Entering the adult world: The experiences of young adults with learning disabilities of social support during the transition into adult services.

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Submitted to the University of Leicester
for the Doctorate in Clinical Psychology, June 1999.

UMI Number: U124095

UMI U124095

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Abstract

The transition into adulthood has been identified as a key life event for people with learning disabilities, entailing the departure of services which are well known and entry into unfamiliar systems. Social support has been conceived as having a stress buffering role. It has also been contended that social support is itself important to the mental health of people. It was hypothesised that the role of social support in the transition period would be important, particularly as the transition process itself may change the structure of the support network around the individual. Traditional concepts of social support have been criticised as lacking conceptual clarity and of being of limited ecological value. They do not take into account the context of relationships which are entailed and the ambiguous nature of support. Moreover, no studies have examined the views of people with learning disabilities about their experiences of social support.

This study aimed to use in-depth interviews to explore the views of people with learning disabilities about their experiences of social support. Six young adults with mild to moderate learning disabilities wee interviewed about their experiences of leaving school and the support that they received at that time. A grounded theory methodology was used to code the transcripts.

The analysis identified various challenges that occur during the transition years. It also delineated the interplay between self-reliant coping responses and social support coping strategies which participants used to respond to these challenges, with particular attention

being drawn to the different pathways to attaining social support and the distinction between unsought social support and initiating support interactions. The intervening conditions of relationships and locations were related through this process. The properties of relationships were discussed, as were the important contextual factors of control and identity. Strategies used to manage social relationships were related both in terms of maintaining positive examples but also in terms of managing conflict within those relationships. The theoretical and clinical implications are discussed.

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Introduction

It has been asserted that of the transitions in our society one of the most important is that from school through to adult life (Hanley-Maxwell, Whitney-Thomas and Mayfield Pogoloff, 1995). For the students leaving school is the beginning of the passage into adulthood and involves the re-negotiation of roles both within the family and within the wider community. Thomson, Ward and Wishart (1995) noted that at least six indicators of successful transition can be identified covering a wide range of social roles. They included in these finding employment, establishing economic self-sufficiency, becoming personally independent, becoming socially competent, taking up an adult role in the home and society and entry into post-secondary school education.

For people with learning disabilities this transition is further complicated because it involves the leaving of services which are well known to both themselves and their families and entry into the unfamiliar and sometimes inaccessible systems of the adult services. Thorin, Yovanoff and Irvin (1996) noted the paradoxical nature of this time for many families with a disabled member. At a time when, for most families, parental involvement and control is expected to diminish, the reality for some families with a learning disabled member is of a greater reliance on parental resources due to the difficulty in finding appropriate resources. Moreover, this transition encompasses complex changes and challenges for both individuals themselves and their parents. Adjustments are necessary as a number of roles and responsibilities change or are

negotiated afresh. These are often complicated as parents are often left with uncomfortable dilemmas about the level of independence which they believe can safely be achieved by their son or daughter.

Transitions and mental health

The effects of such important life events upon mental health have long formed a prominent thread within the research literature since Holmes and Rahe (1967) developed the Schedule of Recent Experiences in an attempt to assess the level of stress associated with life changes. Events and transitions within the life cycle have become widely accepted as factors which affect the mental health of people in the general population and have been developed into theoretical conceptualizations with which to inform clinical practice when working with families (e.g. Carter & McGoldrick, 1982). Empirical work has considered the role of life events in a range of contexts, including the development of psychiatric disorders (Chung et al, 1986) depression (Brown and Harris, 1978) and on the mental health of children (Goodyer et al, 1985).

Life events have also been found to be important in the development of mental health problems for people with mild learning disabilities. Ghaziuddin (1988) concluded that such events appeared to be a significant precursor of behavioural problems for people with mild learning disabilities, whereas for those with more severe disabilities the existence of epilepsy and physical illness were more significant. Similarly, Monaghan and Soni (1992) found that life events had a significant impact on the occurrence of

behavioural problems for people with mild learning disabilities and lead also to a decrease in the ability of the clients to care for themselves. The transition from school through to adulthood clearly has important implications for the mental health of young people with learning disabilities and their ability to forge satisfactory and adaptive adult life-styles.

Transitions

Leaving school is clearly only one of a number of important transitions that individuals undergo in their journey between birth and death. Other potential transitions that might be experienced include developing a career, getting married, buying a home, having children, being made unemployed and retiring. Erikson (1950) initially developed the elaboration of life cycle perspectives to human development and the importance of life-events beyond childhood to psychological development. He was concerned with the way in which psychosocial factors, as opposed to the Freudian notion of psychosexual forces, influenced the psychological development of the individual. Erikson conceived that each of us passes through eight stages, each of them presenting their own challenges and obstacles. For Erikson, each stage of psychosocial development builds upon and incorporates the stages preceding it.

Just as individuals may be thought of as going through a number of stages of life development, so indeed may families. In thinking of a family as it moves through time, relationships between parents, siblings and other family members go through stages as each moves along their own life cycle. Indeed, it is difficult to think of the family as a

whole because of the complexity involved. The work by researchers into the transitions experienced by individuals led to the development by Duvall (1977) of the family model that focused on child rearing as the organising element within family life. According to Carter and McGoldrick (1980) the basic phases of the family life-cycle are that first two people meet and become partners, then there is the birth of children, children starting school, passing through adolescence to adulthood, leaving school and then leaving the family home, the deaths of parents and grandparents and the children forming new relationships.

As with Erikson's (1950) model, each stage of development presents challenges and movement to each new stage can be problematic. This is particularly so if families are at incongruent stages of the life cycle. For example, the decision as to when the son or daughter should leave home is usually a difficult one and can be prolonged until the parents are themselves at a point in their lives when they need care. Further development of theories around the transitions that an individual might undergo, and the order in which they occur, have acknowledged the cultural specificity that is an integral part of transitional processes. For example, in many of the world's cultures *menarche*, the first menstruation, is publicly celebrated with elaborate rituals and ceremonies compared to what is in Westernised countries very much a private event (Paige and Paige, 1981).

However, for people with learning disabilities the number of transitions that they undergo will be affected by their disability and the social stigma attached to it. Sometimes they may experience transitions in a different sequence from that of a previous generation

(Goldberg et al, 1995). For example, the person with learning disabilities may leave home as a child in order to attend a residential school, returning then as an adult to live in the family home for a number of years. Additionally, the possibility of someone with a learning disability leaving home may only be faced when the parents are very old. Moreover, the addition of a person with a learning disability to a family may also change the context for further transitions in the family's life cycle (Rappoport, 1986). For example, future pregnancies may be more distressful due to fears about having another disabled child. Similarly, the progress of a younger sibling may lead to feelings of guilt or helplessness on the part of the parent regarding their child with disabilities. Clearly, these issues present additional challenges to the social support networks of people with learning disabilities.

Supporting the transition into adulthood

According to Halpern (1992), efforts to actively prepare students with disabilities for the transition have at least a thirty year history. During this time transition has become understood as a process that needs coordinated planning and merits consideration throughout the life-span. It is seen as something which involves not only the individual but also the family and community (Szymanski, 1994). In the United States transition planning has become a mandated part of Special Education and Rehabilitation Services (Individuals with Disabilities Education Act [IDEA], 1990). Meanwhile, as Russell (1996) notes, in the United Kingdom the 1993 Education Act introduced the concept of a formal transition plan. This concept embodied the development of continuity of assessment, review and program planning and the co-ordination of the many different

agencies and professions which can contribute to this process. Whilst the transition movement has predominantly focussed upon individuals with moderate to severe learning disabilities, Dunn (1996) found that people with mild learning disabilities experience higher rates of dropping out, unemployment and community adjustment problems than their non-disabled counterparts.

