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ALONE IN THE CROWD

HOW ADULTS WITH LEARNING DIFFICULTIES COPE WITH SOCIAL NETWORKS PROBLEMS

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ABSTRACT

The relationship between perceived social support and mental health has been the subject of a large quantitative research effort. However, quantification leads to inevitable oversimplification of multi-dimensional, intersubjective and contextual features of social support. The present paper explores qualitatively the social networks of six adults with learning difficulties (adults), selected from a sample of 32 because of the strategies which they used to manage their social worlds. Three adults, who lived with parents, attempted to sustain non-confirmed identities in the face of rejection by others. The other three adults, who were separated from their families, had adopted fatalistic attitudes, despite feeling socially isolated and unsupported. The paper argues that non-confirmed identity maintenance and fatalism are both responses to social contexts which do not support an individual's sense of self worth. The former is an attempt to manufacture positive identity in the absence of consensual alternatives. The latter involves acceptance of a social world which does not sustain valued social identities. The paper explores in detail the social contexts in which adults attempted to maintain non-confirmed identities or adopted fatalistic attitudes. The research provides a perspective on the management of behaviour defined from a frame of reference external to the individual as 'challenging' or 'problematic'. Carers saw adults who sustained non-confirmed identities as having behaviour problems. However, these problems arose from adults' attempts to maintain self-esteem in stigmatising social contexts. The fatalistic adults did not cause behaviour 'problems' for carers, but only because they had accepted lives which did not give them any sources of positive self-esteem.

KEY WORDS

Learning difficulties
Social Support
Identity maintenance
Fatalism

INTRODUCTION

'but the actors themselves positively refuse to play the wicked parts, such as those of infames Anglais, brutal Cossacks, and what not, and prefer to appear at a smaller salary, in their real characters as loyal Frenchmen.' **William Makepeace Thackeray, Vanity Fair, 1847.**

According to Thackeray, social identities have a powerful motivational force even if the roles being played are temporary and imaginary, as in a play. The present paper will discuss a qualitative exploration of the coping strategies adopted by six adults with learning difficulties (adults) who were unable to sustain positive social identities through close interpersonal relationships. The term 'adult' will be used as an abbreviated version of 'adult with learning difficulty'. Our focus will not be on adults' cognitive disabilities, but on the strategies which they employ in order to attempt to manage their social worlds.

The term 'social tie' will be used to refer to a relatively long term relationship with a significant other; 'social network' to describe the sum total of social ties maintained by an individual; and 'social support' to refer to the material, informational and emotional benefits which may, or may not, arise from social ties. As will be argued below, social ties, networks and support are both intrasubjective and intersubjective phenomena which can be analysed from the person's point of view, and from the perspectives of significant others.

The concept of social identity has been well developed in the symbolic interactionist tradition. Within this approach, the individual's sense of self worth is assumed to result from being able to play a rich set of social roles which are recognised and validated by the wider society (Thoits, 1983), and which provide both existential meaning and behavioural guidance (Thoits, 1992). Identities cannot readily be manufactured by the individual alone, but depend upon social categorisation, naming and interaction (Burke and Reitzes, 1991).

However, the individual is more than a passive receptacle for a set of roles. Reflected appraisal is central to social identity maintenance, and involves complex processes of communication and interpretation. For example, an association has been found between the subjective happiness of marriages and the extent to which couples overestimate the extent to which their partner agrees with them about the relationship (Bochner, Krueger and Chmielewski, 1982). People generally have some choice about which roles to attempt to play, although the range of options readily available to an individual depends upon their position in the social structure, and people with disabilities often experience a lack of alternatives to lives which they find unsatisfactory (Morris, 1993). Individuals have to decide how much psychological commitment to give to each of the identities associated with the roles which they play, and to integrate these identities into a coherent overall sense of self (McCall and Simmons, 1966). Role performance depends on creative interpretation since societal role definitions are mostly general and abstract, requiring role players to fill in and negotiate concrete details (Cicourel, 1973).

Because individuals have some choice over the roles which they play, and can vary role interpretation, commitment and performance, the relationship between individual psychology and social structure is a two way, dialectical one (Turner, 1988). The present paper slightly extends the standard symbolic interactionist analysis of roles, identities and self by considering what people do when they cannot establish any social identities which they value positively.

There is now an extensive body of quantitative research which suggests that positive social support is an important causal determinant of psychological well-being (Vaux, 1988). This link occurs because social support sustains individuals' identities through feedback processes involving reflected positive appraisal (Burke, 1991). In consequence, benefits do not arise just from being in parental, marital and work roles, but from the quality of experience obtained (Abbey, Abrams and Caplan, 1985; Baruch and Barnett, 1986; McLanahan and Adams 1987; Wheaton, 1990). With respect to the present paper, three issues may be raised about this work.

Firstly, 'social support' has a variety of meanings, and needs to be assessed multi-dimensionally. Distinctions have been drawn between network resources, supportive behaviour and support perceived by recipients (Turner and Marino, 1994). The concept of 'supportive behaviour' implies that supportiveness can be an intrinsic property of behaviour, but it is difficult to see how supportiveness can be defined or identified independently of participants' own judgements. Social support may be viewed through the eyes of givers or receivers, but most studies measure only the latter. Turner and Marino (1994) defend the preference for measures of support received by recipients in the research literature by citing evidence that

it is the best predictor of health outcomes. A more theoretical justification is that individuals respond to the social support which they feel that they are receiving, rather than to that which the donors perceive themselves to be giving. In this sense, an individual's social support network is 'inside' his or her head. Nevertheless, a purely intrasubjective approach fails to assess the extent to which an individual's perceptions of social support match those of significant others. Empirical studies suggest only modest levels of agreement between givers and recipients about the degree of support given (Shulman, 1976; Antonucci and Israel, 1986). Differences between adults and parents in perceptions of social support will be explored qualitatively in the case studies discussed below.

