hud.ac.uk>

Interview Consent Form

PhD Research Student (Social Work): Vanessa Hinchcliffe
Study Title: The Role of Social Support Networks in the Retention and Progression of both Students with Deafness/Hearing Impairment and Autistic Spectrum Disorder

Thank you for agreeing to be interviewed as part of my study. Please could you answer the following questions to ensure that you are clear about the purpose of this study and that you are willing to take part.

Please circle the appropriate answer

1). Are you clear about the purpose of the study and are satisfied that you have been given the opportunity to ask about any queries you may have?

<div align="right">YES/NO</div>

2). Do you understand that participation is voluntary and you can withdraw from the study at any stage?

<div align="right">YES/NO</div>

3). Do you understand that you are free to choose not to answer a question without giving a reason why?

<div align="right">YES/NO</div>

4). Do you recognise that you need to consider your own privacy (and the privacy of your family and friends) when engaging in online discussion?

<div align="right">YES/NO</div>

5). Do you give your consent for extracts from the interview to be used in the study, which may be read by others or published later, on the condition that you will remain anonymous?

<div align="right">YES/NO</div>

I give consent to take part and for the use of my interview extracts
Signed: ……………………………………………………….
Name in Block Capitals: …………………………………………
Date: ……………………………………………………………..

Appendix 2: The Pilot Interview Guide

1). Opening questions – area of interest one: relevant experience

1a). How long have you been a support worker at the university?

1b). Please describe and relevant experience in your private or professional life

1c). Do you enjoy providing support for students with social communication difficulties at university?

Prompt
• Deafness/hearing impairments
• Autistic spectrum disorder

Probe
• Why?
• Why not?

2). Area of interest two: supportive role

2a). How does the university define your role as a support worker?

2b). What type of support does the university expect you to provide?

Prompt
• Reading?
• Scribe/amanuensis?
• Note-taking?
• Mentoring?
• Library/campus assistance?
• Communication support such as BSL, interpretation and understanding of verbal/non-verbal communication?
• Dyslexia tuition?
• Prompting?

2c). What other supportive activities might you be involved in with the students you support?

Prompt
• Group work?
• Breaks during/between lectures?
• Tutorials?
• Work-based experience/placements?
• Project work?

Probe
• Please provide an example of what this may entail

3). Area of interest three: relationship with students

3a). Please describe the relationship you have with the students you support?

Prompt
• Good/bad
• Friendly/unfriendly
• Compatible
• Difficult, strained, stressful
• Professional
• Productive

Probe
• Please provide an example of this

3b). What qualities should a good support worker have?

Probe
• How important is that quality?
• Why is that important?

3c). What qualities should a good support worker develop?

Probe
• How important is that quality?
• Why is that important?

3d). Are there any disparities between the role the university requires and your actual supportive role?

Probe
• How do you manage this?

3e). How would you, if at all, extend your supportive role?

Probe
• Please provide an example of what this may entail

3f). How do other students communicate with students with social communication difficulties?

Prompt
• Verbal communication?
• Non-verbal communication?
• Electronic text – email, mobile phone?

3g). Are you included in this?

Probe
• Please provide an example of how you manage this?

4). Area of interest four: peer support

4a). Do students with social communication difficulties receive social support from friends?

Prompt
• Academic resource sharing – books, paper/pens
• Companionship
• Appreciation of their opinions
• Emotional support

4b). Are you included in this?

Probe
• Please provide an example of this

4c). Do you think you should be included?

Probe
• Why?
• Why not?
• Please explain in more detail

5). Area of interest five: current support provision

5a). Research indicates that support should continue for students with social communication difficulties outside of lectures to encourage development of social support networks, what are your views on this?

Probe
• Why?
• Please explain in more detail
• Advantages/disadvantages?

5b). Please can you describe what you consider appropriate support should entail for students with social communication difficulties?

Prompt
• More/less support?
• Type of support?
• Strategies?
• If none, filter to closing question

6). Closing question – area of interest six: additional issues

6a). Finally, are there any issues or information related to what we have been discussing that you would like to add?

Appendix 3: The Post-Pilot Interview Guide

1). Opening questions – area of interest one: relevant experience

1a). How long have you been a support worker at the university?

1b). Please describe any relevant experience in your private or professional life

1c). *What do you find most rewarding in providing support for student with social communication difficulties?*

Prompt
• Deafness/hearing impairments
• Autistic spectrum disorder

Probe
• Why?

1d). *What do you find most challenging in providing support for student with social communication difficulties?*

Probe
• Why?

2). Area of interest two: supportive role

2a). How does the university define your role as a support worker?

2b). *Do you think that students require other forms of support that have not been recognised by the university?*

Prompt
• Reading?
• Scribe/amanuensis?
• Note-taking?
• Mentoring?
• Library/campus assistance?
• Communication support such as BSL, interpretation and understanding of verbal/non-verbal communication?
• Dyslexia tuition?
• Prompting?

Probe
• *How do you manage this?*

2c). What other supportive activities might you be involved in with the students you support?

Prompt
• Group work?
• Breaks during/between lectures?

- Tutorials?
- Work-based experience/placements?
- Project work?