Thus, professionals have become more aware of the need for greater planning and the implementation of formal protocols to assist the transition process. However, little is known of the role played by less formal types of support in enabling young adults with learning disabilities to cope with the changes implicit in the transition process. It is known, however, that the support gained via social networks can play an important role in helping people cope with life events (e.g. Wills, 1985). Monaghan and Soni (1992) concluded that community teams need to be more sensitive to the changes in the lives of people with learning disabilities so that procedures of support might be implemented early, thereby reducing 'psychiatric morbidity'. Monaghan and Soni did not specify the nature of the support that might be provided and, as shall be discussed in the later section on social support interventions, naturally occurring supportive relationships have been found to be extremely difficult to replicate in clinical practice.

Nevertheless, little research has been done of the views of people with learning disabilities of the importance of social support generally (Grant, 1993), let alone in this important period of transition into the adult world. Research by Morningstar, Turnbull and Turnbull (1995) did find that students with disabilities consider family involvement

in the transition process to be very important. However, this study focused narrowly upon the decisions regarding future placement and ignored the wider implications of social support and the broader issues implicit to the changes inherent in the transition process. Another aspect of social support which has been examined is that of the negotiation of hazards and risks in everyday life (Heyman and Huckle, 1993). However, whilst there is little specialised literature regarding the social support systems of people with learning disabilities there is an extensive literature regarding social support within other populations. This will be reviewed in the next section.

Social support

As noted above, the belief that the support gained via social networks plays an important role in helping people cope with adverse life circumstances has gained widespread currency over the past thirty years (Wills, 1985). Social support has been found to have an important role in areas as diverse as recovery from surgery (Whitcher and Fisher, 1979) and psychological adjustment following bereavement (Parkes, 1972). However, as we shall see, the literature on social support is not as straightforward as one might hope and furthermore it is difficult to make sense of the research as journals contain many conflicting findings (Krause, 1995). One aspect of the literature which has added to this confusion is that the terms social network, social integration and social support have often been used interchangeably, leading to the claim by Ell (1996) that the term 'social support' should be viewed as a 'generic concept' rather than something specific. Furthermore, there has been no dearth of contrasting attempts to define the concept. These have ranged from Myers et al (1975, cited in Lin, 1986) parallel concept of social

integration to the use of surrogate empirical variables such as the use of marital status as an indicator of social support (Thoits, 1982). The research has lacked a clear theoretical framework and this has lead to a variety of definitions and measures being used, often subsuming the concepts social networks and social integration within the operationalisation of the term (Thoits, 1982).

The stress buffering hypothesis of social support

Ell (1996) noted that social support research was spurred initially by epidemiological data rather than theory (e.g. Dean, 1986). Such research attempted to investigate the link between social support as a generic concept and measures of psychiatric morbidity. The first hypothesis, or **stress-buffering hypothesis** as it is known, proposed that social support was beneficial because individuals with a strong social support network should be better able to cope with major life changes whilst those with little or no social support may be more vulnerable. However, Thoits (1982) highlighted that whilst many studies claimed to demonstrate evidence for the buffering hypothesis (e.g. Antonovsky, 1974, 1979) the literature had not resolved a number of problems. Firstly, as described above, the construct of social support had not been adequately conceptualised and operationalised. Therefore, the specific aspects of social support which reduce the impact of a life-event could not be identified. Secondly, the direct effect of life events upon support and the interactive (buffering) effect of support upon events had been confounded in many studies so that results may be biased in favour of the hypothesis. Those who undergo the most life events may as a result of the upheavals generated experience both less support from a weakened network and more distress. Finally, the relationships

between support, life events and psychological disturbance had not been clarified theoretically: the possibility that support itself is an aetiological factor had been overlooked. These considerations led Thoits to propose the **main effect hypothesis** of social support.

The main effect hypothesis of social support

The issues outlined above led Thoits (1982) to propose that social support has a beneficial effect regardless of whether or not someone is distressed by external events. Furthermore, she surmised that not having social support is conversely distressing in and of itself. This hypothesis, known as the **direct** or **main effect** theory of social support. According to Thoits the theory arose out of two sociological traditions: firstly, the symbolic interactionist tradition represented by the writings of Mead (1934, cited in Thoits, 1982) and secondly Durkheimian anomie theory (Durkheim, 1951, cited in Thoits, 1982). Mead posited that as self-evaluation and social identity are important aspects of psychological well-being and originate in social interaction then one would expect that the lack of social support to have a direct effect upon psychological state. Similarly, Durkheim held that the traditional and stable rules of conduct characteristic of socially cohesive groups give members a sense of certainty and purpose in living. Thus social integration, or normative regulation, protects the person against the uncertainty and despair that may lead to disordered functioning.

Measurement and conceptual structure of social support

As noted above, research into the nature of social support has led to the development of two main theories accounting for the nature of social support. The empirical evidence supports both of these theories (Cohen and Wills, 1985; Cohen and Syme, 1985). In some cases it appears that social support is important to people regardless of the presence or not of significant life events and lack of such support is stressful in and of itself. In other cases, meanwhile, the positive effects of having social support are only evident when stressful life events have occurred. Further research throughout the 70's and 80's has sought to elucidate the structure of social support and the nature of its mediation of distress (e.g. Barrera & Ainlay, 1983; Barrera, 1986). Barrera and Ainlay (1983), for example, studied different taxonomies of social support. According to their analysis six categories were repeatedly endorsed in the articles they reviewed; those of *material aid, behavioural assistance, intimate interaction, guidance, feedback* and *positive social interaction*. Lin (1986) argued that social support could come from any of three levels: the *community*, the *social network*, and *intimate and confiding relationships*.

Numerous questionnaires have been developed which demonstrate good reliability as assessments of social support (House & Kahn, 1985). However, researchers have commented upon the comparative independence of these different measures (e.g. Broadhead et al, 1983, cited in Barrera, 1986; Cohen et al, 1982, cited in Barrera, 1986). Barrera (1986) notes that the relative independence of social support measures is a source of despair to those who interpret it as the lack of convergent validity across measures. However, it can also be interpreted as empirical grounds for drawing clear distinctions

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between social support constructs and seriously questions the value of a global construct of social support.

One concept that has become distinguished as a result of the divergence of questionnaires is that of *social embeddedness* which Turner et al (1983, cited in Barrera, 1986) distinguished from that of *social support*; this refers to the connections that individuals have to significant others in the environment. But, as Pearlin (1981, cited in Lin, 1986) notes, being embedded in a network is only the first step towards having access to support. The final step depends on the quality of the relationships one is able to find within the network. This might include such factors as the receptiveness of the network to the needs of others and the ability of the person needing support to be able to inform & or motivate someone to give them that support.

A further important theoretical construct delineated by the ongoing research is the distinction between *perceived* and *enacted* support. For example, Caplan (1979, cited in Lin, 1986) called for a distinction between *objective* and *subjective* dimensions of support. Barrera (1986) noted that perceived support has emerged as a prominent concept that characterizes social support as the cognitive appraisal of being reliably connected to others. Turner (1983, cited in Eurelings-Bontekoe, Diekstra & Verschuur, 1995) concluded that perceived support was in most studies the significant element and most powerful predictor of health. Barrera asserted that this is consistent with Cobb's assertion that social support is information and Cassel's (1976) emphasis on the feedback function of social support.