Even at the intrasubjective level, numerous dimensions of social support can be identified, including aspired level, quality, intensity, durability, frequency, stability, consistency and reciprocity. The number of types of perceived support escalates uncontrollably as more dimensions are considered. Moreover, the effects of social support may depend upon the recipient's relationship to the source (Sarason, Pierce and Sarason, 1994). The social networks described by the adults with learning difficulties involved in the present research revolved around the parental family, even in the absence of social contacts with them. The inevitable oversimplification which occurs when social support is operationalised nomothetically may explain inconsistencies in findings about whether social support benefits mental health directly as well as buffering stress effects (Flannery and Wieman, 1989). Quantitative research needs to be complemented by qualitative, idiographic studies which consider individuals' social networks holistically in relation to their intersubjective context.

A second lacuna in current research is that it focuses on pathological responses to lack of social support, for example depression, suicide, health endangering behaviours and immune system impairment, whilst ways of coping with a lack of social support have received less attention. Research has shown, for instance, that lonely adolescents are more likely than the non-lonely to engage in solitary activities when feeling lonely (Roscoe and Skomski, 1989), and that religious motivation may increase in response to loneliness, at least among the religiously inclined (Burriss, 1994). As the last authors note, such correlational studies provide only limited insight into the meaning of loneliness and other social network problems.

A third limitation of the quantitative approach is that it abstracts measured properties of relationship networks from their wider social structural contexts (Thoits, 1992). We might expect social support to have a quite different significance, for example, amid sectarian strife in Bosnia, in the impoverished, crime-ridden inner city areas of Great Britain, among the wealthy of the City of London, or for people with disabilities. Wider structural conditions for adults with learning difficulties include segregation, stigmatisation and lack of control over material resources (Chappell, 1992). Their networks cannot be understood without taking these conditions into account.

Limited social ties have long been recognised as a common condition of life for adults with learning difficulties living in western cultures (Flynn and Saleem, 1986; Richardson and Richie, 1989; Firth and Rapley, 1990; Chappell, 1994), as for other stigmatised groups such as psychiatric patients (Link et al., 1989). Individuals in group homes report less life satisfaction than those living with families, or in supervised apartments, and this difference has been statistically associated with lower levels of support, as perceived by recipients, in group homes (Burchard et al., 1992). However, some adults with learning difficulties do report that they have supportive networks (Mest, 1988).

Several related reasons why adults with learning difficulties may find it particularly difficult to develop reciprocal, supportive social ties in our culture have been suggested. Firstly, they are stigmatised in societies obsessed with individual achievement (Susman, 1994). Secondly, their lives are frequently segregated, revolving around increasingly scarce community services and the parental home (Lutfiyya, 1991). Thirdly, many adults living with family members lack personal mobility because their parents consider the wider community to be too dangerous, and find it difficult to meet friends outside an institutional setting (Heyman and Huckle 1993a; 1993b; 1995). Fourthly, adults often lack material resources which facilitate social contacts, e.g. money, access to private transport and personally owned living space (Chappell, 1992). Fifthly, some adults have problems communicating verbally, although these problems may result as much from lack of practice due to social isolation as from cognitive defects.

Low social worth, lack of self-esteem, segregation, limited personal mobility, communication problems and social isolation may mutually reinforce each other. Carers can unintentionally strengthen this vicious circle by attributing the resulting problems to the adult's disability, ignoring or taking for granted the dynamics of exclusion.

The present paper will focus on the lives of six adults with learning difficulties who were selected from a larger study because they related to their social worlds mainly in one of two ways, considered below, which we will call 'non-confirmed identity maintenance' and 'fatalism'. The term 'non-confirmed identity maintenance' will be used to refer to a complex, variable social process in which an individual maintains a role, e.g. hero, adventurer, lover, which is not validated, or is invalidated, by others. This process is thus interpersonal rather than psychological. Its identification does not depend on the researcher's judgements of the truth value of individuals' accounts of themselves, but on the responses of significant others to such accounts.

As one of the schizophrenic patients interviewed by Barham and Hayward (1991) commented:

We used to talk about philosophy basically, but if I started getting him out of his depth he'd say I was fantasising (p. 18)

Labelling life stories as fantastic implies a contrast with true stories, and divides classes of people who are considered to generate the two types. The implicit challenge to the veracity of a story labelled a fantasy may, in some cases, be justified because events depicted in the story did not take place, but the status of 'normal' true stories lies unexamined in the background. To treat fantasy as a purely psychological phenomenon is to risk reproducing the inequalities in social power which people with learning difficulties, and members of other stigmatised groups, currently have to live with. Non-confirmed identity is a relational concept which refers to the social processes by which stories become defined as possessing or lacking truth status. Our focus is on non-confirmed identity maintenance, not on resort to fantasy.

The qualitatively induced concept of fatalism corresponds to the construct of external locus of control, as used in an extensive body of quantitative research. Rotter has defined external control as the degree to which individuals expect that a personal outcome is '*a function of chance, luck or fate, is under the control of powerful others, or is simply unpredictable*' (Rotter, 1990). Fatalism is normative in some groups, e.g. among the poor in Bangladesh (Bhaduri, 1992), but not in western, achievement oriented societies (Smith and Stone, 1989), in which it violates implicit cultural assumptions, and must be invented by individuals. One reason that the concept of external control has been so popular in psychological research is that it seems to capture the reality of powerlessness for socially disadvantaged groups (Lefcourt, 1992), including people with disabilities.

Non-confirmed identity maintenance and fatalism may be related strategies for coping with social network problems. Individuals who lack identities which they value positively and which are confirmed by others may respond by inventing roles which they attempt to play in the absence of social support. This strategy is likely to lead to conflicts between the individual and significant others about that person's 'real' identity.

Fatalism may then reflect

his or her decision to stop trying to sustain any positive social identities in the face of disconfirmation from network members. Although we have represented fatalism as a discontinuation of attempts to establish a positively valued identity, it is a life strategy which has potential compensations, including inner peace, avoidance of interpersonal conflict and enhanced enjoyment of present time. Ironically, in the present study, it was the adults who tried to maintain non-confirmed identities whom carers saw as having behaviour problems.

It is unsafe to generalise from small-scale qualitative studies, or to extrapolate the findings of research with adults with learning difficulties to other stigmatised or non-stigmatised groups. However, our research may have a wider significance in illustrating the potential value of qualitative studies of social support networks. In addition, it can be justified on the grounds of concern for the welfare of people who have no social identities which they value positively, and on the grounds that it provides a useful perspective for carers who are attempting to manage 'behavioural' and mental health problems.