Probe
- Please provide an example of what this may entail

2d). Please can you describe what you consider appropriate support should entail for students with social communication difficulties?

Prompt
- *More/less support?*
- *Type of support?*
- *Strategies?*

3). Area of interest three: relationship with students

3a). Please describe the relationship you have with *each of* the students you support *with either deafness/hearing impairments and/or autistic spectrum disorder*?

Prompt
- Good/bad
- Friendly/unfriendly
- Compatible
- Difficult, strained, stressful
- Professional
- Productive

Probe
- Please provide an example of this

3b). What qualities should a good support worker have?

Probe
- How important is that quality?
- Why is that important?

3c). *If you were paid to do so,* how would you, if at all, extend your supportive role?

Probe
- Please provide an example of what this may entail

3d). How do other students communicate with students with social communication difficulties *and vice versa?*

Prompt
- Verbal communication?
- Non-verbal communication?
- Electronic text – email, mobile phone?

3e). Are you included in this?

Probe
• Please provide an example of how you manage this?

4). Area of interest four: peer support

4a). To what extent do students with social communication difficulties receive social support from friends?

Prompt
• Academic resource sharing – books, paper/pens
• Companionship
• Appreciation of their opinions
• Emotional support

4b). Are you included in this?

Probe
• Please provide an example of this

4c). *How do you feel about this*?

Probe
• Why?
• Why not?
• Please explain in more detail

5). Area of interest five: current support provision

5a). *Do you think students with social communication difficulties would like more support?*

Prompt
• *Socially*

5b). Research indicates that support should continue for students with social communication difficulties outside of lectures to encourage development of social support networks, what are your views on this?

Probe
• Why?
• Please explain in more detail
• Advantages/disadvantages?

6). Closing question – area of interest six: additional issues

6a). Finally, are there any issues or information related to what we have been discussing that you would like to add?

Appendix 4: Development of the Templates

The Initial Template Construction

The initial template, as set out below in Figure 12 consisted of six higher-order codes, 'Relevant Experience' (1), 'Supportive Roles' (2), 'Relationship with Students' (3) 'Peer Support' (4) and 'Current Support Provision' (5) and 'Additional Issues' (6) covering the central issues of the analysis. This type of hierarchical coding allows for broad higher-order codes that depict the general direction of the interviews and detailed lower-order codes that provide more description. The transcripts were re-read with an eye to how the data 'fit' into these higher-order codes and thus similar data were clustered accordingly to form lower-order codes as set out in Figure 12 below. The higher-order codes were sub-divided to reflect more detailed description at second, third, fourth, fifth, sixth and seventh levels of analysis (see King, 2004). The extent of this sub-division broadly reflects depth of analysis. For clarity purposes, tabular coding levels hereafter will be referred to numerically, with the highest being one.

1 RELEVANT EXPERIENCE
1.1 Personal experience
1.1.1 Confidence
1.1.2 Accepting
1.2 Professional experience
1.2.1 Good academic support
1.2.1.1 Student/ESW satisfaction
1.2.1.2 Student/ESW confidence
1.2.2 Poor academic support
1.2.2.1 Student/ESW dissatisfaction
1.2.2.2 Student/ESW low confidence
1.2.3 Type of experience
1.2.3.1 Formal ESW support
1.2.3.1.1 Signer
1.2.3.1.2 Academic mentor
1.2.3.1.3 Note-taker
1.2.3.2 Informal peer support
1.2.3.2.1 Peer mentoring
1.2.3.2.1.1 Commitment
1.2.3.2.1.2 Mentor frustration
1.3 Barriers to support
1.3.1 Communication skills
1.3.1.1 Building rapport
1.3.1.2 Student/ESW isolation
1.3.1.3 Quality of provision
1.3.1.3.1 Advice
1.3.1.3.2 Understanding
1.3.2 Access to resources
1.3.2.1 Formal ESW support
1.3.2.2 Informal peer support
1.3.2.3 Extracurricular activities
1.3.2.4 Staff training
1.3.3 Age differences
1.3.3.1 Power imbalances
1.3.3.2 Competence
1.3.3.3 Confidence
1.3.3.4 Peer interaction
1.3.3.5 Dependency
1.4 Communication responsibility
1.4.1 Conception of difference
2 SUPPORTIVE ROLES
2.1 Role conflict
2.1.1 Formal ESW academic support
2.1.1.1 Hierarchy of role responsibility
2.1.1.1.1 Teacher of the deaf
2.1.1.1. 2 BSL communicator
2.1.1.1.3 Mentor
2.1.1.1.4 Amanuensis

