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**NOT WORTH THE RISK?  
ATTITUDES OF ADULTS WITH  
LEARNING DIFFICULTIES,  
AND THEIR INFORMAL AND FORMAL CARERS  
TO THE HAZARDS OF EVERYDAY LIFE.**

Heyman B. and Huckle S. (1993) Not worth the risk? Attitudes of adults with learning difficulties and their informal and formal carers to the hazards of everyday life, *Social Science & Medicine*, **12**, 1557-1564.

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## **BIOGRAPHICAL DETAILS**

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## **ABSTRACT**

20 adults with learning difficulties (adults) living at home with informal carers, mostly parents, and attending Adult Training Centres (ATCs) were interviewed about their everyday lives and information was also obtained from informal and formal carers. The problem of dealing with the hazards of everyday life emerged as an important theme. The thinking of adults and informal carers could be understood in terms of the moral dimension of hazards, through the distinction between risks, to be calculated, and dangers, to be avoided. Adults and informal carers within families largely agreed in their categorisation of hazards but differences were found. In families where the head of household had had a professional or skilled manual occupation, adults and informal carers were most likely to agree that hazards for the adult were dangers to be avoided. In families which had a history of unemployment or unskilled occupations, adults and informal carers were most likely to treat certain hazards as risks to be taken. The latter families were also less likely to have 2 informal carers. Adults from more risk-tolerant families appeared to be achieving more of their potential in everyday living skills. Formal carers at ATCs were more accepting of risks for adults with learning difficulties than informal carers and there was misunderstanding and conflict between formal and informal carers as a result.

## **KEY WORDS**

Adults

Learning Difficulties

Risks

Service Provision

## **INTRODUCTION**

This paper is concerned with the ways in which adults with learning difficulties (adults) approach the hazards of everyday life and with relationships between adult approaches to hazards and those of informal and formal carers. The initial aim of the research to be discussed in this paper was to explore the friendships and opposite sex relationships of adults attending adult training centres (ATCs).

Themes concerned with hazards of daily life stood out in the data and became the focus for analysis. As this issue is neglected in research into the lives of adults with learning difficulties and in the wider social science literature, we will begin the paper with a wider analysis of the concept of hazard.

There is a body of research which analyses hazards from psychological perspectives. Two of its main concerns are subjective estimates of risk <sup>1</sup> and individual differences in propensity to high risk behaviour <sup>2</sup>. This approach fails to ask how hazards are socially constituted or why social groups come to selectively treat certain human actions as hazardous. For example, the hazards of childhood masturbation and the breeding proclivity of 'degenerate' types might have been major concerns for a risk psychology of the late nineteenth century but do not appear in the lists of risks used in psychological studies of the late twentieth century. The psychological approach is 'culturally innocent' in that it mistakenly treats cultural norms as universals of human nature <sup>3</sup>.

Anthropologists and sociologists have been more concerned with the social constitution of hazards but it does not seem to be, currently, a central concern, and is hardly mentioned in recent medical sociology texts <sup>4 5 6</sup>. Two approaches which have addressed hazards from a more sociological perspective are those of Douglas <sup>7</sup> and Giddens <sup>8</sup>. Douglas treats judgements about hazards as essentially moral, concerned with the acceptability of incurring the hazard or having it imposed. We will try to show that judgements made about hazards faced by adults with learning difficulties are essentially moral.

Giddens argues that attempts to control risk are central to 'modern' consciousness, as against consciousness based on fate or divine justice. Risk analysis is bound up with modern time consciousness through (attempted) 'colonisation of the future'<sup>9</sup> and 'risk profiling'<sup>10</sup>. However, risk analysis is unsettling since it requires contemplation of the possibility that things can go wrong, particularly as our colonisation of the future is so insecure. Thus, medical advice about lifestyles which are claimed to reduce the risk of disease is often contradicted (e.g. jogging may cause arthritis, vegetables may contain toxins, our bodies may need saturated fats). Success, in industrialised countries, in producing reliable sources of food, water, energy and material goods has merely mortgaged the middle distance future through causing the world ecological crisis.

Our limited ability to colonise the future is the weak point of 'modern' consciousness and a source of deep unease. In order to maintain a sense of control in the face of a world which is uncertain and threatening, we have to surround ourselves in a 'protective cocoon' which is based on a 'substratum of trust'<sup>11</sup>. This protective cocoon perhaps contributes to the relative neglect of risk as a topic of social scientific enquiry.