METHODOLOGY

A grounded theory approach was taken to data collection and analysis which were carried out concurrently, with emergent themes followed up in subsequent interviews.

In total, 32 adults were interviewed. Participants were identified through social services, day centres, advocacy groups and personal networks. Only two adults refused to participate. Where appropriate and possible, a formal carer, e.g. the key worker, and the main informal carer(s) were also interviewed. Within

the obtained sample of 32 adults were 19 men and 13 women, with an age range of 19-67 years. Nineteen adults lived with parents, six independently, four in community homes, and three in hostels or hotels. Only four adults were in full or part-time paid employment, and 25 were receiving some form of day care. The research participant names used in the paper are fictitious.

The aim of sampling was not to achieve representativeness, as in a quantitative paradigm, but to explore the perspectives of people with learning difficulties living in a variety of conditions through individual case studies. The only common criterion for entry into the sample was possession of some verbal communication ability, however limited. Interviewers identified members of the sample through personal knowledge, invitations to participate, or by asking professionals to identify cases on the basis of criteria specified by the researchers. For example, the criteria for selecting two adults from day centres were that professionals believed that they had personal problems, and that, unlike other members of the sample, they were not involved in advocacy groups.

This qualitative sampling strategy was based on maximum variation and theoretical sampling (Kuzel, 1992). Initially, cases were selected to be as varied as possible in terms of living situation, service use and employment. As discussed below, theoretical sampling was then used to guide the selection of new cases, and of existing cases for more intensive analysis. No quantitative generalisations can be drawn from the research, which is concerned with what exists rather than how much.

As the research progressed, data was selected on the basis of theoretical relevance to the emerging core category of 'coping with social network problems'. This theoretical sampling was undertaken in a number of ways. Firstly, further data collection with four adults and their carers was oriented towards exploration of the core category. Secondly, the existing data set was examined for cases which illustrated the key sub-categories of non-confirmed identity maintenance and fatalism. The discovery of two new examples, one illustrating non-confirmed identity maintenance (Anne), and the other fatalism (David), provided supporting evidence for the validity of the emerging theory. Thirdly, towards the end of the data collection period, the contrasting case of Michael, illustrating identity confirmation based on support from a limited social network, was selected for investigation in depth.

Qualitative interviews were undertaken by four interviewers with individuals in confidential settings, including their homes, The University and the day centres or community bases which the adults attended. Interviews, which were taped and fully transcribed, covered leisure, daytime activities, home life, mobility and personal relationships. They were non-standard and conducted over one to seven sessions, depending upon the quality of data which was being obtained, and the willingness of adults to participate.

The methodology contained some innovations intended to facilitate the flow of information. These included: talking about adults' own photo albums; asking them to discuss photographs which they took with a disposable camera supplied by the researchers; use of the *Just About Me* game which invites the adult and the interviewer to talk in response to open ended cards, with messages such as '*I feel sad when -*'; and use of the *People I Know* diagram, a series of concentric circles with a heart at the centre, to map how close the adult felt to significant others.

DATA ANALYSIS

The results will be presented in four sections. The first will briefly outline the case study of Michael in order to illustrate the ways in which adults with learning difficulties can maintain a positive sense of self based on identities derived from a limited social network. The other three sections will focus on the lives of six adults, three of whom maintained non-confirmed identities, and three of whom had become fatalistic. The first of these sections will consider adults' perceptions of their social worlds, and will, where possible, compare their perspectives with those of significant others. The second will discuss adults' use of non-confirmed identity maintenance and fatalism as strategies for coping with these social worlds. The final section will analyse the implications of these coping strategies for adults' wider, non-family, social networks. In each section, data on adults who maintained non-confirmed identities will be presented first, followed by data on those who had become fatalistic. Two case studies, of Peter and William, illustrating non-confirmed identity maintenance and fatalism respectively will be discussed in more detail.

The three adults who sustained non-confirmed identities all lived with parents, whilst the other three, who had adopted fatalistic attitudes, lived independently. This pattern of results can be explained on the assumption that the six adults all had difficulty in maintaining valued social identities, but that the problems

were less severe for the adults living with parents, who had troubled close relationships, than for those living independently, who had none. It is not being argued that having troubled close relationships is necessarily better than having none, only that this was the case for these particular individuals.

The data presented below does not provide direct evidence to support the hypothesis that fatalism, for these adults, was based on a decision to discontinue efforts to establish satisfying social identities. However, we will discuss the suggestive life story of William who appears to have responded to overwhelming family rejection by becoming fatalistic, a shift associated, from a medical perspective, with 'recovery' from schizophrenia; of Peter who represented himself as an adventurer but, at the end of the data collection period, was considering acceptance of life in a day centre as the only option open to him; and of Tim who, at the end of the study period, had almost given up hope of finding a girlfriend.

Coping with a Limited Social Network: The Case of Michael

Individual subjective social networks, in their intersubjective social context, have unique emergent properties, and it is, therefore, not possible to specify a 'typical' social network which did enable adults with learning difficulties to maintain social identities which they valued positively. Nevertheless, the following brief case study illustrates the way in which the other 26 adults included in the study were able to build a positive sense of self based on very limited social networks, despite severe restraints on their autonomy.

Michael lived with his elderly, widowed mother. She sent a note to his first interview, introducing him, and expressing pride at his achievements. At her own interview, she said that she was pleased that Michael lived with her, and that, as a result, she had not had to live alone after her husband had died. His sister would look after Michael when she died. Michael, whose speech was limited, attended a day centre, but did not have any relationships with other service users. He had one friend with learning difficulties, whom he saw weekly, and attended cubs and church. He enjoyed going on holiday with his mother once a year, the source of many of the photographs in his album.

There was evidence of some tension between Michael and his mother. He felt that she stopped him from doing many things because she worried about him unnecessarily. For example, he had been to the coast on his own, by public transport. He was confident that he could manage the trip, but had decided not to go again, even though he would have liked to, because he did not want his mother to become anxious. Michael's mother understood this, but felt too worried to allow him to make further journeys on his own. The example illustrates the everyday powerlessness of adults with learning difficulties, and the way in which risk avoidance could reduce their autonomy (Heyman and Huckle, 1993a; 1993b; 1995). It also shows that Michael, despite severe cognitive disability, could recognise and manage a difference in perspective between himself and another person. His mother wanted him to spend more time in his own room, so that she could have more privacy. Michael was aware of this, and expressed some resentment which his mother recognised. According to Michael's mother, he would frequently characterise her decisions as '*not fair*'.