2.1.1.1.5 Note-taker
2.1.1.1.6 Library/campus support
2.1.1.2 Positive role recognition
2.1.1.2.1 ESW respect
2.1.1.2.2 Professional identity
2.1.1.2.2 1 Status
2.1.1.2.2.2 Power
2.1.1.3 Negative role recognition
2.1.1.3.1 Student disclosure
2.1.1.3.1.1 Stigma
2.1.1.3.1.2 Unrelatedness
2.1.1.3.1.3 Nonacceptance
2.1.1.3.1.4 Low confidence
2.1.1.3.1.5 Dependency
2.1.1.4 Hierarchy of role priorities
2.1.1.4.1 Academic support
2.1.1.4.2 Quality of support
2.1.1.4.3 Student holistic need
2.1.1.4.3.1 Personal need
2.1.1.4.3.2 Independence
2.1.1.4.3.3 Autonomy
2.1.2 Informal ESW academic support
2.1.2.1 On campus
2.1.2.1.1 Café lunch/coffee
2.1.2.1.1.1 Advice
2.1.2.2 Off campus
2.1.2.2.1 Pub lunch/drinks
2.1.3 Casual peer mentoring
2.1.3.1 Similar age peer friendships
2.1.3.2 Informal academic discussion
2.1.3.3 Sharing experience
2.1.3.3.1 Less challenged
2.1.4 Withdrawn student support
2.1.4.1 Peer mentoring
2.1.4.1.1 Financial
2.1.4.1.2 Human resources
2.2 Appropriate support
2.2.1 Communication skills
2.2.1.1 Signing/translating
2.2.1.2 Writing/note-taking
2.2.1.3 Non-verbal
2.2.1.3.1 Mutual rapport
2.2.2 Personal support
2.2.2.1 Settling in
2.2.2.2 Access to information
2.2.2.2.1 Medical care
2.2.2.2.2 Uni support system
2.2.2.2.3 DSA allowance
2.2.2.2.4 Entitlements

2.2.2.2.5 Peer mentoring
2.2.2.3 Student referral
2.2.2.3.1 Disability office
2.2.2.3.1.1 Anxiety
2.2.2.3.2 Academic staff
2.2.2.3.2.1 Academic issues
2.2.3 Role extension
2.2.3.1 SCD integration
2.2.3.1.1 ESW discretion
2.2.3.1.2 Contact with academic staff
2.2.3.1.3 Experiential training
2.2.3.1.3.1 BSL communication
2.2.3.1.3.2 Understanding SCD
2.2.3.1.3.3 Coping strategies
3 RELATIONSHIP WITH STUDENTS
3.1 Attachment
3.1.1 BSL communicator
3.1.2 Friends
3.1.2.1 ESW exclusion
3.1.2.1.1 Awkward
3.1.2.1.2 Role confusion
3.1.2.1.2.1 Distance
3.1.2.1.2.2 Time constraints
3.1.2.1.2.3 Poor rapport
3.1.2.1.2.4 Poor support
3.1.3 ESW pseudo friendships
3.1.3.1 Lunch with students
3.1.3.1.1 Good supportive advice
3.1.3.1.2 Enhances wellbeing
3.1.3.1.2.1 Psychological
3.1.3.1.2.2 Emotional
3.1.3.1.2.3 Understanding
3.1.3.1.2.4 Cultural diversity
3.2 Building rapport
3.2.1 Benefits of ESW rapport with management and lecturers
3.2.1.1 Advice/guidance
3.2.1.2 Information
3.2.1.3 Acquiring lectures notes
3.2.2 Benefits of ESW rapport with students
3.2.2.1 Opening support channels
3.2.2.1.1 Resources
3.2.2.1.2 Information
3.2.2.1.3 Academic integration
3.2.2.1.3.1 Increases confidence
3.2.2.1.3.2 Increases participation
3.2.2.1.4 Student preferences
3.2.2.1.4.1 Professional distance/discretion

3.3 Peer relationships
3.3.1 Close friendships
3.3.1.1 In-depth communication
3.3.2 Acquaintances
3.3.2.1 Brief communication
3.3.2.1.1 Mediation from friends
3.3.2.1.1.1 Peer convenience
3.3.2.1.1.2 Enhances friends confidence
3.3.2.1.1.3 ESW guilt
3.3.2.1.1.3.1 Student unimportant
3.3.2.1.1.3.2 Less responsibility
4 PEER SUPPORT
4.1 Limited support
4.1.1 Stifling
4.1.2 Loud
4.1.3 Seating positions
4.1.3.1 Signers
4.1.4 Polite acknowledgement
4.2 ESW not included
4.2.1 Concentrate on support provision
5. CURRENT SUPPORT PROVISION
5.1 Formal networking support
5.1.1 Formal communication
5.1.1.1 Involving ESW
5.1.1.2 Asking questions in lectures
5.1.2 Individual need
5.1.2.1 Unwelcome attention
5.1.2.2 Peer jealousy
5.1.2.2.1 Disappointment
5.1.3 Self-help skills
5.1.3.1 Gaining peer trust
5.1.3.1.1 Studying
5.1.3.1.1.1 Knowledge dissemination
5.2 Informal networking support
5.2.1 Negative consequences
5.2.1.1 ESW age differences
5.2.1.1.1 Powerless
5.2.1.1.2 Incapable
5.2.1.1.3 Unconfident
5.2.1.1.4 Reliant
5.2.2 Positive consequences
5.2.2.1 Increased social skills
5.2.2.1.1 Independence
5.2.2.1.1.1 Peer interaction
5.2.2.1.1.2 Establishing friendships
5.2.2.1.1.2.1 Student less stressed
6 ADDITIONAL ISSUES
None at present

Figure 12: Initial Template for ESW Views of their Current Role in the Contribution of Establishment and Maintenance of Social Support Networks of Students with SCD

The Intermediate Template Construction

As can be seen in Figure 13 below, two higher–order codes emerged from the clustering of codes from the initial template (see Figure 12 above); 'Formal Academic Support' (1) comprised general formal support activities and 'Informal Personal Support' (2) comprised any support activities outside of formal academic support, as set out below.