Our sense of security in the modern world requires both interpersonal trust and trust in the functioning of social institutions. The latter depends upon the development and accreditation of expertise and implies deskilling, placing the responsibility for decisions in the hands of those who can best assess risk, e.g. the medical profession for health problems. However, the status of expertise is problematic for two reasons. Firstly, knowledge is contingent on presuppositions which experts may not share, e.g. a reductionist versus a holistic approach to medicine. Secondly, even within a particular paradigm, the future is notoriously difficult to predict because of the number of variables involved and the prevalence of multi-directional feedback in complex natural and social systems.

Experts are required to provide pragmatic prescriptions in the face of uncertainty. As a result, bodies of expertise about human behaviour are constantly challenged and the individual is faced with choice

between competing claims. In relation to adults with learning difficulties there is controversy, for example, about whether friendships largely confined to other adults with learning difficulties are harmful<sup>12</sup> or not<sup>13</sup>. Paradoxically, this fragmentation of expertise empowers people by giving them choices.

Giddens postulates trust as a general background condition of modern consciousness. However, at the micro-social and individual levels, trust is multi-dimensional and variable. In relation to adults with learning difficulties, we found that some informal carers and adults saw 'the community' as a dangerous place which the adult should not enter without protection. For them, a basic dimension of trust was lacking. Other adults and informal carers had enough trust to risk the adult venturing out.

### **RISKS, DANGERS AND HAZARDS**

We have found it useful to distinguish between 'hazards', 'risks' and 'dangers'. We will use the word 'hazard' to describe the individual's perception that there is a probability that an action will lead to an outcome which he or she judges to be adverse. The term is morally neutral and the same hazard (e.g. the adult going out alone) may be viewed as a risk or a danger, depending upon the viewer's moral stance. Hazards have certain perceived properties including the probabilities of favourable and adverse consequences; the extent to which the actor and/or others can control these probabilities; the cost/benefit ratio of the action; and the direction of costs and benefits (who faces costs, who faces benefits).

We will describe a hazard as a 'risk' if a social actor is prepared to consider taking it. The term 'danger', in contrast, will be used to describe a hazard which is rejected. A risk may be appraised whilst a danger should be avoided. This concept of risk corresponds to the lay notion of a 'wager' and does not have the negative connotations found in medical usage<sup>14</sup>. Focus on subjective definitions of



hazards allows us to place them in a rational context and contrasts with a medical approach which seeks to define objective risks independently of actors' own belief systems.

The distinctions we will draw correspond roughly to nuances of meaning in English. We would expect to find equivalents in other languages because they express differences in moral attitude to hazards which every culture needs to negotiate. The difference in usage is illustrated by the following quotation

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'*Risk* is an inherent element in the process of social work and the related professions. The nature of the work makes *risk* inevitable and it increases when dealing with vulnerable clients, like mentally handicapped people. Although we would all agree with the inevitability of *risk*, it does not follow that clients must be placed in *dangerous* situations, liable to mischance, loss or injury.' (*Our italics*).

The above quotation suggests that risk is acceptable whilst danger is not. However, in order to understand differences between adult, informal and formal carer perspectives on hazards, we must locate the distinction between risks and dangers in the perceiver's judgement, not in properties of the hazard. As well as demonstrating differences in usage of the terms risk and danger, the quotation illustrates, as will be argued below, the cultural orientation of the caring professions towards risk appraisal.

The decision to treat a hazard as a risk or a danger has consequences for feedback from experience of the hazard. Risks will sometimes be taken and will provide direct, inductive evidence about the properties of the hazard. For example, informal carers who did allow the adult to go out alone in restricted circumstances usually found that serious problems did not occur. They could use their experience, however limited, as evidence that the risks involved were acceptably low. In contrast, direct information about dangers which were avoided could not be obtained. Informal carers did draw

upon indirect social evidence, in the form of anecdotes involving other adults. But these anecdotes were usually sensational 'horror stories' which confirmed that the hazard was dangerous. Therefore, dangers were unlikely to be re-classified as risks whilst risks could readily be re-classified as dangers if adverse consequences were experienced, as will be illustrated below. This analysis gives a rational explanation for the apparent 'over-protectiveness' of informal carers.