Michael did not put his mother in the closest circle in the '*People I Know*' diagram and showed clear signs of loneliness in the interviews. For example, he expressed strong disappointment that he had not been able to renew contact with a local child whom he had met whilst away on holiday, and was reluctant to end the research interviews. Nevertheless, he did not, to our knowledge, maintain a non-confirmed identity, and was not fatalistic about the future, since he continued to seek new social relationships, and was prepared to challenge his mother, although from a position of powerlessness.

Features of his social world which may have helped Michael to maintain positive social identities included his mother's orientation towards achievement rather than disability; her inclusion of Michael as a major positive element in her own social network; and good mutual understanding of the other's perspective, particularly in areas of disagreement.

The Family Backgrounds of Adults who had Social Identity Problems

The six adults whose stories we will now discuss had been affected by a variety of family difficulties including marital breakdown, parental death and personal rejection. Our main concern is not with these difficulties themselves, but with their meaning for the adults and other family members.

Three adults lived with their families and, as will be argued in the next section, maintained non-confirmed identities. Their accounts of their lives, and those given by family members, revealed a variety of interpersonal conflicts. In brief, Tim avoided his father, although the latter described their relationship positively. Anne was upset by family disputes. Peter had problems in his relationship with his father, who had divorced and re-married. His mother found him difficult to live with, and he showed signs of awareness of the problems she was having with him.

Tim lived with both parents, although at the time of the research, his father was terminally ill. He indicated that his relationship with his father was so bad that he isolated himself completely from the family, even eating meals in his room when his father was at home. In the interviews, Tim, who usually expressed himself telegraphically, using a minimum of words, said that his father *'shouts'* at him *'all the time'*. He responded by going *'upstairs'* whilst his mother went *'in the kitchen'* (kept out of the way). In consequence, he frequently felt estranged from his mother.

However, Tim's parents, interviewed jointly, presented a positive version of family relationships. His father said that he was now *'talking more. I mean, one time, it would take me hours to get owt of him, but now ... he opens up every night.'*

As with Peter, discussed below, and in contrast to Michael, Tim's parents emphasised continuous personal disability, originating in childhood, over and above his cognitive disability. His father said that Tim had been *'a loner all the time [from childhood]'* but was *'quite happy with his own company most of the time'*. Tim, however, said that he kept to himself at home in order to avoid his father, had felt unhappy for as long as he could remember, and wanted to have a girlfriend. Thus, in contrast to Michael and his mother, Tim's account of his life (perspective) did not match his parents' account of his perspective (metaperspective). Tim was unable or unwilling to recognise photographs of himself taken with the camera provided by the researchers, although he was visibly distressed by them, and readily identified pictures of others, a disturbing reflection of the negativity of his self-image. When the interviewer, at the end of the session, assured him that there was nothing wrong with his looks, he replied *'Oh, come on, [interviewer]'*, one of his least telegraphic utterances in over 10 hours of interviews.

Anne lived at home with her elderly parents. Her mother had health problems, and *'just sits on a seat and watches TV'*. Anne helped her father with domestic tasks, but felt that it was *'sad'* that he *'has to do everything'*, despite poor health. Her key worker advised the researchers not to approach the parents because of the level of family conflict. Anne got *'fed up with dad shouting. I tell him to stop, but he won't'*, and said that their pet parrot told him to stop by saying *'Shut up dad'*.

As a result of parental divorce, Peter had moved from a middle class to a socially deprived neighbourhood. The memory was still painful to him.

PETER: I don't like speaking about that house.

INTERVIEWER: Why is that?

PETER: Because my Dad had to sell it.

Peter visited his father once a week, but did not stay overnight. His mother felt that these visits were of little value because he just stayed in the house with the younger children.

Peter's accounts of the visits became more critical in later interviews. At the first interview, Peter said *'I go to museums with him [father]'*. At the fourth interview, one month later, Peter said that he did not go out with his father because he had *'lost the road tax for his car. I told him to get the tax'*. At the sixth interview, four months later, Peter complained that the visits were *'bloody awful'* because his father was *'pushing me around'*. It is possible that Peter became more frank in later interviews, or that his level of frustration had increased. In the second version, he defended his father against implied criticism with the story about a tax disk, and asserted his social power to *'tell'* his father what to do. The problematic nature of this claimed social power is seen in the third extract.

Peter lived with his mother and four year old half-sister. His mother, although expressing concern for his welfare, found the relationship stressful, and, like Tim's parents, emphasised his personal disability. The two major problems which she highlighted were, firstly, Peter's temper and destructiveness (although never violence towards people) and, secondly, his endless fantasies about stealing cars. Destructiveness, arising from brain damage, was, for her, the most salient feature of Peter's past, and was linked to the present through *'horror stories'*.

PETER'S MOTHER: ... Well, when he was younger he was very destructive ... We bought him tonka toys, thinking he couldn't break them, but he managed ...

INTERVIEWER: So, did he continue to be destructive?

PETER'S MOTHER: Yes. He still is ... My eldest daughter gave him a cassette radio which I had given her for her birthday, a long time ago ... The next thing I know, it's in bits in his room.

Peter's version of this event was that he had thrown the radio out of the window after it had caught fire. His neighbour's shed had been set alight, and he had put the fire out. He used stories in which he was the hero to sustain his self-esteem against the assaults which he frequently experienced.

During Peter's teens, his mother had felt that she could no longer cope, and he had spent a year in residential care.

INTERVIEWER: And why did you go to the Social Worker?

PETER'S MOTHER: Because he was - his temper. It was getting much worse ... Er, there must have been other reasons as well ... I was just, I was getting to breaking point.

Peter's mother thought that he had enjoyed his stay in residential care, and that it had benefitted him. However, Peter said that he had not liked being away from home, and felt bitter that his mother had sent him away. As in the case of Tim and his family, Peter's perspective about important aspects of his life contradicted his mother's metaperspective.

Although Peter's mother felt that his self-control had improved, she still saw his behaviour as highly problematic.