Cautions regarding the effect of perceived support upon mental health

However, whilst there is empirical support in the literature of a positive correlational relationship between perceived support and psychological health, the question has to be asked whether this reflects a causal relationship between social support and psychological health. As Gore (1981) pointed out, if the socio-emotional quality of support is measured through subjective reports the correlations between support, subjective stress and mental health are likely to be spuriously high. Felce and Parry (1995) illustrated this point in their analysis of the concept of quality of life. They concluded that despite its subjective nature equating quality of life solely with personal satisfaction and treating the latter as a commentary on the acceptability of one's life conditions should not be accepted uncritically. Similarly, Edgerton (1990) commented on the possible independence between life conditions or events and subjective reports of wellbeing. He cited his and others' research (e.g. Costa, McCrae, & Zonderman, 1987) to sustain the argument that reports of wellbeing owe more to internal dispositions than to external conditions. Significant life events may induce temporary changes in reports of wellbeing but regression to a characteristic level occurs over time. Hence, the longitudinal pattern is relatively stable with the best predictor of current satisfaction being its past rating. Reports of well-being may only be sensitive to gross and immediate changes in life conditions and not provide the subtle indicator of quality of life that is presumed. Similarly, it may be that the correlational relationship between psychological health and perceived support may be a facet of dispositional variables. Furthermore, it may be a spurious correlation which is the result of people reporting that their social support is

adequate due to a lack of negative life events with which to test it. This hypothesis is supported by Sarason et al's (1983, cited in Barrera, 1986) finding that satisfaction with support was not related to positive events but did show a negative relationship to negative life events.

Conclusion

As can be seen from the above discussion, research into social support has developed since the early naïve epidemiological hypotheses regarding the stress-buffering model of social support. The field has expanded to the point where there has been a proliferation of measures regarding social support (House and Kahn, 1985) and of typologies of social support functions (Barrera & Ainlay, 1983). Important distinctions have also been made regarding the differences between the concepts of social embeddedness, perceived support and actual support (Barrera, 1986; Lin, 1986). However, despite this progress the research findings remain difficult to interpret and the nature of the complex relationship between social support and well-being unexplicated (Krause, 1995). A further important strand of research has taken place into the application of these ideas into social support interventions. It is to this aspect of the literature that we will turn in the next section.

Social support interventions

Social support interventions have begun to be widely used in health fields. These have tended to be one of two types (Barrera, 1991). The first is the modification or mobilisation of *existing support structures* whilst the second is the *creation of new*

support networks. For example, Lamothe et al (1995) found that a social support intervention taking the form of discussion groups lead to better adjustment to university as measured by transition adjustment and social support measures. However, numerous authors have noted the complexity of providing social support for people in different situations and the problems that such interventions often come up against. For example, Dadds and McHugh (1992) assessed the effect of social support upon the effectiveness of child management training for single parents when allied with the impact of adjunctive ally support training. They found that, whilst both groups improved and changes were maintained at follow up, the adjunctive ally support training produced no additional gain. However, the improvements in both groups were correlated with high levels of social support from friends. Social support therefore clearly plays a role in in child management. However, the study demonstrates the difficulty in attempting to mimic naturally occurring support systems. Similarly, Heller et al (1991, cited by Vaux, 1991) sought to improve the well-being of elderly women by providing friendly telephone contact with staff or peers. However, again their study failed to find any benefit for the participants from this intervention.

These studies demonstrate the difficulty to be found in trying to promote effective social support interventions. In a review of Heller et al's (1991) intervention, Barrera (1991) noted the gaps in social support intervention knowledge. He pointed out the importance of intimacy in social support exchanges and the difficulties inherent in attempting to compensate for deficiencies in family support with new friendships. However, in asserting the primacy of intimacy Barrera has not fully explored the complex relationship

between support and life events. For example, there is some evidence that when older people who are stressed make demands for assistance others may view them as burdensome, thereby diminishing the quality of the support that is offered (Krause & Liang, 1993).

Vaux (1988, 1991) has asserted that social support is still too often approached as a static feature of the environment. He asserts that it would be better viewed as a dynamic process of transaction between the person and the environment that takes place in an *ecological context*. Other writers have also written of the need to increase the *ecological validity* of our current conceptualisations of social support (Tracy & Whittaker, 1987; Barrera, 1991). Barrera has cited Barry Commoner's (1968, cited in Barrera, 1991) third law of ecology: 'nature knows best'. According to this caution should be exercised whenever planned interventions are considered as, firstly, there may be unforeseen and undesirable consequences and, secondly, interventions that attempt to mimic naturally occurring processes such as social support may miss elements that are vital for their success. Lassner (1991) has argued that the inconsistency in findings as to the efficacy of social support interventions may be as a result of an inadequate theoretical conceptualisation and operational definition of social support, two criticisms that the above review of social support research has raised as pertinent. We turn now to look at some of these criticisms in more depth.

Limitations of social support research

As the above discussion relates, until recently the social support literature has emphasised the beneficial effect of social support on individual well being. This perspective has now been recognised as too simplistic (Ell, 1996). Implicit in social support research is the assumption that recovery and adaptation will be negatively affected when social support is absent or perceived as inadequate, misinformed, misguided, excessive or unwanted. Moreover, as Wellman (1981) pointed out, not all social ties are supportive and it is important to determine under which conditions support might be obtained. In this section theoretical issues that have been raised will be discussed along with the limitations of the questionnaire methodology.

Theoretical criticisms

As we have seen in the above discussion, the conceptualisations of social support within the research literature have been criticised as lacking clarity (Ell, 1996) and being of limited ecological value (Barrera, 1991; Vaux, 1991; Tracy & Whittaker, 1987). Coyne and Bolger (1990) wrote that:

> "A cursory examination of social support literature should raise concerns about whether a plateau was reached some time ago in terms of genuine progress in the field..... The continued growth of the literature is now largely a matter of investigators replicating past findings, applying alternative measures of support, or examining whether support matters for adaptation in yet another population facing a particular problem"
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> (Coyne & Bolger, 1990; p.148)

Coyne and Bolger (1990) have argued that what is needed are concepts of social support that are grounded in the identifiable features of interpersonal relationships. They have asserted that a plurality of methodologies are required that go beyond the "current practice of correlating measures of perceived support with well-being" (Coyne & Bolger, 1990; p.149). Finally, in order to design preventative and therapeutic interventions that utilise people's involvement in relationships, more specific guidance is needed than vulnerable populations need more social support.

Where might current social support theorists look to for conceptualisations that might prove useful? Lassner (1991) has suggested that family systems theory may prove a beneficial adjunct to the social support literature in explaining some of the inconsistent findings that have occurred and providing clinicians with ideas of how to intervene. One important aspect of relationships which the social support literature has not explored is the ambiguous nature of many of our relationships. For example, family members may also engage in double-bind communication patterns that will impair supportive exchanges (Gates, 1988, cited in Ell, 1996). Moreover, optimal support exchange requires clear communication of need as well as the ability of the support provider to meet the expressed need. Knowing that one has access to support does not mean that support will be mobilised. Recruiting support supposes that one has the skill to do so and that one is prepared to accept the possible negative consequences of receiving support as well (Schreurs & de Ridder, 1997). Communication is, therefore, a vital conduit for providing support. Family communication has been shown to influence both family and the

individual's adaptation to illness. For example, less satisfactory reallocation of roles, more role conflict and role strain, less family cohesion and greater family conflict have been found to result from poor communication (Lichtman, Taylor & Wood, 1987, cited in Ell, 1996).