The distinction between risks and 'dangerousness' has been drawn by Castel in the context of a Foucauldian analysis of historical shifts in the surveillance of the mentally ill by psychiatrists and social workers<sup>16</sup>. Classical psychiatry was based on the idea that the mentally ill were dangerous to themselves and others and that the danger was to be prevented by containment. The notion of dangerousness contained a paradox within it. Dangerousness was a property of persons. It could not be identified directly if it was to be prevented, only through symptoms indicating dangerousness. But the relationship between symptoms and dangers could only be tenuous and the preventative strategy could only work if applied to huge masses of people whose symptoms suggested dangerousness. This paradox has led to a transformation of the ways in which psychiatrists, social workers and other caring professionals understand their work. The transformation has involved a move from strategies designed to prevent dangers associated with persons to strategies designed to reduce risk in entire populations on the basis of epidemiological data.

Castel illustrates with the example of the law, passed in France in 1975 'in favour of handicapped people.' This set up special trajectories for handicapped people, not necessarily medical ones, for example the Centre d'aide par le Travail (CAT) which seem to correspond closely to the Adult Training Centres (ATC) operated in Britain. These provide an administrative assignation based on a medico-psychological diagnosis.

Castel's analysis was carried out from the perspective of agencies of control. He treats as unproblematic the co-operation of those who are controlled. The work to be outlined below was carried out

primarily from the perspective of adults with learning difficulties and their informal carers. We arrived at a similar distinction to Castel between dangers to be avoided and risks to be calculated. However, our conclusion is that many adults and informal carers treat hazards as dangers to be avoided. This suggests a disjunction between the ways in which formal carers and clients construe adults' needs.

## **METHODS**

Qualitative and quantitative analysis was carried out of interviews with 20 adults attending two ATCs in an urban area of Northern England. The adults, 10 male and 10 female, were aged 19-35, and lived either with parent(s) (19 adults) or other relatives (1 adult). The area in which the adults lived is socially deprived relative to the standards for Britain as a whole but has substantial pockets of affluence. The criteria for inclusion in the sample were that the adult should attend an ATC and be able to communicate well enough to be interviewed. The sample represented the upper ability range of those attending the ATCs and included all but 4-5 eligible adults, excluded for reasons of availability and convenience. For each adult, at least one informal carer was interviewed. The interviewer (SH) kept a diary and noted views of formal carers at the ATC. Eight interviews were conducted with formal carers at the 2 ATCs and will be discussed further below. All persons who were approached agreed to participate.

Interviews were carried out independently and confidentially with adults over several sessions at the ATC, and with informal carers over 1 session in their homes. Total interview times ranged between 6-9 hours for adults and 3-6 hours for informal carers. The interviewer visited the ATC on 4 occasions before interviewing commenced in order to establish rapport. Interview questions were open-ended in order to minimise acquiescence<sup>17</sup> with funnelling techniques used to cover any areas which had been omitted. Interview topics were explored at length and adults were encouraged to express their own opinions about sensitive topics, e.g. sexual relationships. More personal areas were only raised after

trust had been established. Care was taken to ensure that adults fully understood the purpose of the interview and that interviews ended on a light-hearted note <sup>18</sup>.

Interviews with adults and informal carers were semi-structured around standard questions in the following areas: leisure, employment, education, friendship, relationships with the opposite sex, relationships at home and prospects for the future. The principal focus in the adult interviews was on their own views but they were also asked about the views of informal carers. Interviews with informal carers focused mainly on how they saw the adult's views, needs and capabilities. There were some additional questions concerning their own needs and feelings, e.g. how they would feel if the adult left home.

Analysis was largely qualitative but counts and relationships were also utilised once the main categories of risks and dangers had been established <sup>19</sup>. The reliability of all quantitative coding was checked through comparing independent ratings undertaken by the two researchers, with an agreement level of at least 90%.