INTERVIEWER: What about people? Is he violent towards people.

PETER'S MOTHER: Not violent, abusive ... If someone says something to him which he doesn't like, then he'll become abusive ...

INTERVIEWER: What sort of thing does he not like?

PETER'S MOTHER: ... He takes things far too seriously. I mean, the kids round here, they call him chicken legs, and things like that, and he doesn't like it.

This account, and that of his day centre manager, suggest that Peter responded with anger to threats to his social identity.

Peter's mother could not see any prospect of future progress. Her own view of his future was fatalistic.

PETER'S MOTHER: ... I don't think about that [Peter's future]. I just think from day to day, what's happening ... It's just beyond me to think about it, cos I don't know what will happen.

She felt herself to be completely unsupported.

PETER'S MOTHER: ... It's just me ... I don't get any help from anybody ... He drives me up the wall at times ... And I keep thinking, 'Eh, I wish somebody could take him away', just for a week even, you know.

Peter did not appear, at first sight, to realise that his mother found him difficult. He located her in the first (closest) circle in the *People I Know* diagram, whilst putting his father in the outermost circle because he had divorced his mother. He treated her friends as his, in the absence of friendships of his own.

INTERVIEWER: Where did you have those cans of lager [on his birthday]?

PETER: Friends ... Mine and me mam's friend.

He saw his mother as supporting him when he had conflicts with the day centre about getting up late.

INTERVIEWER: How does your mum react to that [getting up late]?

PETER: She knows I get up in my own time.

Although Peter described his relationship with his mother in terms of friendship, he showed some awareness of her difficulty. He felt bitter that his mother had sent him into residential care. He had rescued the photographs of his childhood which his mother had thrown in the bin, and had put them in an album himself. He had tried to take a picture of his mother and (her) friends with the camera we supplied, but she had run out of the photograph.

PETER: I was standing, and I asked her ... She didn't want her photograph took, so she started moving away ... I said, 'Are you real, or what?'

The other three adults, who approached the world from a position of fatalism, had more or less lost contact with their families. In brief, David saw his father weekly, but the relationship was marred for him by conflict with his stepmother. Andrew's parents had died, and he visited his sister only once a month, despite wishing to have more contact with her. William, whose case will be discussed in more detail, had been rejected by his father when his mother died, and his attempts to re-establish relationships with him, and with his sister, had been rebuffed. In the absence of current, supportive social ties, these adults were left with memories of past family relationships.

David lived alone in a flat, and had a job. His mother had left home when he was about 10, and his father had remarried. His stepmother had, in his view, thrown him out of the house. His father had gone along with this because *'he was bad at the time, so he just agreed with everything to get ... peace and quiet'*. David was still attached to his father, whom he visited once a week, but did not get on with his stepmother, of whom he said *'we've got one thing in common. We hate each other.'*

Although David expressed a wish to live nearer to his father, he felt unable to confide in him because *'it's when I phone him, and [stepmother] is always there, anyway.'* David met his grandmother and one of his brothers regularly, but saw these relationships as mainly meeting their needs. He went to stay with his grandmother when she was worried about being alone, even if he did not want to. *'She [grandmother] rings and rings down here, so I just give in, in the end.'* His brother contacted him *'when he wants something done'*.

Andrew's parents had both died. He lived in the parental home, receiving 24 hour support from a number of formal carers between whom there was some conflict. Andrew had happy memories of life with his parents, and expressed a wish to live with his sister and her family. When asked what he liked about his sister's house, he replied *'everything'*. However, he only saw her about once a month.

William had lived at home until he was about 25. He had been much closer to his mother than to his father, and appears to have been ejected from the family home at the time of her death.

INTERVIEWER: And why did you end up in the streets.

WILLIAM: Got locked out.

INTERVIEWER: Right. How did this happen?

WILLIAM: Don't know. Door was locked when I went home.

William had lived on the streets for *'a couple of months'*, had been arrested, according to his key worker, for stealing a Mars bar, and had ended up in prison. He had gone from there to a locked hospital ward, and then to a community home which he shared with two other adults with learning difficulties.

William's sister had told his key worker that he had started to cause problems in adolescence. He had become aggressive, had begun to live in a fantasy world, and had been diagnosed as schizophrenic. William had had one close friend, a barmaid, whom he had felt protective towards. This relationship had come to an end when he went to the pub one night and tried to stab her boyfriend, saying that aliens were trying to get her. The contrast between this reported 'schizophrenia' and his later ultra-compliant fatalism, discussed in the next section, is a critical example for the thesis put forward in this paper, that non-confirmed identity maintenance and fatalism are related means of coping with interpersonal difficulties.

William felt that his present life was inferior to that which he had led with his mother because *'we had good times when I was little'*. He had attempted, largely unsuccessfully, to re-establish contact with his father and sister. William's response to this most recent rejection illustrates the theme of fatalism which will be explored in the next section.

INTERVIEWER: Would you like to see him [father] again?

WILLIAM: No. [Father is] too busy.

INTERVIEWER: How do you feel about that?

*WILLIAM: It's alright. **He cannot help it.** [Authors' emphasis]*

Coping with Family Relationship Problems

This section of the paper will discuss non-confirmed identity maintenance and fatalism as strategies which the adults used to cope with family relationship problems.

Three adults had created their own identities in contexts of family conflict. Tim and Anne lived through unreciprocated romantic relationships, whilst Peter, who will be discussed in more detail, presented himself as living a life of crime.

At the time of the interviews, Tim's inner life revolved around a woman with learning difficulties, Sheila, whom he had known at a previous day centre, but now saw only at a distance once each day, as she waited for the bus, and did not speak to. In interview, he was passive and withdrawn until the interviewer showed him the 'People I Know' diagram. Tim said 'Heart', the first conversational topic which he had initiated in three hours of interview, and chose Sheila, as the only person in the closest circle. At the end of the session, he asked the interviewer to write a letter to her from him, wondered if her name was on a list of students on the interviewer's wall, and asked if he could use the camera which we supplied to take her picture.