Another strand of research that has not been well integrated with the research on *social support* is that of *coping*. Although both social support and coping have developed within the same frame of reference, that is the paradigm of stress and health, these two fields of research have developed independently (Schreurs & de Ridder, 1997). Thoits (1986) has advocated an interpretation of social support in terms of coping assistance. She argues that the same strategies used by individuals when coping with stress may be applied by the social environment in helping an individual to cope. This perspective on social support also allows for negative types of social support. For example, when helping behaviour from the social environment is lacking or when the support given encourages people to demonstrate dependent behaviour, as in the case of 'victimising support' (Wortman, 1984). Network members may also indirectly communicate their view of the person's ability to cope by being overprotective and thereby sending the person the message that they are incompetent (Thompson, 1992).

Moreover, coping and social support as strategies for coping with negative life events may sometimes conflict. For example, in the Michigan Heart Study it was found that when a wife held back her own anger and anxiety (relationship-focused coping) her husband's efficacy in coping with his infarct was influenced positively, but it had a

detrimental effect on her wellbeing (Coyne & Smith, 1991, 1994). Schreurs & de Ridder (1997) concluded from their review of the data that the empirical evidence shows that chronic disease in the family not only affects the individual but those in his or her support network. They also asserted that seeking social support may have very different functions, specifically the contrasting functions of distraction and problem approaching strategies.

Methodological criticisms

As was noted above, a variety of questionnaires have been developed to assess 'social support' which demonstrate good reliability (House & Kahn, 1985). However, reliability should not be mistaken for validity (Deutscher, 1973) and there are a number of difficulties which underlie the use of these questionnaires, particularly with respect to their use in the development of theory concerning social support. The first difficulty is that these tools have been designed to measure different constructs according to the varying theoretical assumptions underpinning them. Secondly, as Potter and Wetherell have discussed in Discourse and Social Psychology (1987) there are a number of issues with the traditional social psychology research paradigm that much of the research into social support has taken. Social psychology has in the past tended to play down the issue of variation in areas crucially concerned with it. Moreover, procedures used by psychologists to manage discourse such as questionnaires often act as management strategies for *suppressing variability*. Potter and Wetherell have distinguished such strategies which obscure variability and detail in the accounts that participants give. The strategy most pertinent to the use of questionnaires is that of *restriction*. This involves

techniques which prevent the variability in participants' discourse becoming in any way apparent. For example, some early studies of social support equated it to marital status (e.g. Myers, 1975) without considering the nature of the marital relationship and its context. Potter and Wetherell (1987) assert that experiments are situations where the value placed upon consistency of behaviour in our culture is made particularly salient to participants. In general, experiments are designed to wipe out variability of interpretation and response. Indeed, Potter and Wetherell point out that this is supposed to be their strength and rationale, although they may be obscuring some of the most interesting and important features of social life in the process.

Furthermore, as Felce and Perry (1995) have pointed out, the basis for reaching a judgment on satisfaction is comparative: it is impossible to divorce expressions of satisfaction from their context. Thus, a person may be satisfied with his or her support until he or she is confronted by a life event that places that support network under considerable pressure. Such contextual factors may be specific or general, as in the typical circumstances a person has experienced in his lifetime and seen experienced by peers. It is tempting to equate the satisfaction with perceived support expressed in numerous studies as if it were the expression of judgment under conditions of free choice, unconstrained opportunity, equality of expectation and a standard comparative frame of reference. This is clearly not the case; satisfaction is a personal assessment, the frame of reference of which is personal and affected by experience and the judgment of what is possible and typical for a person in one's situation. Expectations and referents may be set

high or low and may themselves change in the life course and in response to personal circumstance.

In particular, expressions of satisfaction may adjust to rather than reflect life circumstance. Quality of life defined as synonymous with personal satisfaction, without regard to widely different life conditions, is a less appealing formulation when reasonable independence and autonomy of action cannot be assumed (Felce and Perry, 1995). Similarly with the assessment of social support, the questionnaires used often assume that those people who are providing self-reports of the level of effective social support that they receive have comparative frames of reference. There are good reasons for being wary of this assumption as people have very different experience of social support as they grow up and therefore are likely to have very different expectations of what is typical or what is realistic. This is particularly the case when considering how current theories of social support might apply to people with learning disabilities.

Finally, the dependence of much of the research into the social support field upon the questionnaire methodology has afforded little opportunity to assess the possibility of individualistic bias. Bolger, Kessler & Shilling (1989, cited in Coyne & Bolger, 1990) have provided a demonstration of what can be done using a diary methodology with multiple informants. Husbands and wives were asked to keep diaries in which they indicated on a daily basis their level of distress and whether they gave or received support. They found that when a partner gave support and the respondent recognised it there was no effect on distress. Conversely, when spouses reported giving support and

their partners did not recognize the support, levels of distress were significantly lower than on days when the spouse gave no support. Coyne and Bolger (1990) asserted that the results of the Bolger et al (1989) study lead to a number of hypotheses as to why unnoticed support might be more efficacious than support of which the recipient was aware. They suggest that when supportive efforts are noticed they entail a threat to self-esteem with the possible implication that the recipient is less than competent or self-sufficient. Further, the support that went unnoticed may have occurred in different contexts to the support that was noticed. Theoretically, Bolger et al's (1989) study underlines the importance of considering the many ways that relationships matter for adaptation other than the narrow view of them as sources of perceived support.

Conclusion

The concept of social support is now seen as one which requires further conceptual clarification and contextualisation within associated psychological constructs such as coping and theories about family systems. The present state of the literature suggests that its use is as no more than a generic concept at present (Ell, 1996; Coyne & Bolger, 1990; Schreurs & de Ridder, 1997). Vaux (1991) has pointed out that research strategies which have been predominantly used to investigate social support as a phenomenon have placed priority upon internal validity and the construct validity of the causal relationship will play an important role in evaluating social support interventions. However, Vaux points out that this strategy has a number of drawbacks also. Most importantly, rigor often demands inflexibility and specification which constrain exploration. Coyne & Bolger (1990) have also urged a diversity in the methods used to study social support. We now

turn to consider how social support might be applied to the lives of people with learning disabilities.

Social support and people with learning disabilities

As we have seen in the above section, the research into the nature and structure of social support in the general population has a number of shortcomings in and of itself. It has been criticised as simplistic and has not taken into account the context in which supportive actions take place. There are further reasons why we should be cautious of applying the research to young adults with learning disabilities as it stands when considering what type of social support would be needed during the transition into adulthood. Firstly, this is because people with learning disabilities have throughout the years been and remain stigmatised by the general population and therefore remain set apart.

Bercovici (1981) has asserted that people with learning disabilities are not and do not perceive themselves to be part of the normal community. She concludes that they may be seen as inhabitants of a physically separated and culturally distinct social system. Kielhofner (1979) has written of the *human career*, suggesting that experiences taken for granted within the general population do not often present themselves to people with a learning disability. This is supported by research which consistently shows that people with learning disabilities experience unusual patterns of social interaction (e.g. King, Raynes & Tizard, 1971; Hastings & Remington, 1996). Bercovici (1981) has

hypothesised that therefore they may as a result of these different life experiences build up qualitatively different ways of interpreting the world around them. It is important to understand the ways in which adolescents with learning disabilities perceive their social world and the support they receive from it in order to be able to better plan and initiate strategies. These might seek to mobilise or modify the social support available to them as they undergo the transition from child and adolescent services to those of the adult population.