Formal Academic Support

The researcher established that there was too much similar content between the codes 'Barriers to support' (1.3) and 'Appropriate support' (2.2) (see initial template, Figure 12 above). They both comprised, at various levels, similar detail of 'Communication skills' (2.2.1) pertinent to formal academic support. As such, they were considered too similar to remain apart. These two codes were thus clustered to create 'Professional' (1.1.1) experience (see Figure 13: below). The remaining individual lower-order codes that detailed description of this newly created 'Professional' (1.1.1) experience were clustered accordingly; consequently 'Support skills' (1.1.1.1) was created to index these changes (see Figure 13: below).

Distinct content evidenced at various levels within 'Relationships with students' (3) in the initial template (see p.465) were also clustered in the intermediate template to prevent overlap. This clustering formed a newly created code 'Qualifications' (1.2.2.1), subsumed under 'Working flexibly' (1.2.2), because it became apparent that this was a distinctive issue evident within content of various individual codes (see Figure 13 below).

Informal Personal Support

After the clustering and re-organisation of the higher-order code 'Formal Academic Support' (1) a number of codes had been displaced within the initial template. Their content (words/phrases with similar connotation) was re-examined and aligned with a new higher-order code 'Informal Personal Support' (2), see Figure 13 below. Beneath this, content was re-organised into appropriate newly created codes 'ESW non-prescribed support' (2.1), 'Peer support' (2.2) and 'Peer mentoring' (2.3) and subsequently, lower-order codes that allowed more detailed indexing of the content were clustered accordingly under each new code.

The above coding is shown in an integrated manner in Figure 13 below.

1 Formal Academic Support

1.1 RELEVANT EXPERIENCE

1.1.1 Professional
1.1.1.1 *Support skills*
1.1.1.1.1 Good support skills
1.1.1.1.1.1 Good communication
1.1.1.1.1.1.1 Establishes rapport
1.1.1.1.1.1.2 Opens support channels
1.1.1.1.1.1.2.1 Access to resources
1.1.1.1.1.1.2.2 Access to information
1.1.1.1.1.1.2.3 Access to Disability Office
1.1.1.1.1.1.2.4 Access to academic staff
1.1.1.1.1.1.2.4.1 Mutual satisfaction
1.1.1.1.1.1.2.4.2 Mutual confidence
1.1.1.1.1.1.2.4.3 Academic integration
1.1.1.1.2 Poor support skills
1.1.1.1.2.1 Poor communication
1.1.1.1.2.2 Difficulties establishing rapport
1.1.1.1.2.3 Closes support channels
1.1.1.1.2.3.1 Mutual dissatisfaction
1.1.1.1.2.3.2 Mutual low confidence
1.1.1.1.2.3.3 Mutual isolation
1.1.2 Personal
1.1.2.1 *Confidence with students*
1.1.2.2 *Acceptance of difference*

1.2 PRESCRIBED ROLE
1.2.1 Support priorities and boundaries
1.2.1.1 *Formal support*
1.2.1.1.1 Overt support
1.2.1.1.1.1 Positive consequences
1.2.1.1.1.1.1 ESW respect
1.2.1.1.1.1.2 Professional identity

1.2.1.1.1.1.2.1 Status
1.2.1.1.1.1.2.2 Power
1.2.1.1.1.2 Negative consequences
1.2.1.1.1.2.1 Disclosure of SCD
1.2.1.1.1.2.1.1 Student stigma
1.2.1.1.1.2.1.2 Student non-acceptance
1.2.1.1.1.2.1.3 Student unrelatedness
1.2.1.1.1.2.1.4 Student low confidence
1.2.1.1.1.2.1.5 Student dependency on ESW
1.2.1.1.1.2.1 6 Peer jealousy
1.2.1.1.1.2.1.7 Peer distrust in student ability
1.2.1.1.2 Covert support
1.2.1.1.2.1 Peer integration
1.2.1.2 *Quality of support*
1.2.1.2.1 Standardised training
1.2.1.2.2 Understanding SCD
1.2.1.2.3 Support coping strategies
1.2.1.3 *Personal support*
1.2.1.3.1 Student referral
1.2.1.3.1.1 Disability Office
1.2.1.3.1.2 Academic staff
1.2.2 Working flexibly
1.2.2.1 *Qualifications*
1.2.2.1.1 ESW exclusion
1.2.2.1.2 Role confusion
1.2.2.1.2.1 Awkward
1.2.2.1.2.2 Distanced
1.2.2.1.2.3 Time constraints
1.2.2.1.2.4 Poor rapport
1.2.2.1.2.5 Poor support