Tim's key worker felt that Sheila would be completely uninterested in him. Subsequently, Tim told the interviewer that he had spoken to her, and that she had ignored him. Following this incident, he had, according to his key worker, lashed out at another service user who was teasing him, and had been very apologetic about this uncharacteristic behaviour. At our next interview, we played the *Just About Me* game and Tim mentioned 'not having a girlfriend' as something about which he was disappointed. He asked the interviewer to write a Christmas card to another service user. Again, his key worker felt that Tim was being unrealistic, and that the woman would not be interested in him.

Anne talked about a boyfriend called Geoff whom she claimed to have met on holiday in Spain, six months ago, and wore a ring which she said was an engagement ring he had given her. According to Anne, Geoff was a singer in a pub, and had appeared on television, but her key worker said that she liked a television performer with the same name, the probable source of the story. Anne's description of this relationship was quite specific. For example, she said that 'when I'm 24, I will get married and have a baby, and Geoff will be the dad'. Gently challenged by the interviewer, Anne insisted that 'he really is my boyfriend'. Her stories often occurred in the context of discussions about her brothers and sisters, all of whom had boy or girl friends. They may, in part, have been an attempt to hold her own with her siblings, as well as to compensate for family problems.

Peter spent his time at a day centre, mainly doing gardening which he hated, at home (watching television or sleeping according to his mother), or wandering the streets alone. He had been given an old bicycle with bent wheels, but, despite its importance to him, had been unable to get it repaired.

Peter presented a very different picture of himself in conversation. Fast cars, friendship, social power and rebellion against authority were frequently recurring themes. He described a stolen car chase up the wrong lane of the motorway, stealing a bus, selling his mother's boyfriend's car after throwing him out of the house, arresting a 'big lad' who had bothered a girl whom he knew, borrowing a juke box from a pub and going mountaineering with his mates for the weekend. Most of the interview time was spent discussing these themes. Like Anne, Peter resisted the interviewer's suggestion that some of his stories might be untrue.

Peter's stories were often triggered by accounts of real events which emphasised his social isolation and powerlessness. The next extract was preceded by an admission that trips with his mother happened 'not very often'.

INTERVIEWER: What would you do when you get to [shopping centre]?

PETER: Go into the showrooms. Quite a lot of cars. We start them up. When the blokes is busy we rev the engines ... We leave the handbrake and push the accelerator fast, screech on the floor.

The triggering factor in the next example was Peter's painful memory of his father's divorce, mentioned above.

INTERVIEWER: Do you still see your dad?

PETER: Only on a Saturday ... He gives me the keys to the car, and told me to go out somewhere meself ... I'm driving along the motorway.

Associations between Peter's sense of powerlessness, interpersonal conflicts and stories about cars can be traced back to his childhood. His father used to describe him as *'huffy'*, a form of language which implied a critical, humorous acceptance of his inflexibility. However, this language minimised the severity of his father's response, which was *'to lock us out'*.

Peter described an incident when, locked out, he had driven his father's car out of the garage. His mother referred to the same event, which occurred when he was 14, as the only time, to her knowledge, when he had actually driven a car. The incident establishes a possible connection between Peter's interpersonal powerlessness and his development of an identity involving stealing and driving cars.

The three adults who did not live with their families had each adopted a fatalistic approach to interpersonal problems. David saw other people, apart from his father, as selfish, stupid and untrustworthy. He was not *'bothered'* (a frequently used phrase) that his mother had left home when he was young, and felt that he was better off without her. He was not *'bothered'* that one of his brothers had lied to the police and tried to get him into prison because *'you couldn't do a thing about it'*. David was not *'bothered'* that another brother was only *'alright when he wants something'* because *'I just do it for me dad, really'*.

Despite his fatalism, David maintained a fighting quality and had succeeded in passing a Communication Skills course *'just because me stepmother says I can't do it, so I worked harder at it'*. This fighting quality may have survived because one close relationship, with his father, was partly intact.

David's fatalism was based on a pessimistic view of human nature, whilst that of Andrew, and of William, discussed below, was more accepting.

INTERVIEWER: How do you feel when people tell you what to do?

ANDREW: Well, Nothing ...

INTERVIEWER: Do you think you're a happy person, or a sad person?

ANDREW: Happy.

INTERVIEWER: Happy. But there's been a lot of sad things in your life.

ANDREW: Yes.

The defining moment of William's present life was being locked out of the parental home when his mother was dying.

INTERVIEWER: How did you feel when you couldn't get back in?

WILLIAM: Mad.

INTERVIEWER: And did you try going back in again?

WILLIAM: Na.

After he had walked away, William felt *'alright'*. He seems to have concluded, in response to this specific, traumatic incident, that there was no point distressing himself about adverse events, since nothing could be done to change them.

William chose his dead mother as the person whom he felt closest to in his present life, but was fatalistic about her death.

INTERVIEWER: How did you feel when she [mother] died?

WILLIAM: OK. Nothing I could do. [Authors' emphasis]

William lived in a community home with two other adults with learning difficulties whom he didn't get on with, and had failed in his attempt to re-establish contact with his family. However, he did not see himself as trying to change things.

INTERVIEWER: What sort of plans would you like to make for the future?

WILLIAM: Just let it happen.

When asked to describe the decisions which he made in his everyday life, William said, *'I don't make any'*. Concerning decisions about his life made with staff, he would *'do what I am told'*, as staff would be acting *'for your own good'*.

Although accepting what he saw as his fate, William was aware of other possibilities, that there were *'a lot of things I'd like to do, but I can't.'* Asked what made him happy, William replied *'when you can do what you want'*.

However, his efforts to control his life were confined to choosing the least bad of the options which others offered him. For example, William had agreed to live with two other adults in a community home *'because I was trying to get out'* of hospital. Similarly, he would feel *'alright'* about doing a job which he didn't like because *'at least you've got something'*.

William's accepting fatalism had an important advantage for him. By giving up on long term goals, he was able to enjoy present time in a way which is often overlooked in our future-oriented culture.

INTERVIEWER: Can you think of any times when you felt happy?

WILLIAM: Sometimes I am happy.

INTERVIEWER: What are you doing when you are happy?

WILLIAM: Just sitting round and having a smoke.

Non-family Relationships

The strategies which adults adopted to try to cope with serious interpersonal problems had the unintended consequence of creating barriers between themselves and their wider social worlds. Alternative sources of support tended to be blocked off, and a self-reinforcing vicious circle was created.