Social networks of people with learning disabilities

Numerous authors have concluded the need for research into the functioning of social support networks for people with learning disabilities (e.g. Grant, 1993; Rosen & Burchard, 1990). Studies have quite often looked at these support structures from the point of view of the main carers of the person with the disability (e.g. Grant, 1993). These have shown that the support networks of people with learning disabilities tend to be quite small, with many people within the network taking on a number of roles. However, how the persons with the disability themselves view the support network around them and how they value the support they receive has not been researched much. That social support patterns among people with learning disabilities has received so little attention is a critical omission. This is particularly so given that many individuals with learning disabilities seem to attribute greater life satisfaction and successful community adjustment to the presence of family and friends and active social lives (Edgerton, Bollinger & Herr, 1984; Landesman-Dwyer & Berkson, 1984). In addition, Clegg and Standen (1991) found that amongst a group of adults with learning disabilities those who

described themselves as being without a peer-group friend had lower self-esteem than those who described themselves as having friends.

Methods based on social network theory have been used to elicit information about social support systems and to quantify these and compare them with those of the general population. Bercovici's (1981) claims about the lives of people with learning disabilities are not entirely borne out by the empirical research. For example, Todd, Evans and Beyer (1990) examined the community activities and social networks of people with developmental disabilities living in the community. They found that whilst people with developmental disabilities were engaging in a wide variety of community activities, opportunities for interaction with non-disabled people from the wider community were restricted. Additionally, the presence of non-disabled people within the friendship *network* of people with developmental disabilities was also limited. Similarly, Rosen and Burchard (1990) concluded that whilst the disabled participants in their study were neither inactive nor perceived themselves as socially isolated when compared to a control group of single adults from the community, their actual level of community integration was extremely limited.

Thus it can be seen that the available research indicates that whilst adults in the community are accessing community resources their level of integration within the community remains low. These data support Bercovici's view that there are qualitative differences between the networks of people with learning disabilities and those of the non-disabled population. Furthermore, much has been made of the way the support

networks of people with learning disability constrict as they become older and family members and friends leave through either death or relocation (Grant, 1986, 1993; Clegg and Lansdell-Welfare, 1995).

Family relations

However, whilst research into the views of people with learning disabilities of their social networks has been limited, research into the family relations of people with learning disabilities and the nature of their friendships has taken place. Families clearly play a central role within the lives of many people with learning disabilities. Much of the literature regarding people with learning disabilities suggests that as adults they often lead lives that are in many ways dominated and determined by others (Firth and Rapley, 1990). One aspect which strongly affects the nature of the relationship between carers an people with learning disabilities is that carers must cope with their need to keep their offspring in a childlike state and the difficulty they experience of 'letting go' (Richardson, 1989). Given the fears that exist for parents, it is not surprising that there is a tendency for some to be protective in ways which inhibit friendships and opposite sex relationships.

As a result of the fears that many parents express in relatin to their sons and daughters, Hutchinson (1983) found that the time and activities of people with learning disabilities living at home are family-centred. The peer relationships of people with learning disabilities are limited and constraints of privacy and physical recreation hinder experimentation in interpersonal relationships. Card (1983) also found that parents were

reluctant to encourage the use of independent living skills practised at Adult Training Centres. Regarding research undertaken with people with learning disabilities and their families, Heyman and Huckle (1993) noted that previous studies gave a rather monolithic picture of over-protective and restrictive parents. They researched the risk management strategies that families with a learning disabled member undertake. Their research suggested that parents of learning disabilities use varying strategies in order to assess risks and to negotiate, or otherwise, with their sons and daughters which 'hazards' were to be accepted and which were not.

Friendships

As might be expected from the work on social support reviewed above, close friendships have been associated with the subjective well-being of people without disabilities (Deiner, 1984). However, personal relationships were rated as the second most difficult aspect of living independently by people with learning disabilities (Halpern, Cose & Nelson, 1986). Clegg and Standen (1991) looked at the difference between people with learning disabilities who had friends and those without. Flynn (1987) interviewed all adults with learning disabilities who lived in unstaffed accommodation in one region and found that the longer they had lived independently, the less satisfactory were there personal lives in terms of numbers of visitors, experience of loneliness, and number of positive relations with people. These findings support those of Gollay, Freedman, Wyngaarden and Kurtz (1978), who found that difficulty with social interaction was a significant problem for 40% of the 440 de-institutionalised people that they interviewed.

However, in a participant-observer study, Kaufman (1984) found that people who had lived independently longest were the most socially satisfied.

Social-ecological research has brought a unique perspective to factors influencing friendship development among adults with learning disabilities (e.g. Landesman-Dwyer & Berkson, 1984). Two findings from this research are that affiliative behaviour is influenced by the intelligence level of the whole social group rather than its individual members (Romer & Berkson, 1980) and that social behaviour does show change between settings (Heller, Berkson & Romer, 1981). However, account needs to be taken of the fact that for people with learning disabilities the experience of loneliness does not covary with the amount of social contact they encounter (Rook, 1984). Social skills training is often recommended to help people with learning disabilities make and maintain friendships. Yet, as Schloss and Schloss (1985) have suggested, the absence of a broad conceptual framework will hamper development in this area.

Clegg and Standen (1991) elicited constructs from people with learning disabilities who were classified for the purposes of the study as having or not having friends. They concluded that there were no differences in the constructs of those who did or did not have friends. Clegg and Standen also suggested that many people with learning disabilities who do have friendships nevertheless experience a relatively superficial level of relationship. Similarly, Zetlin and Murtaugh (1988) observed a lack of intimacy and empathy in interactions between adolescents with learning disabilities. Clegg and Standen (1991) have suggested social-emotional developmental models may aid the

development of theoretical understanding of the quality of friendships among people with learning disabilities. Clegg and Standen also suggest that people's reactions to being a member of a disabled group suggests that service providers approach discussion regarding the personal limitations with extreme care it appeared to them that those with non-disabled friends were less likely to identify themselves as disabled. However, the social identity of people with learning disabilities may be determined as much by their experiences of how others react and behave towards them.

Reasons behind network differences

Why do these qualitative differences between the support networks of those who are disabled and those who are not exist? Edgerton (1967) proposed that many people with disabilities make exaggerated efforts to remain inconspicuous as a means to deter exposure of their past life in an institution. This may be one reason for the low level of contact between disabled and non-disabled citizens in the community. However, it appears that the lack of social contact is also a feature of the lives of people who have never lived in institutional care (McConkey, Walsh & Mulcahy, 1982). McConkey et al (1982) also found that family members have key roles to play in supervising how people with learning disabilities access services in the community. This research has been supported by that of Heyman and Huckle (1993) who conducted a grounded theory analysis into the complex and shifting balance between risk taking and danger avoidance struck by families. They developed a typology of three categories: shared risk taking, shared danger avoidance and conflict. Heyman and Huckle found that of the twenty families in their study eleven adopted the shared danger avoidance pattern, two were in

conflict and seven the shared risk taking strategy. Heyman and Huckle (1993) also discussed the cyclical nature of such a control cycle when hazards are treated as dangers to be avoided. They give the example of an adult not being allowed to see a partner without supervision because of the possible dangers of pregnancy and upon the assumption that because of their disability they will be unable to behave responsibly. Heyman and Huckle posit that in these circumstances adults may develop unrealistic and immature ideas about relationships which in turn 'prove' to carers that they are not capable of being responsible, leading to further restrictions.

A further factor which may influence the nature and type of the social ties held by people with learning disabilities is Festinger's (1954) social comparison theory. Gibbons (1985) applied this theory in a study of attitudes of people with learning disabilities towards one another and towards people without disabilities. He found that individuals with learning disabilities who lived in institutions rated their abilities and attractiveness more highly than those with learning disabilities who lived in the community. He thought that the institutionalised group enhanced their self-esteem by downward social comparison. This may have implications for the formation of social ties of those in the community. Similarly, Sinason (1992) has suggested that people with learning disabilities develop secondary handicaps in addition to those they already possess as a fulfillment of a social role.