2 Informal Personal Support

2.1 ESW NON-PRESCRIBED SUPPORT

2.1.1 Extracurricular activities
2.1.1.1 *Positive consequence*
2.1.1.1.1 Enhances student settling in
2.1.1.1.2 Access to personal information
2.1.1.1.2.1 Medical care
2.1.1.1.2.2 Uni support system
2.1.1.1.2.3 DSA allowance
2.1.1.1.2.4 Entitlements
2.1.1.1.3 Access to additional advice
2.1.1.1.3.1 Enhances student wellbeing
2.1.1.1.3.1.1 Psychological
2.1.1.1.3.1.2 Emotional
2.1.1.1.3.1.3 Understanding
2.1.1.1.3.1.4 Cultural diversity
2.1.1.1.3.2 Increases student social skills
2.1.1.1.3.3 Opportunities to encourage peer interaction
2.1.1.1.3.4 Independence
2.1.1.2 *Negative consequence*
2.1.1.2.1 Age differences
2.1.1.2.1.1 Power imbalances
2.1.1.2.1.2 Student inadequacy
2.1.1.2.1.3 Dependency

2.2 PEER SUPPORT
2.2.1 Close friendships
2.2.1.1 *In-depth communication*
2.2.1.1.1 Limited peer support
2.2.1.1.1.1 Stifling
2.2.1.1.1.2 Loud
2.2.1.1.1.3 Classroom seating positions
2.2.1.1.2 ESW not involved
2.2.1.1.2.1 Concentrate on formal support
2.2.2 Acquaintances
2.2.2.1 *Brief communication*
2.2.2.1.1 Polite acknowledgement
2.2.2.1.2 Mediated by close friends
2.2.2.1.2.1 Acquaintance convenience
2.2.2.1.2.2 Enhances close friends confidence

2.3 PEER MENTORING
2.3.1 Positive consequences of peer mentoring
2.3.1.1 *Similar aged*
2.3.1.1.1 Sharing experiences
2.3.2 Negative consequences of peer mentoring
2.3.2.1 Student commitment
2.3.2.1.1 Mentor frustration
2.3.3 Withdrawal of peer mentoring
2.3.3.1 *Human resources*
2.3.3.1.1 Financial support

Figure 13: Intermediate Template for ESW Views of their Current Role in the Contribution of Establishment and Maintenance of Social Support Networks of Students with SCD

Appendix 5: List of Codes for Each Transcript

Interview with Participant A

ESW FORMAL SUPPORT

Relevant Experience
Professional support skills
Good communication
Establishes rapport
Opens support channels
Access to resources
Access to information
Access to academic staff
Mutual satisfaction
Quality of support
Standardised training
Understanding SCD
Support coping strategies
Personal support skills
Confidence with students
Acceptance of difference
Insight into support needs

Prescribed Role
Support priorities and boundaries
Formal support
Negative consequences
Mediation of communication
Disclosure of SCD
Student stigma
Student low confidence
Student dependency on ESW
Peer jealousy
Peer distrust in student ability
Personal support
Student referral
Disability office
Academic staff
Working flexibily
Qualifications
ESW exclusion
Role confusion
Awkward
Time constraints
Poor support

INFORMAL SUPPORT

ESW Non-prescribed Role
Extracurricular activities
Positive consequences
Access to additional advice
Cultural diversity
Increases student social skills
Opportunities to encourage peer
interaction
Independence
Negative consequences
Age differences
Power imbalances
Student inadequacy
Dependency
Professional boundaries
Intrusion into personal lives

Peer Support
Close friendships
In-depth communication
Stifling
Classroom seating positions
ESW not involved
Concentrate on formal support
Acquaintances
Brief communication
Polite acknowledgement
Mediated by close friends
Acquaintance convenience
Enhances friend's confidence
Networking support
Individual support needs

Peer Mentoring
Similar aged

Interview with Participant B

ESW FORMAL SUPPORT	INFORMAL SUPPORT
<u>Relevant experience</u> **Professional support skills** Good communication Establishes rapport Opens support channels Mutual satisfaction Quality of support Understanding SCD **Personal support skills** Acceptance of difference Insight into support needs <u>Prescribed role</u> **Support priorities and boundaries** Student achievement Mediation of communication Personal support Student referral **Working flexibily** Time constraints	<u>Peer support</u> Individual support needs

Interview with Participant C

ESW FORMAL SUPPORT	INFORMAL SUPPORT
<u>Relevant experience</u> **Professional support skills** Good communication Access to resources Quality of support <u>Prescribed role</u> **Support priorities and boundaries** Formal support Personal support	<u>ESW non-prescribed role</u> Positive consequences Access to personal advice Medical care Uni support system DSA allowance Entitlements <u>Peer support</u> **Acquaintances** Brief communication **Networking support** Individual support needs <u>Peer mentoring</u> **Positive consequences** Similar aged Sharing experiences Encourages social integration **Negative consequences** Student commitment Mentor frustration **Withdrawal of peer mentoring** Human resources Financial support

Interview with Participant D

ESW FORMAL SUPPORT	INFORMAL SUPPORT
<u>Relevant experience</u> **Professional support skills** Good communication <u>Prescribed role</u> **Support priorities and boundaries** Formal support Positive consequences Student achievement Negative consequences Mediation of communication Personal support **Working flexibly** Qualifications Role confusion Time constraints Poor rapport	<u>ESW non-prescribed role</u> Positive consequences Access to additional advice Enhances wellbeing Opportunities to encourage peer interaction <u>Peer support</u> **Close friendships** Limited peer support ESW not involved **Networking support** Individual support needs