Non-confirmed identity maintenance interfered with adults' wider social relationships in various ways. Tim, whose identity revolved around women to whom he did not talk, did not communicate with other service users at the day centre. The only interactions which he mentioned positively involved his key workers, whom he described as *'funny'* [amusing]. These relationships were unequal and fragile. During a period of about 10 months, he was passed from a woman key worker to a man, a move he said was *'brilliant'*, and back to the woman again. Tim's communication skills were limited. He would make a tremendous effort to communicate when he wanted to, but his efforts were directed towards unreciprocated relationships. By the end of the research period, Tim was beginning to give up hope of getting a girlfriend. He mentioned *'opening doors'* as something which he hated doing, a witty, telegraphic reference to his feelings about being rejected, as he saw it, by women. With unusual fluency, he asked *'What shall I do, [interviewer]?'* about not having a girlfriend, and appeared ready to abandon his efforts.

Anne talked openly about her boyfriend at the base which she attended. The manager said that it was staff policy not to humour her, and had observed that other service users tended to imitate the staff line, of either indulging or correcting Anne's fantasies. An incident had occurred when she had alleged, untruly according to the manager, that one of the bus drivers had got her pregnant, and that she had had to have an abortion. The manager had told the drivers not to collude with her stories.

Despite these problems, Anne's stories did not seem to isolate her from peers in the same way as was the case with Tim and Peter. Unlike them, she could name friends at the base, but her father was a barrier to her seeing them in other social contexts.

INTERVIEWER: Do you ever go to [friend from base's] house?

ANNE: No ... Not allowed ... Not a stranger's house ... I wish I could [go].

Peter was socially isolated, and friendships which he had developed had broken up in conflict. Although he talked continually about his friends, the photographs which he took contained only one picture of an adult of his own age, a service user whom he did not know very well. The other people in his photographs were of his mother's friends or young children.

Peter's stories generated hostile reactions.

INTERVIEWER: So, do the kids tend to make a bit of fun of him?

PETER'S MOTHER: But, again, it could be his own fault because he goes around telling people that he's got a car, and that he's getting a motorbike.

Peter was caught in a conflict between his own need to assert his autonomy, and pressure from others to conform. His approach to personal relationships contrasts sharply with that of the adults who had adopted fatalistic attitudes, discussed below.

INTERVIEWER: Do you think you are going to keep on going to the centre?

PETER: I will if they stop pestering, messing me around ... Things to do that I don't want to do ... It goes on and on.

At the time of the final research interview, Peter had left the day centre, and looked physically unwell. During most of the interview, he affirmed strongly that he was not going to go back, but, towards the end, he said that he might be 'sensible' and return because he was 'bored' at home. This contradiction of his previous presentation of himself as a high adventurer suggested that he was considering acceptance of life in the day centre. However, he did not go back.

The adults who had adopted fatalistic attitudes saw little point in trying to change existing relationships or develop new ties. David had one (male) friend whom he saw regularly. His friend 'wants to be a gardener, but he thinks the work is going to come to his door.' Asked whether he would talk to his friend about a confidential matter, he replied 'if I wanted everybody else to hear, I might'. Not surprisingly David only liked his friend 'sometimes'. He had some friends at work, but would not try to see them afterwards because 'there's different attitudes when they leave'. He was not 'bothered' about having once had a girlfriend, because 'she chucks one to go to another', and did not want to get married because 'that's when the fighting starts'. Thus, David had grave reservation about his one friend, and felt that a wider circle of supportive acquaintance was not open to him.

Andrew, whose mother and father had died, saw his sister once a month, relied on his key worker for social outings, and never used the phone. He claimed to have a best friend at the day centre. However, when asked who this was, he said 'all of them'. Despite this social isolation, Andrew thought that things would be 'the same' five years into the future. Asked to think back to a time when he had felt really happy, he replied, 'my mum and dad'. Unable to retrieve a valued past, Andrew did not believe that he could change the future.

William lived in a group home, had no outside contacts, and didn't get on with the two other residents who didn't 'like me living here'. However, he had not objected to living with them, 'just did what they asked us to', and had not attempted to change his living circumstances, despite the depth of his isolation.

William did not expect his wishes to be met. For example, he accepted that he could not go to a football match because a member of staff would only take them if all three residents wanted to go. 'He [resident] doesn't want to go. You cannot solve it.'

He identified more closely with staff than residents.

INTERVIEWER: Do you think that, if you had a choice, you would rather live in a house without staff, or with staff?

WILLIAM: With staff ... They're a nice gang. I get on well with them.

However, his relationships with staff were restricted.

INTERVIEWER: Have you seen her [staff] doing things about the house?

WILLIAM: No. She just does her book work ...

INTERVIEWER: Do you think they should do so much book work?

WILLIAM: Aye. They've just got to do it. I don't know why. They don't say.

DISCUSSION

The limited relationships experienced by many adults with learning difficulties have often been discussed (e.g. Firth and Rapley, 1990; Chappell, 1994). However, the adults described in the present paper stand out even from this bleak background in terms of their lack of social ties promoting self worth. The qualitative, retrospective methodology employed in this study does not allow any causal influences to be disentangled. All that can be said is that the stories which these adults told did not contain roles for themselves which they valued, and which were confirmed by others.

The use of non-confirmed identity maintenance and fatalism by the six adults discussed in this paper is a reflection of the activeness of the human mind. Lacking social worlds which could sustain their sense of self, they either attempted to create such a world for themselves, or lowered their expectations and tried to make the best of what they had. Since their culture did not provide them with ways of meeting a fundamental need, they invented their own, but only at a price. Adults who maintained non-confirmed identities had to face conflict with people around them who would not accept their versions of reality. Those who became fatalistic relinquished active management of their futures.

Ironically, it was the adults who tried to sustain non-confirmed identities, including William before he was excluded from the parental home, who caused problems for carers. The fatalistic adults were ultra-compliant. From a management perspective, the actions of adults who maintained non-confirmed identities could be seen as (mild) 'challenging behaviours' requiring modification through therapeutic intervention. Anne was corrected by formal carers when she told stories about boyfriends. The workers at Peter's day centre attempted to use behavioural techniques to ensure his conformity, deliberately ignoring him when he avoided taking part in officially prescribed activities. Tim's keyworker sought to discourage him from trying to develop 'unrealistic' relationships.