## **RESULTS**

### **The Prevalence of Hazards**

Both adults and their informal carers saw the adult as beset, in their everyday lives, by a variety of hazards. These included physical hazards, e.g. traffic, getting lost, cooking; hazards from 'normal' members of the community, e.g. being teased, attacked, robbed or kidnapped; and hazards associated with sexual relationships, particularly AIDS. Most adults were also afraid of 'getting wrong' or 'getting into trouble' with formal and informal carers. Although the interview schedule did not contain questions on hazards, about 10% of the interviews, as measured by transcript length, was spent in discussing hazards introduced by adults and informal carers. Adults introduced an average of 8.1

topics concerning serious hazards (range 3-17) and informal carers an average of 8.8 topics (range 3-15).

The following quotation illustrates the strong fears which were often expressed and the connection between danger avoidance and informal carer protectiveness.

INTERVIEWER Do you go out on your own?

ADULT I go out with my parents. I can't go out on my own ...

INTERVIEWER Why not in the dark?

ADULT Because people in cars might take you away.

INTERVIEWER So are you afraid on a night time because of these people?

ADULT You don't know what they are like. They might hurt you. They might kidnap me.

### **Adult and Informal Carer Views of Risks and Dangers**

In theory, three patterns were possible. Both formal and informal carer could see a hazard as a danger or as a risk or their views could conflict, for example the informal carer seeing danger where the adult saw risk. Most adults and their informal carers shared strongly mutual views about hazards. Shared danger avoidance, which predominated in 11 families, is illustrated below.

INTERVIEWER Would you like to be able to go out on your own?

ADULT No ... It's very dangerous.

INTERVIEWER Why is it dangerous?

ADULT Because the cars come along on the corner where I get my coach. There are too many accidents.

INTERVIEWER Would you ever let \_\_\_\_\_ to go out on his own?

INFORMAL CARER No ... I would worrying all the time, wondering what he was doing. Its too dangerous.

The second pattern, illustrated below, was for both informal carers and adult to treat a hazard as a risk and predominated in 7 families.

INTERVIEWER What things do you do with your boyfriend?

ADULT I go to see him on my bike or I get the bus ...

INTERVIEWER How do you get home on the dark nights?

ADULT ... He gets the bus back with me to make sure I'm alright.

INTERVIEWER Can she go out on her own?

INFORMAL CARER Yes, she walks to [*boyfriend's*] or goes on her bike or on the bus. I worry about strangers with her because she is easily led and will talk to anyone.

Although we were not able to observe the processes through which shared, family perceptions of hazards were arrived at, it seems probable that there were power differences in favour of informal carers. Adult views did not, however, correspond completely to those of informal carers. In 2 families there was overt conflict.

INTERVIEWER Have you ever spoken to your mum about leaving home?

ADULT Yes.

INTERVIEWER What did she say?

ADULT I says, "Mam can I leave home?". She says, "No". My mam believes I can't look after myself.

Too much bills. Too much electric.

INTERVIEWER Do you think that you could look after yourself if you left home?

ADULT Yes.

INFORMAL CARER One of his friends \_\_\_\_\_ wanted to get a flat once and he wanted one too, so I really went to town on him saying that he couldn't cook, clean, look after himself, but he thought he could look after himself.

More commonly, adults expressed needs which informal carers did not perceive. For example, 18 of the 20 adults wanted to see friends from the ATC more frequently outside the ATC but only 4 of their informal carers identified this need. Not recognising the adult's needs perhaps had a psychological function for informal carers, enabling them to minimize (perceived) losses to the adult arising from danger avoidance. However, it was harder for adults to downgrade their own needs, as illustrated below.

INTERVIEWER Would you like to go to more places [*with friend*]?

ADULT Yes I would.

INTERVIEWER Where would you like to be able to go?

ADULT To his house .... my house .... shops .... down the street .... out on a night .... I'm always stuck in the house all the time .... boring.

INTERVIEWER Do you think \_\_\_\_\_ has enough to do in his spare time?

INFORMAL CARER Yes, because we never see him here. When he comes home he is straight upstairs with his radio cassette and he is up there a long time ... There is nothing else he wants to do.

Some informal carers who were primarily oriented to danger avoidance tried to compensate by providing the adult with activities requiring carer involvement, e.g. shopping trips, visits to clubs, holidays. For them, the adult was a central project in their lives.

### **The Boundary Between Risks and Dangers**

Adults and informal carers used evidence from their experience to maintain or shift the categorisation of hazards as risks or dangers.

The decision to treat a hazard as a danger was often reinforced by 'horror stories' which helped to reassure both adults and informal carers that the sacrifice of the benefits given up was justified.