Interview with Participant E

ESW FORMAL SUPPORT	INFORMAL SUPPORT
<u>Relevant experience</u> **Professional support skills** Good communication Opens support channels Mutual satisfaction Academic integration Quality of support Standardised training Understanding SCD Support coping strategies **Personal support skills** Acceptance of difference Insight into support needs <u>Prescribed role</u> **Support priorities and boundaries** Formal support Positive consequences Student achievement Negative consequences Mediation of communication Disclosure of SCD **Working flexibly** Qualifications ESW exclusion Role confusion Awkward Distanced Time constraints	<u>ESW non-prescribed role</u> **Extracurricular activities** Positive consequences Enhances student settling in Increases student social skills Opportunities to encourage peer interaction Negative consequences Professional boundaries Intrusion into personal lives <u>Peer support</u> **Close friendships** Limited peer support ESW not involved Concentrate on formal support **Acquaintances** Brief communication Polite acknowledgement Acquaintance convenience **Networking support** Individual support needs

Interview with Participant F

ESW FORMAL SUPPORT

Relevant experience
Personal support skills
Acceptance of difference
Insight into support needs

Prescribed role
Support priorities and boundaries
Formal support
Positive consequences
Student achievement
Negative consequences
Student unrelatedness
Personal support
Student referral

INFORMAL SUPPORT

ESW non-prescribed role
Extracurricular activities
Positive consequences
Enhances student settling in
Access to additional advice
Enhances student well being
Psychological
Emotional
Increases student social skills
Opportunities to encourage peer
  interaction
Independence
Negative consequences
Professional boundaries
Intrusion into personal lives

Peer support
Close friendships
Limited peer support
Acquaintances
Brief communication
Networking support
Individual support needs

Peer mentoring
Positive consequences
Sharing experiences
Encourages social integration

Interview with Participant G

ESW FORMAL SUPPORT

Relevant experience
Professional support skills
Good communication
Opens support channels
Access to resources
Access to information
Access to Disability Office
Access to academic staff
Academic integration
Quality of support
Standardised training
Understanding SCD
Support coping strategies
Personal support skill
Acceptance of difference
Insight into support needs

Prescribed role
Support priorities and boundaries
Formal support
Student achievement
Working flexibly
Qualifications

INFORMAL SUPPORT

ESW non-prescribed role
Negative consequences
Age differences
Professional boundaries

Peer support
Close friendships
In-depth communication
Networking support
Individual support needs

Peer mentoring
Positive consequences
Similar aged
Encourages social integration
Withdrawal of peer mentoring
Financial support

Interview with Participant H

ESW FORMAL SUPPORT	INFORMAL SUPPORT

ESW FORMAL SUPPORT

Relevant experience
Personal support skills
Acceptance of difference
Insight into support needs

Prescribed role
Support priorities and boundaries
Formal support
Positive consequences
Student achievement
Personal support
Student referral
Disability office

INFORMAL SUPPORT

ESW non-prescribed role
Extracurricular activities
Positive consequences
Enhances student settling in
Access to additional advice
Enhances student well being
Psychological
Emotional
Understanding
Increases student social skills
Opportunities to encourage peer
  interaction
Negative consequences
Professional boundaries
Intrusion into personal lives

Peer support
Close friendships
Limited peer support
Networking support
Individual support needs

Interview with Participant I

ESW FORMAL SUPPORT

Relevant experience
Professional support skills
Good communication
Establishes rapport
Opens support channels

Prescribed role
Support priorities and boundaries
Formal support
Positive consequences
Student achievement
Negative consequences
Mediation of communication
Personal support
Working flexibily
Qualifications
Role confusion
Time constraints

INFORMAL SUPPORT

ESW non-prescribed role
Positive consequences
Access to additional advice
Enhances wellbeing
Opportunities to encourage peer
  interaction

Peer support
Close friendships
Limited peer support
ESW not involved
Networking support
Individual support needs

Interview with Participant J

ESW FORMAL SUPPORT

Relevant experience
Professional support skills
Good communication
Opens support channels
Access to resources
Access to information
Academic integration
Quality of support
Standardised training
Understanding SCD
Personal support skill
Acceptance of difference
Insight into support needs

Prescribed role
Support priorities and boundaries
Formal support
Student achievement

INFORMAL SUPPORT

ESW non-prescribed role
Positive consequences
Enhances student settling in
Enhances student well being
Negative consequences
Age differences
Professional boundaries

Peer support
Close friendships
In-depth communication
Limited support
ESW not involved
Concentrate on formal support
Networking support
Individual support needs

Appendix 6: Student Recruitment Letter, Information Sheet and Consent Form

Recruitment Letter

Dear Student,

I am undertaking a PhD by research here at the University ███████ that examines the experience of students receiving student support services and their wider social support networks, and ultimately making recommendations to improve the support that students receive. To do this, I would like you to consider recording a short daily diary over a period of 4 weeks. This can be conveniently completed via the Internet.