A further aspect of the supportive relationships is the notion of reciprocity. Rosen and Burchard (1990) concluded that reciprocity was almost non-existent in the relationships

of people with learning disabilities. Grant (1993) has written that often in studies the directionality of ties has often been presumed, which creates the impression of the 'cared for' as passive, unable and lacking in influence (e.g. Wilkin, 1979; Ayer & Aleszewski, 1984). Similarly, Taylor and Bogdan (1989), in writing about accepting relationships between people with learning disabilities and non-disabled people as the converse aspect to labelling and stigmatisation, noted 4 themes expressed by people explaining the nature of their relationships; those of family concern, religion, humanitarianism and feelings of friendship. In all first three themes the tie was conceived as unidirectional in nature. However, Grant (1993) has chronicled that as carers become older the nature of the relationships become more reciprocal, although imbalance in ties, or asymmetry, may nevertheless be indicative of differences in the status and power of individuals concerned.

Finally, Ell (1996) pointed out that accessing social support requires complex skills involved in the management of relationships. Abraham (1989) has argued in a similar fashion that developing networks within the community require complex skills. Even where social skills training is available many people with a learning disability remain less skilled interactants who break social rules more frequently and are less able to repair friendships through remedial action. It is interesting to note that in her paper discussing the role of social support in ameliorating distress, Thoits (1982) added the caveat that pre-existing 'psychological disturbance' may determine individual's social support levels and their life experiences.

The poverty of research into the social support (Grant, 1993) means that little is known about how people with a leaning disability view or use such support. Morningstar, Turnbull and Turnbull (1996) have examined the views of children with special needs as to the importance of family involvement in transition planning. However, little research has studied how people with learning disabilities experience the emotional or instrumental support they derive from those with whom they come into regular contact.

Conclusion

As can be seen from the above discussion of the existing literature, little of ecological value is known about the functional process of social support in the general population. The state of theoretical development does not lend itself to the development of social support interventions which might aid people in the general population, far less those with learning disabilities whose experiences of stigmatisation will produce a different experience of the social networks around them. In order to support the development of such interventive approaches which might seek to mobilise or establish social support for young adults with learning disabilities undergoing the important transition from school to adult life. The author decided it would be important to try to understand how such support systems functioned during the transition phase.

Research Questions

It was the aim of the current study, therefore, to examine the views of people with learning disabilities who are currently experiencing the transition from school to adult services as to the nature of the supporting relationships they experience. The study also tried to explore the criteria by which they judge the relationships as supportive or otherwise. It also attempted to study which dimensions of social support are important to people with learning disabilities in which circumstances, looking at, for example, factors such as location, parental attitudes, and the abilities of people with learning disabilities. It is important to consider how these might affect how the person with learning disabilities perceives the potential supportiveness or otherwise of the social network around them.

Assumptions

Whilst all research necessarily makes assumptions about the phenomena under study, qualitative methodologies generally hold that it is important for the researchers taking part in an investigation to be aware of their own prejudices and assumptions (Dey, 1990). The main assumption made in asking the above questions was that as support networks have been found to be important with people in the general population, so it would be important for people with learning disabilities. A second assumption related to the conceptualisation of social support. Normally the term is recognised only as referring to support received from informal sources of support such as friends and family and not to

people paid for their services to the individual (e.g. Thoits, 1982). However, for the purposes of this study it was assumed that people with learning disabilities may well perceive their social support as coming from people paid to provide a service for them, particularly when living in staffed residences.

Methodology

When considering the methodology to be used, a grounded theory methodology was decided upon for two reasons. Firstly, Henwood and Pidgeon (1995) have argued that over-reliance upon theory testing and verification can lead to a neglect of strategies for the systematic generation of new theories. They argue that this is minimally necessary where theory is non-existent, such as a new domain of inquiry, or where new theories are required in response to old paradigms that have run their course. As can be seen from the foregoing literature review, the literature on social support has not lead to the development of theories with good ecological value. Theories that have been developed cannot be easily applied to problems of understanding how social support may affect the transition from school through to adulthood made by adolescents with learning disabilities. The concept of social support has been poorly developed within the research literature and has not been theoretically developed (Ell, 1996).

Furthermore, the existing research into the social support structures of people with learning disabilities indicate that the social worlds and experiences of people with learning disabilities are substantially dissimilar to those of the general population. Therefore, it is likely that people with learning disabilities have different expectations and understandings of social relationships. Grounded theory is a methodology that is specifically designed for the *development* of theory, as opposed to its *testing* (Strauss and Corbin, 1990), and therefore proves useful in the development of theories which explain the process of support interactions.

Secondly, research has shown that carers' judgements often differ from those of the individuals with learning disabilities. It has been found that it is not the 'objective' level of social support which correlates with self-ratings of well-being but the perception of support. Thus, who is felt by a respondent to form part of a support network and what is considered to be a supportive act is clearly a judgement with a large subjective element to it. This element of subjectivity further suggests that a research paradigm which enables the researcher to encourage the participants to express themselves about their own social worlds through their own terms of reference rather than through predetermined categories and questions would be of benefit. Finally, in relation to understanding the perspective of people with learning disabilities themselves, Heal and Sigelman (1995) have written of the importance of helping devalued groups speak for themselves so that professionals and the wider community can be more aware of their concerns and experiences.

Qualitative Research Methodologies

Grounded theory is one of a number of qualitative research methodologies alongside others such as discourse analysis and protocol analysis (Denzin & Lincoln, 1994; Orford, 1995). Qualitative research differs primarily from quantitative research in that it seeks to use data in forms other than those of numbers. The goal of qualitative research is the development of concepts to gain understanding of complex psychosocial phenomena whilst giving due emphasis to the experiences and views of the participants (Pope & Mays, 1995). Bogdan and Taylor (1981) have asserted that in qualitative studies

researchers are usually interested in understanding people's subjective states, what are referred to as their perspectives, world views or cognitive maps. As the literature concerning social support indicates that there is little correlation between measures of objective support and perceived support (Barrera, 1986; Tracy & Whittaker, 1987) this suggests that cognitive factors such as the perception and evaluation of social support are significant.

Whilst qualitative methodologies have always been part of the methodological repertoire of psychology they have often been seen as an adjunct or pilot phase to the main task of quantitative data gathering and analysis (Henwood & Nicolson, 1995). Recent authors, however, have asserted the importance of qualitative methodologies to the study of psychological phenomena and have linked this to developments in epistemology (e.g. Henwood & Pidgeon, 1992). According to this narrative, the quantitative research techniques belong to the natural science's positivist paradigm of psychology which emphasize universal laws of cause and effect based on an explanatory framework that assumes a realist ontology (Denzin & Lincoln, 1994). By contrast, qualitative research is seen as including a commitment to constructivist epistemologies which view the scientific process as generating working hypotheses and theoretical frameworks rather than immutable facts. This is seen as including an attitude towards theorising which emphasises the emergence of concepts from data rather than their imposition in terms of *a priori* theory (Henwood & Pidgeon, 1992).

The above paragraph has briefly outlined how quantitative and qualitative methodologies in psychology have been ascribed to extreme epistemological positions. However, this narrative takes no account of the variety of epistemological positions which have been described and which apply equally to the natural sciences of physics and chemistry as to the human sciences of psychology and sociology (Chalmers, 1978). Latour (1987, cited in Henwood & Pidgeon, 1992) has suggested that quantification is but one manifestation of the common practice of deriving coherent, mobile and combinable inscriptions in science. By this argument qualitative and quantitative research procedures are but different forms of the analytic practice of re-representation in science in that both seek to arrange and re-arrange the complexities of 'raw' data. The current author would agree with Bryman (1988) that the choice of methodology should be justified on pragmatic grounds of which is most suitable to answer the particular research question.