Incidents from childhood were used to justify danger prevention in adulthood.

INFORMAL CARER I'm afraid that if \_\_\_\_\_ was going out for a walk on her own, I would be bringing her back in. She was given a bike when she was younger and, you see, she used to ride away ... By the time we had found her I was a nervous wreck.

As noted above, risks could more readily be re-classified as dangers than vice versa. The quotation below suggests that even informal carers who were prepared to risk the adult going out alone had a fragile 'substratum of trust' in the local community.

INTERVIEWER Have you ever stopped \_\_\_\_\_ going out on her own?

INFORMAL CARER No, not really. She can come and go as she pleases. Apart from once we stopped her going to the pub on her own ... A strange lad tried to get funny with her outside. It was seen, he tried to put his hand up her skirt, but some of the other lads in the pub got hold of him and gave him a good hiding outside. So we stopped her going there.

### **The Limits to Risks**

Although some families were more willing to treat hazards as risks, there were clear limits to the areas in which risk taking was tolerated. Informal carers, almost without exception, ruled out activities other



than those which would be normal for a young child within a family, including independent living, work, sexual relationships, marriage and parenthood. Thus, risk taking, where it was tolerated, was confined within the family system. However, a number of the adults had aspirations in at least some of these areas and formal carers at the ATC felt that all the adults had considerable unrealised potential. The 2 families where there was overt conflict were the only ones in which the adults systematically rejected family boundaries, seeking to marry, work and live independently.

### **Classification of Families**

Within the limits of qualitative research, we were able to classify the families in terms of their approach to hazards and to relate this classification to features of the interviews, formal carer judgements about the adults and family background. The results will be briefly outlined below.

The adults could be classified into 2 groups, a 'limited autonomy' and a 'minimal autonomy' group. The 7 adults (5 female and 2 male) in the 'limited autonomy' group were able to go out on their own locally with some freedom and so were able to enjoy autonomous everyday activities such as visiting pubs and clubs, shopping and outings with friends. The 13 adults (5 female and 8 male) in the 'minimal autonomy' group were only able to go out alone on specific prescribed journeys, e.g. to local shops, and could only enjoy leisure and social activities outside the home when accompanied by carers. (This group contained the 11 families who approached hazards primarily in terms of danger avoidance and the 2 families where there was overt conflict between informal carers who were oriented to danger avoidance and adults who wished to become more independent.)

In the interviews, both adults and informal carers in the 'minimal autonomy' group introduced more topics concerning dangers and less topics concerning risks than did adults and informal carers in the 'limited autonomy' group. All the comparisons were statistically significant but the differences were greater for informal carers than for adults, perhaps reflecting the greater social power of the former.

For example, informal carers in the 'minimal autonomy' group mentioned an average of 9.7 dangers compared with 2.4 in the 'limited autonomy' group ( $t=5.1$  with 18 d.f.,  $p<.0001$ ). Informal carers in the 'minimal autonomy' group discussed, on average, only 0.5 hazards which they were prepared to treat as risks, compared with 3.6 in the 'limited autonomy' group ( $t=3.4$  with 7 d.f.,  $p=.01$ , separate variance estimates).

A formal carer in the 2 ATCs was asked to rate each adult as 'capable', 'capable with training' or 'incapable' in 19 areas, covering everyday living skills, sexual relationships, employment and independent living. Adults were judged 'capable', on average, in only 42% of the areas in which they were seen as at least potentially capable (capable or capable with training) with a range of 14-83%. A correlation of .69 between formal carer ratings and blind ratings by one of the researchers of the above 'achievement scores' was found, showing that they were reasonably reliable.

Adults in the 'limited autonomy' group were judged, on average, to be achieving their potential in 62% of the areas, compared with only 31% for adults in the 'minimal autonomy' group ( $t=3.4$  with 8 d.f.,  $p=.01$ , separate variance estimates). There was virtually no difference in estimates of the mean potential of the 2 groups, as measured by the total number of areas in which they were judged either capable or capable with training. The data suggest that adults in the 'minimal autonomy' group may have achieved less of their potential due to the danger avoidance strategy adopted by their informal carers.