This diary is intended to give me a way to record your everyday experience of academic and peer support at university. It asks you to comment on both positive and negative experiences of the time you spend with support workers, tutors, other students, friends and family, writing only the amount you feel comfortable with. This research has full ethical approval from the University with procedures in place to protect your confidentiality, and to ensure full anonymity.

Examples of the diary questions are set out below:

> Think about your day and the people you have spent time with. What has happened which has made you feel unhappy or happy about your studies?
>
> How did this make you feel?
>
> How might things have been better?

If you think you could contribute to this study, which will make recommendations to improve support and wider University practices, please email me at <v.hinchcliffe@hud.ac.uk>. I will then arrange a mutually convenient time to meet you to discuss the research further.

Thank you for considering my request.

Vanessa Hinchcliffe (BSc, PGCE, MSc, MIfL) <v.hinchcliffe@hud.ac.uk>

Dr. Viv Burr (BA, PhD, AFBPS, Reader, Director of Postgraduate Research) <v.burr@hud.ac.uk>

Diary Information Sheet

Thank you very much for agreeing to take part in the study. I am a PhD researcher in the Department of Behavioural and Social Sciences at the University of Huddersfield, exploring the subject of student social support networks. The aim of the study is to gain an understanding of your experience as a student. I will ask you to freely describe issues you consider being an important part of your experience at university in a daily diary, over a period of 4 weeks. You have already received a copy of the diary schedule in advance. Participation in the study is voluntary; you have the right not to answer specific questions and to freely withdraw from the study at any stage of the research process, without giving a reason and without difficulty.

The diary is ethically approved by the University and will be carried out in accordance with Economic and Social Research Council guidelines. A daily diary (electronic format) will be conducted online (over the Internet), saved and stored. Transcripts will be erased on completion of the study. You will not be asked to reveal your name or to identify yourself in any way and any potentially identifying information spontaneously provided will be deleted from the transcripts. Steps have been taken to ensure security but privacy cannot be totally guaranteed over a public network and you need to take responsibility in guarding your own privacy and that of family and friends by not revealing personal information unrelated to the study over the Internet.

In line with the Research Governance Framework (DOH 2001, 2003), findings will be made available to all participants and disseminated to University disability support services and teaching staff were applicable.

The thesis will be on display in the University of Huddersfield library and may include conference papers, journal publications and reports from staff development.

Thank you very much again for your time.

Vanessa Hinchcliffe (BSc, PGCE, MSc, MIfL)
Email: <v.hinchcliffe@hud.ac.uk>

Diary Consent Form

PhD Researcher: Vanessa Hinchcliffe
Study Title: The Role of Educational Support Workers and the Contribution of Social Support Networks in the Retention and Progression of University Students with Social Communication Difficulties

Thank you for agreeing to complete a daily diary as part of my study. Please could you answer the following questions to ensure that you are clear about the purpose of this study and that you are willing to take part.

Please circle the appropriate answer

1). Are you clear about the purpose of the study and are satisfied that you have been given the opportunity to ask about any queries you may have?

YES/NO

2). Do you understand that participation is voluntary and you can withdraw from the study at any stage?

YES/NO

3). Do you understand that you are free to choose not to answer a question without giving a reason why?

YES/NO

4). Do you recognise that you need to consider your own privacy (and the privacy of your family and friends) when engaging in online activity?

YES/NO

5). Do you give your consent for extracts from the diary to be used in the study, which may be read by others or published later, on the condition that you will remain anonymous?

YES/NO

I give consent to take part and for the use of my diary and interview extracts
Signed: ……………………………………………………………
Name in Block Capitals: …………………………………………
Date: ……………………………………………………………….

Appendix 7: The Pilot Diary Schedule

Research Diary Guidelines

The purpose of this diary is to give the researcher a way to see what your everyday experience of non-medical support is like at University. Please comment on anything you think will help the researcher understand non-medical student support, writing as much or as little as you feel comfortable with. For multiple instances or repeat contacts on the same day, either with the same or a different person, please record these as separate diary entries.

I am equally interested in both positive and negative experiences of the time you spend with support workers, tutors, other students, friends, family, how this makes you feel, what could have been better (i.e., advice, assistance, situation, people) and why.

To help you consider construction of your diary entries I have provided an example of the questions and types of answers that I am interested in receiving.

N.B Please do not comment on medical support

If you have any problems or need additional advice relating to the diary keeping please do not hesitate to contact the researcher: v.hinchcliffe@hud.ac.uk

Example of a Completed Diary Entry

<u>**Today is Monday 6th October 2008**</u>

1) Think about your day and the people you have spent time with, please tell me about anything that has happened, or any person, which has made you feel unhappy or happy about your studies:

I arrived early to the lecture to make sure that my support worker was there and that I had a front seat so that I could hear some of the lecture. This is not always the best place to sit because tutors tend to fire off questions at those nearest to them and most think I am a swat, my fellow students probably think this too. I felt very lonely again this morning; as usual the other students all sat behind me leaving me to sit on my own with a support worker, I should be used to this by now as people tend to distance themselves due to my deafness – it bothers some people if they are sat on my left side, as they have to constantly repeat themselves. I just want to 'fit' in and wish other students would move nearer to the front so that I do not stand out as much. This made me feel self-conscious and then I started to think that maybe I'm just being paranoid and it isn't my deafness but my personality, or that I talk too loud that puts people off. I find it difficult to mix with others and worry what people might think of me. I needed someone to discuss these feelings with and seek advice on what to do, so at the end of the lecture I asked my support worker if we could have a chat at lunchtime. They agreed and I was very grateful as I had no one else to turn to at the time and I don't want to bother my family because they would only worry about me. The advice given was very good, and helpful

2) Please tell me how this made you feel:

At first I felt very lonely, self-conscious and a little down but after talking with my support worker I felt a lot happier, less self-conscious and comforted by their advice

3) Where did this happen, time of day and duration?