However, the data presented in this paper show that such behaviour can be meaningfully understood from the actor's frame of reference, as part of a strategic attempt to maintain self-worth in adverse circumstances. For example, Peter's statement that he would leave the day centre unless service providers stopped '*messing me around*', quoted above, can be understood as classifying staff behaviour towards him as challenging, and in need of control through behavioural techniques. The definition of behaviour as problematic or challenging entails a value judgement, usually implicit, that its meaning should be defined from the perspective of others, and supports the deficit model of disability (Shaddock and Zilber, 1991). There has been little research into the relationships between stress, social support and behaviour problems (for others) for people with learning difficulties, perhaps because they are implicitly viewed as a source of rather than as experiencers of stress (Hasazi et. al., 1992).

This last study found that life event stress and perceived social support both independently predicted the residential satisfaction of people with learning difficulties and/or mental health problems, but that behavioural problem severity, as assessed by carers, was predicted only by life event stress. One possible explanation of the lack of a direct relationship between social support and behavioural problems in this study is suggested by our qualitative data. It is that people with learning difficulties, and others, may respond to low levels of social support by developing non-confirmed identities, creating behavioural 'problems' for others, but manage very low levels of social support by becoming fatalistic and ultra-compliant, despite dissatisfaction with their life conditions.

Neither of the coping strategies discussed in this paper should be thought of as irrational or as a form of individual pathology. Non-confirmation of identity is a social rather than individual process and, for people with learning difficulties, is associated with stigmatisation. Fatalism is an entirely rational way of coping with a world in which one feels powerless (Lefcourt, 1992), and has potential benefits, such as enhanced enjoyment of the present, which western, achievement oriented, cultures tend to discount.

Research participants' life histories suggested, in two cases, that they might possibly have adopted a particular way of coping in response to specific incidents. Peter had started his father's car when he was 14, after being ejected from the house for being '*huffy*'. The stories about adventures with cars which he elaborated over the next 10 years appear to have originated from this incident. The influence of a specific experience can be seen most clearly in the case of William who had felt '*mad*' (angry) when he was locked out of the house, and rejected by his family, but had become strongly fatalistic about subsequent events.

Like those who are categorised as having a learning difficulty, people diagnosed as suffering from a chronic mental illness experience exclusion from the labour market (Link et. al., 1987), negative stereotyping (Link et. al., 1987), and restricted social support networks (Link et. al., 1989). Their lives have also been studied in terms of their own perspectives and ways of coping with a stigmatised existence

(Strauss, 1989; Handyside and Heyman, 1990; Barham and Hayward, 1991; Corin and Lauzon, 1992). However, comparison of this work with the present study suggests significant differences in the underlying social network problems which people with learning difficulties and long term psychiatric patients have to deal with. The latter face the dilemma that revealing a history of mental illness is likely to lead to social rejection, whilst concealment is difficult in close relationships (Barham and Hayward, 1991, pp 13-16). This dilemma may underlie, at least in part, the finding of one study (Corin and Lauzon, 1992) that schizophrenics who avoided re-hospitalisation were likely to adopt a strategy of 'positive withdrawal'. This strategy involved avoiding close relationships, particularly with other patients; maintaining more distant ones, e.g. through church membership; and positively reframing the meaning of the resulting social isolation, for example as giving space for contemplation, or as a form of distancing from an inhuman society.

Positive withdrawal is rarely open to people with learning difficulties, whose social worlds are segregated, and whose stigmatised condition cannot usually be concealed. Strategies for coping with stigmatisation appear to vary considerably, and to depend upon the social conditions in which it occurs. Participation in collective actions with other members of the stigmatised group, briefly discussed below, is another possible coping strategy.

In conclusion, the implications of the present study for service provision in Britain will be briefly considered. Effective support for people in the predicament described in this paper requires identification of their individual aspirations, the creation of environments which make it possible for them to meet these aspirations, the establishment of collaboration between people with learning difficulties and their formal and informal carers, and the provision of opportunities to learn new skills. In Britain, the NHS and Community Care Act of 1990 created mechanisms designed to make services sensitive to individual needs. Every service user should be assigned a key worker who has the role of assessing individual need and establishing an appropriate package of support. The key worker has to produce a written, annual care plan for each service user, based on agreement arising out of discussions with him or her and any informal carers. Unfortunately, day centre workers were, in the present study, overwhelmed by the demands of managing the physical needs of large groups of disabled people, and there were no indications that residential staff were addressing adults' need for social support.

The requirement to manage large groups may preclude a move in practice away from pathological models based on behavioural or biochemical control, despite evidence of a paradigm shift in this direction among service providers (Blunden, 1990). One key worker expressed open cynicism about care plans, which she regarded as no more than a managerial paper exercise. Key workers, asked to indicate when 'challenging' behaviour would be deemed sufficiently serious to warrant referral to specialist services, frequently responded that the time dimension, rather than the problem itself, was crucial. They would refer a service user if they could not control the problem themselves quickly.

These care workers did appreciate that challenging behaviour could be understood from the actor's view point. For example, one described challenging behaviour as a form of communication. But the requirement to process service users en masse prevented them from engaging with individuals. Such disengagement from the individual has been identified as a general characteristic of modern health care systems (Castel, 1991; Gigerenzer, et. al. 1989, pp. 46-47). Service user fatalism, leading to compliance and a strategy of attempting to make the best of one's existing situation, matches the requirements of a system of mass care. In contrast, those who try to maintain identities they have chosen for themselves come into continual conflict with such a system.

It is hard to see how the needs of adults with learning difficulties who have serious interpersonal problems can be effectively addressed within the present system of community care in Great Britain. There is a gap between the rhetoric of individualised care and the provision of services which, because of resource limitations, can only be delivered en masse. Moreover, it is difficult to see how such care can address social structural problems, such as segregation and exclusion from the labour market, which make it more difficult for people with learning difficulties to develop strong social support networks. Obtaining, sustaining and managing social support appears to be one of the main ways in which people are the primary producers of their own health (Stacey, 1976). The assertion of collective rights through the disability movement (Hasler, 1993) may provide people with learning difficulties with more promising ways of developing positive social identities.

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