There were a number of strong relationships between the 'achievement scores' and adult and informal carer attitudes to risks and dangers of which only the strongest and most theoretically interesting will be described. All correlations were significant at better than the .005 level on 2-tailed tests. Firstly, there was a correlation of .75 between the number of themes concerning dangers mentioned by adults and informal carers, suggesting that this concern was strongly influenced by family negotiation.

Secondly, the frequency with which hazards were treated as risks was negatively associated with the frequency with which they were treated as dangers. For example, there was a correlation of  $-.66$  between the number of hazards treated as risks by informal carers and the number of dangers mentioned by adults.

Thirdly, 'achievement scores' were positively associated with treating hazards as risks and negatively associated with treating them with dangers. The strongest correlation,  $.75$ , was between 'achievement scores' and the frequency with which informal carers treated hazards as risks.

Approaches to hazards were strongly associated with family background. Families were classified into 2 groups on the basis of the present or past occupation of the 'head of household'. One group contained 12 families in each of which the 'head of household' held or had held a professional or a skilled manual occupation, as determined by the registrar general's classification of occupations (social classes I to IIIM). In 10 of these families the adult lived with both parents. The second group contained 8 families in which the 'head of household' had had a history of unemployment and low-paid, semi-skilled or unskilled jobs (social class IV & V). Seven of the adults lived with a single carer. Housing and living conditions, as seen in home visits, were visibly worse in the second group.

The families in the first group were markedly more likely to treat hazards as dangers than were those in the second group. Of the 12 adults in the higher social class group, 11 were classified as having 'minimal autonomy' compared with only 2 of the 8 adults in the lower social class group ( $p=.005$ , Fischer's exact test, 2-tailed).

Three reasons for this strong relationship can be suggested. Firstly, adults in the less privileged group had fewer material resources enabling them to be protective towards adults. For example, they did not have cars and so there was greater immediate need for adults to develop independent mobility.

Similarly, they had less personal resources enabling them to be protective where there was only one informal carer in the family. In addition, informal carers in this group, as noted by formal carers, made less use of facilities provided by the ATC, e.g. trips and outings, and so were further deprived of caring resources. Secondly, attitudes towards hazards may have differed culturally between the two groups, e.g. middle class cultural values may favour protectiveness. Thirdly, the presence of two informal carers in most of the families in the first group may have led to more cautious attitudes through the process of group polarisation towards culturally preferred values<sup>20</sup>.

### **Formal and Informal Carers**

Information about the views of formal carers at the two ATCs was obtained from informal discussions and semi-structured interviews with a convenience sample of 8 formal carers including the managers of the 2 ATCs, 4 senior care officers and 2 care assistants. The interviews covered adult capability and need for independence, hazards, attitudes of informal carers and relationships between formal and informal carers. Unless otherwise indicated, the views briefly outlined below were expressed by all the formal carers interviewed.

Formal carers saw most of the adults as failing to achieve their potential.

INTERVIEWER Do you think there are any clients in the ATC that are ready to progress?

FORMAL CARER Yes, nearly all. I think many could be more independent travel-wise. They could come to the centre on the bus by themselves and some could go to work.

Informal carer attitudes were seen as an important barrier to adults becoming more independent.

INTERVIEWER What is their [*informal carers*] attitude to letting them go out on their own or use a bus?

FORMAL CARER They are against it. They have been locked for so long in this over-protective way ...

Three of the 8 formal carers, including both the managers, felt that younger informal carers were more willing to encourage independence, perhaps reflecting greater therapeutic optimism in managers who were more removed from everyday care. All the formal carers indicated, however, that they would try to work with informal carers to try to promote greater adult independence. They all believed that less segregated alternatives to ATCs such as day centres and home-based training would also help to promote independence.

The formal carers were all 'pro-risk', believing that adults had to be exposed to hazards if they were to progress.

FORMAL CARER We are all subject to risk and they will not learn without taking risk.

The quotation below illustrates, again, the way in which a single incident could be used to re-classify a risk as a danger and the implicit assumptions on which such induction was based.

FORMAL CARER We had one client who we had trained to travel, then ... she stepped in front of a car. Her parents then stopped her travelling immediately. The thing is there are lots of so-called 'normal' people getting knocked down in traffic accidents. But because she had a mental disability the parents stopped her travelling.