It took place in the Student Union bar area; it was lunchtime and lasted about 1 hour

4) Who was involved?

Just myself and one of my support workers - there were other students around on my course but they did not come and sit with us

5) How might things have been better?

It might have been better if other students are encouraged to fill the seats at the front so that I do not stick out like a sore thumb. Discussing things with a friend may have been better because it felt awkward revealing my personal feelings to a support worker and because they were not being paid for the extra time spent with me

Today is

1) Think about your day and the people you have spent time with, please tell me about anything that has happened, or any person, which has made you feel unhappy or happy about your studies:

2) Please tell me how this made you feel:

3) Where did this happen, time of day and duration?

4) Who was involved?

5) How might things have been better?

Appendix 8: The Post-Pilot Diary Schedule

Please insert your student number

To entry the web-based diary, please click 'Proceed to Diary'

Proceed to diary

Research Diary Guidelines

The purpose of this diary is to give the researcher a way to see what your everyday experience of non-medical support is like at University. Please comment on anything you think will help the researcher understand non-medical student support, writing as much or as little as you feel comfortable with. For multiple instances or repeat contacts on the same day, either with the same or a different person, please record these as separate diary entries.

I am equally interested in both positive and negative experiences of the time you spend with:

- support workers
- tutors
- other students
- friends
- family
- Please tell me how this makes you feel
- Please tell me what could have been better and why (i.e., advice, assistance, situation, people)

If you feel you have nothing to enter on a particular day, please use the diary to explain why there will be no entry that day.

To help you consider construction of your diary entries I have provided an example of the questions and types of answers that I am interested in receiving.

N.B Please do not comment on medical support

If you have any problems or need additional advice relating to the diary keeping please do not hesitate to contact the researcher: v.hinchcliffe@hud.ac.uk

Example of a Completed Diary Entry

<u>**Today is Monday 6th October 2008**</u>

1) Think about your day and the people you have spent time with; please tell me about anything that has happened, or any person, which has made you feel unhappy or happy about your studies. Please include location, time of day, duration and who was involved:

I arrived early to the lecture to make sure that my support worker was there and that I had a front seat so that I could hear some of the lecture. This is not always the best place to sit because tutors tend to fire off questions at those nearest to them and most think I am a swat, my fellow students probably think this too. I felt very lonely again this morning; as usual the other students all sat behind me leaving me to sit on my own with a support worker, I should be used to this by now as people tend to distance themselves due to my deafness – it bothers some people if they are sat on my left side, as they have to constantly repeat themselves. I just want to 'fit' in and wish other students would move nearer to the front so that I do not stand out as much. This made me feel self-conscious and then I started to think that maybe I'm just being paranoid and it isn't my deafness but my personality, or that I talk too loud that puts people off. I find it difficult to mix with others and worry what people might think of me. I needed someone to discuss these feelings with and seek advice on what to do, so at the end of the lecture I asked my support worker if we could have a chat at lunchtime. They agreed and I was very grateful as I had no one else to turn to at the time and I don't want to bother my family because they would only worry about me. The advice given was very good, and helpful. It took place in the Student Union bar area; it was lunchtime and lasted about 1 hour. There was just myself and one of my support workers present - there were other students around on my course but they did not come and sit with us

2) Please tell me how this made you feel:

At first I felt very lonely, self-conscious and a little down but after talking with my support worker I felt a lot happier, less self-conscious and comforted by their advice

3) How might things have been better?

It might have been better if other students are encouraged to fill the seats at the front so that I do not stick out like a sore thumb. Discussing things with a friend may have been better because it felt awkward revealing my personal feelings to a support worker and because they were not being paid for the extra time spent with me

Today is

1) Think about your day and the people you have spent time with; please tell me about anything that has happened, or any person, which has made you feel unhappy or happy about your studies. Please include location, time of day, duration and who was involved:

2) Please tell me how this made you feel:

3) How might things have been better?

Appendix 9: The Web-Based Diary Exit Survey.

The web-based diary interface was used here as a revolutionary data collection technique, please can you provide comments on the following:

1. From your perspective what are the advantages of using web-based diaries?

2. From your perspective what are the disadvantages of using web-based diaries?

3. Did you find the web-based diary interface easy to use? Please explain:

4. Were you confident in using the web-based diary?

5. Were you comfortable in using the web-based diary?

6. Did the web-based diary enable you to reflect on your support experience adequately? Please explain

7. Did you enjoy using the web-based diary? Please explain

8. Was doing a regular web-based support diary beneficial? Please explain

9. Would you use a web-based diary again?

10. Did keeping a support diary change your actions? Please explain