Grounded theory

As noted above, it was decided to conduct a grounded theory study of the phenomena of social support due to the lack of general theoretical development with genuine ecological validity and the distinctiveness of the social experiences of people with learning difficulties. The primacy that such a research effort would give to the voices of the participants was also a key factor in choosing the methodology. Henwood and Pidgeon (1992) have asserted that grounded theory makes a significant contribution to the generation of psychological theory in the provision of explicit skills and techniques. Glaser and Strauss (1967) originally used the term grounded theory to refer to theory that is generated in the course of the close inspection and analysis of qualitative data.

Strauss and Corbin (1990) assert that the process of grounded theory gives research the necessary rigour to make the theory good science. The specific techniques help the analyst break through the biases and assumptions brought to, and that can develop during, the research process. Their aims are to provide the grounding, build the density and develop the sensitivity and integration needed to generate a rich, tightly woven explanatory theory that closely approximates the reality it represents. Originally, grounded theory was presented as a primarily inductive process. According to Strauss and Corbin (1994) the original work by Glaser and Strauss (1967) greatly underplayed both the potential role of extant theories and the unquestionable fact that trained researchers are theoretically sensitised. Theoretical sensitivity in this sense refers to a personal quality of the researcher (Strauss & Corbin, 1990). It indicates an awareness of the subtleties of meaning within the data. Use of literature, both technical and non-technical, and professional and private experience can enhance theoretical sensitivity. In addition the analytic process may also provide an additional source of sensitivity.

Research design

Participants: Participants were approached through a number of social and education services within Sheffield. The services included a college of further education, two work placements within the city and the social work team aimed specifically at working with young people with learning disabilities. The purpose of the research was explained to the

staffs who were then asked to suggest possible participants who had recently undergone the transition from school and would be willing to take part. The criteria for taking part in the study were:

- sufficient verbal communication skills to be able to hold a conversation

- no evidence of autistic spectrum disorders

- to have attended one of two named schools within Sheffield whose remit was specifically for people with mild/moderate learning disabilities

- age range of 18 to 21

Once the participants had agreed to meet with the researcher an appointment was arranged so that they could be given the necessary information about the study (see Appendix 1) and their consent and the agreement of their carers could be sought. Seven people were suggested by the agencies approached as suitable for the study, one of whom was declined due to the diagnosis of an autistic spectrum disorder. Of the remaining six, who agreed to take part in the study, five consented to a second interview subsequent to the first.

A central aspect of grounded theory is that of theoretical sampling. According to Strauss and Corbin (1990), the aim of this is to maximise the findings of difference at a dimensional level in order to be able to fill in poorly developed categories and to maximise the opportunities for verifying the storyline. Following through on these variations allows the researcher to add density and variation to the theory, thereby

increasing the depth of understanding of the phenomenon under study. Due to the time constraints of the study, theoretical sampling did not proceed as it would under better conditions as it was not possible to cycle the process of coding and further sampling, which would be the optimal method. However, the author was aware of the need to talk to participants with a variety of abilities and varying experiences of the transition process. A number of factors were thought of as key in considering who to talk to: the gender of participants, the outcome of the transition and the nature of the social network from which they came. In order to achieve theoretical sampling a range of organisations which young adults with learning disabilities were likely to attend were approached and, where necessary, the sampling needs of the study were discussed with the person involved. As the study progressed the author became aware of the need to interview female participants and also those who had taken vocational options as opposed to educational ones.

Interview guide: In line with Strauss and Corbin's writings on theoretical sensitivity (Strauss & Corbin, 1990, 1994) an interview guide (see Appendix II) was developed which was based upon typologies of social support found in the research literature (Barrera & Ainlay, 1983). The aim of using a guide rather than a structured schedule was to allow the participants and researcher the flexibility of following any themes that developed as the participants described their experiences of transition and social support. The guide consisted of several areas for discussion and examples of possible open-ended questions and more specific prompts for each section.

Use of open and exploratory questions was considered important as these have been shown to reduce acquiescence and 'nay-saying' compared to closed questions (Atkinson, 1988). When given 'either-or' questions people with learning disabilities tend to choose the latter and researchers have been advised to ask questions in multiple formats in order to be able to estimate the validity of responses (Heal & Sigelman, 1995). Furthermore, it was recognised that questions should be kept as simple as possible and that interviews should proceed at a pace appropriate for the participant (Lowe & De Paiva, 1988). Following on from these recommendations, the researcher's aim throughout the interview became the welding of the questions and themes in which he was interested onto the flow of scenarios and experiences related by the participant.

Interview procedure: It was decided to interview the participants twice. It was felt that this would be important methodologically as social support is a sensitive area which touches upon subjects which might be important and delicate for the participant. It was hoped that the use of double interviews would enable the interviewer and the participant to become familiar with one another in an initial interview which would cover less emotive issues regarding support and transition. It was anticipated that the interviewer would then be better placed to attempt to talk about more sensitive areas such as relationships and emotional support in the second interview. This would also enable the interviewer to be better understand the participant's language and able to judge the pace of the interview. On occasions when it was not easy to understand what was meant, because of unclear speech or ambiguity in the response, and in these cases closed

questions, forced choice questions and reflections were used to ascertain clarity as to the meaning of the participant's responses.

Transcription: The resulting tapes of the interviews were transcribed verbatim. Every effort was made to produce an accurate record of what was said during the interview. Occasions when the speech on the tape was too indistinct to transcribe were represented by question marks.

The Analytic Process

The analytic process in grounded theory is a iterative one which consists primarily of three forms of coding: *open coding, axial coding* and *selective coding* (Strauss & Corbin, 1990). The analysis cycles through increasingly abstract levels of data collection, description, classification connection and account. Whilst open and axial coding are presented as different forms of coding, during the actual analysis of data the two were used in an interactive way. During the coding process the 'fit' of the developing categories was continually tested and questioned and ideas reviewed as a result. The researcher was aware of Strauss and Corbin's exhortation that categories and hypotheses shouldn't be forced onto the data. This was avoided by stepping back and questioning, maintaining an attitude of skepticism and seeing all categories and codings as provisional. This process was aided by having several transcripts partially coded by

another researcher, thereby providing further corroboration, or otherwise, of the codes and categories developed.

Open coding

Open coding is the process of labelling phenomena and conceptualising the data. It is the first step in the analytic process during which the data are broken down into discrete parts. The aim of this is to question and explore one's own and other assumptions about the phenomena. These conceptualisations may then be grouped together into categories, which need to be developed in terms of their properties and dimensions. Coding can be done on a line by line basis, or by sentence or paragraph or by an entire document. During this part of the coding process the codes were written onto index cards and the use of the technique of **constant comparison** was central to the coding process, whereby data was compared to previous codes in an attempt to differentiate new phenomena from those already coded. In practice this researcher found it difficult to maintain an overview of the profusion of different categories that arose out of the process of open coding. Indeed, it was necessary to undertake a review whereby the categories which had been created through the process of open coding were rationalised in cases of duplication and the relationships and types of categories. The process became easier to manage cognitively when the researcher began moving more fluidly between open coding and axial coding after an initial period of open coding the first eight transcripts. The researchers assumptions and emerging concepts were questioned using the technique of negative case analysis, whereby the researcher looks for examples within the data which run counter to the current theoretical ideas.