There was some tension evident between formal and informal carers. Formal carers believed that informal carers were often over-protective and financially motivated to keep adults in the ATC. Informal carers sometimes felt that the ATC was trying to push adults into dangerous situations because they lacked intimate knowledge of the adult's limitations.

INFORMAL CARER Every time I go to the review they keep saying it is time she got a job. But she is epileptic and could not work in a kitchen. I tell them what she is like. I should know. I made her. But the centre don't see this.

## **DISCUSSION**

Concrete decisions made by adults with learning difficulties and their carers can be understood in relation to a more general analysis of the meaning of hazards. Adults and informal carers themselves differed in the ways that they categorised hazards, with the higher status families more likely to treat them as dangers to be avoided. Adults were sometimes more willing to treat hazards as risks than were their informal carers. But the most marked divide was between formal and informal carers. Formal carers at the ATC thought that informal carers were too unwilling to allow adults to take risks and that this was preventing them from helping the adults to learn new skills. Informal carers felt that the ATC was pushing the adults onto dangerous ground because the workers did not really understand the limitations of their children, often for reasons of administrative convenience.

Quantitative analysis showed that informal carer and adult orientations towards risk taking and away from danger avoidance were strongly associated with the extent to which adults were seen as achieving their potential, as also found in an American study<sup>21</sup>. This finding appears to support the view of formal carers that adults were being held back by informal carer over-protectiveness.

However, two important qualifications must be made. Firstly, formal carers seemed unaware of differences in tolerance to risk among informal carers, perhaps because the poorer informal carers, who were more risk tolerant, were less likely to contact the ATC. Secondly, formal carers overlooked the rational basis of formal carer protectiveness. Like many researchers, they made an implicit value judgement that informal carers were 'over' protective and then gave psychological or economic explanations of this irrationality, for example that informal carers were emotionally dependent on

adults or that they were financially motivated to keep the adult in the ATC. But informal carers, and most adults, saw this protectiveness as a rational response to a dangerous world.

There was a fundamental conflict in the ways that formal and informal carers viewed the role of the ATC. As the most able members of the ATC, the adults in our sample were a marginal group and therefore difficult to classify. Informal carers assumed that the adult would continue to live dependently within the family for as long as possible. They saw the ATC as a caretaking institution, which would keep adults busy and happy during the day and provide a source of social contacts. Informal carers saw attempts to move adults out of the ATC, e.g. into sheltered employment, as a threat because, if things didn't work out, the adult would have lost their place in the ATC. Formal carers, in contrast, saw the ATC as training the most able adults to move on, e.g. to independent or semi-independent living and sheltered employment, both for the adults' own benefit and to release places for the less able.

The approach of formal carers can be put into a broader context using the ideas of Castel, summarised above. Formal carers were oriented towards the management of risk but felt hampered by the attitudes of parents. Following Castel, this attitude can be seen as part of a wider post-modern culture shared by health professionals attempting to process masses of individuals. However, informal carers were not part of this culture. For them, there was still a 'subject', unsurprisingly, since the adult was a close relative. Informal carers' main orientation was to protect the adult from danger. Even those informal carers who were willing to allow adults to take limited risks did so with considerable anxiety and a readiness to respond to adverse outcomes by switching to danger avoidance.

The cultural divide between formal and informal carers can be understood in terms of Giddens' idea that a personal feeling of security in a modern world oriented towards the control of risks depends upon trust. Many of the informal carers and adults lacked this trust. For example, those adults, the majority, who were not able to go out by themselves described the dangers in lurid terms, e.g. being kidnapped, raped or deprived of one's clothes. In this world, as they saw it, caution was only natural.

Recent debates about the development of services for adults with learning difficulties<sup>22 23</sup> have criticised the traditional concept of normalisation as using behavioural techniques to make adults with learning difficulties conform to normal patterns of social behaviour. The alternative, supported by many other writers, is based on autonomy, citizenship, rights and self-advocacy. This shift is reflected, in Britain, in increased criticism of ATCs and the development of alternatives such as advocacy groups, day centres and home based learning.

However, moves towards greater autonomy for adults with learning difficulties will be thwarted unless adults, formal and informal carers have greater understanding of each other's attitudes towards hazards. Strategies need to be developed which start from the **adult's** ways of dealing with the dilemmas raised by hazards and which involve adults, informal and formal carers in teamwork to support the adult in his or her preferred strategy.



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