Axial coding

Axial coding is a set of procedures whereby data is reassembled in new ways after open coding by making connections between the different categories. Strauss and Corbin (1990) proposed a paradigmatic model whereby the events, incidents and happenings (**causal conditions**) that lead to the development or occurrence of a **phenomenon**, which is the central event, happening or idea to which the set of actions are related. The **context** is the set of properties which belong to and define the phenomenon, whilst the **intervening conditions** are the structural conditions which facilitate or constrain the strategies taken within a specific context. The **action/interaction strategies** are those designed to respond to a phenomenon under a specific set of perceived conditions and the **consequences** are the outcomes of results of actions or interactions. The application of Strauss and Corbin's (1990) paradigm model to the developing open codes for social support was found to be particularly difficult due to the reflexive nature of social support. This lead to ambiguities about where categories and concepts would fit into the paradigmatic model proposed by Strauss and Corbin. For example, some categories, such as **abuse** and **isolation** could be conceived of as having dual roles within a process model of social support. Not only are they important aspects of an individuals social support network, thereby providing an information of the **context** in which supportive interactions take place, but such concepts were also described as a 'challenge' to the individual resulting in emotional responses which may themselves require support. Axial coding in this study therefore followed a process of connecting the categories and identifying several main categories within which others could be grouped.

Selective Coding

Strauss and Corbin (1990) assert that in a fully successful grounded theory a 'core category' emerges. This is the central phenomenon around which all other categories can be integrated. After some time of collecting and analysing data the task becomes one of integrating the categories to form a formal grounded theory (Strauss & Corbin, 1994). Integration is not much different from axial coding, it is simply done at more abstract level of analysis. The aim of selective coding is therefore to develop the story line which best accounts for the categories generated. This is the conceptualisation of the story or the *core category*. Clegg, Standen and Jones (1996) have posited alternatively that other organising structures such as a typology of interactions may prove an alternative and equally valid aim for a grounded theory study.

The Analysis

This section of the report will attempt to convey the model of social support in the transitional stage when an adolescent with learning disabilities leaves school and begins an adult life which was developed using the coding procedures outlined in the Methodology section above.

In the following section of the report the major categories using the coding procedures have been printed in **bold type** and the properties and ranges of categories have been printed in *italics*. Sub-categories have been <u>underlined</u>.

The Model

An outline of the model of social support (see Figure 1) will be described here to contextualise the following, more detailed description. This begins with the **challenges** inherent in the transition process and the participant's lives more generally. These may themselves be the repercussion of previous **challenges** experienced by the individual. They may also be affected by the participants' abilities to **manage their social network**. The model then proceeds to explore the mediating factors that determine how an individual responds to the **challenges** with which they are presented. These include **emotional states** and **relationship factors** such as the nature of the participants' <u>relationships</u> and <u>locality</u>. **Contextual factors** are also considered and the manner in

which they affect decisions taken by participants regarding the use of **self-reliant coping** or **social support**. Analyses of these categories and **consequences** are complemented by an analysis of **social network management**. The reflexive aspects of social support is represented by the way in which <u>unsatisfactory consequences</u> presenting new **challenges** and the way in which the context of someone's support system can present challenges through the difficulties they experience in trying to cope with developments.

The conceptual model that has been outlined above will now be described in more detail and with reference to interview excerpts. This will enable the reader to judge the appropriateness of the interpretation presented by the author.

Challenges

I: Carry on, was it leaving school. What was that like?

P: (Sigh) Difficult.

Participant 1, Interview 1:6-7

The initial interview began by asking participants to describe the experiences and challenges they had during the time of leaving school and entering into adult life. This lead naturally into the development of the category **Challenge**, which was defined as the problems and difficulties identified by participants in their lives. This category sub-divides into those of <u>occupation, social connectedness, abuse, practical difficulties</u> and

Figure 1: Diagrammatic representation of the support and coping model showing the relationships between the major categories.
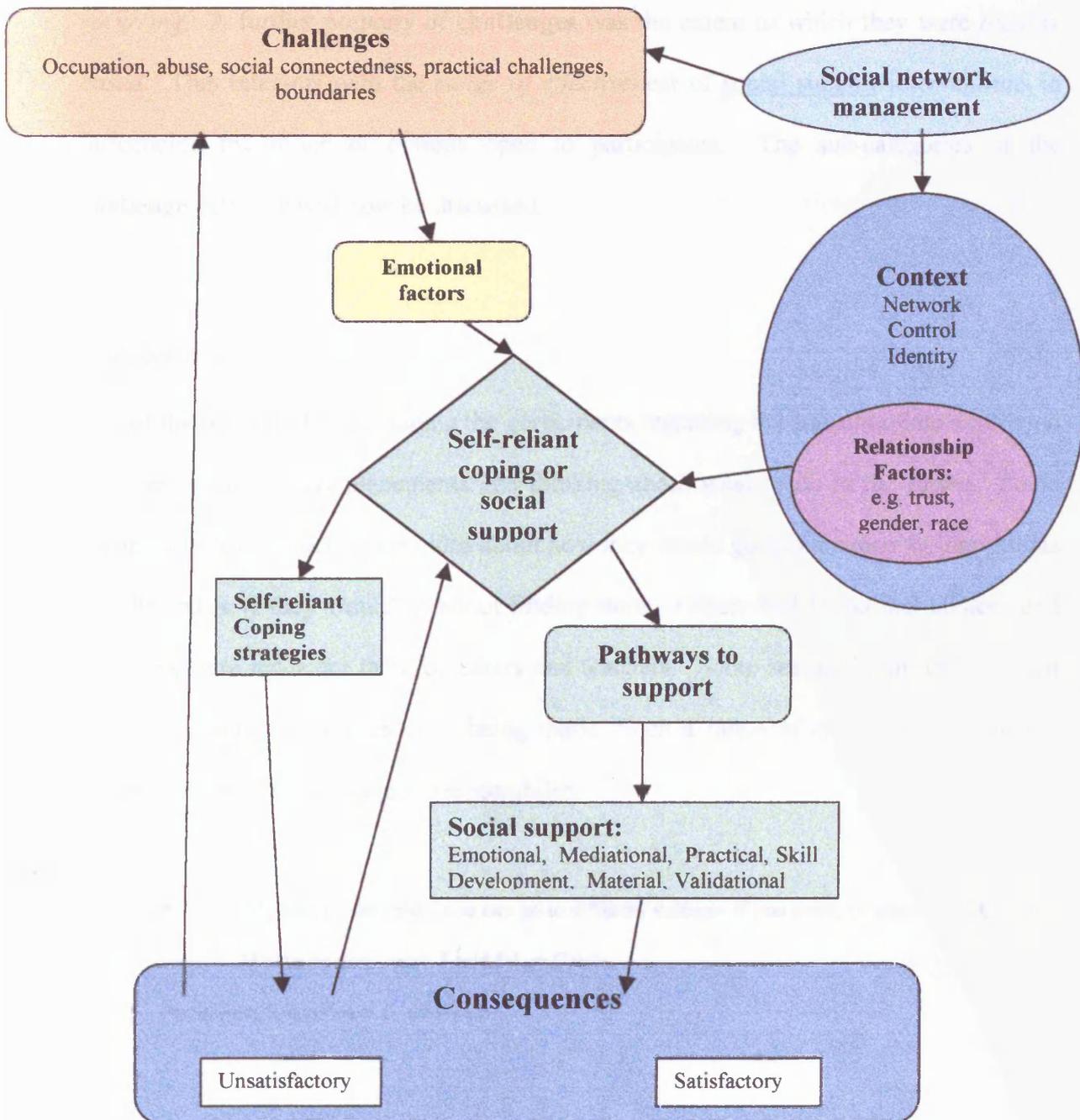
boundaries. Whilst the constructs of occupation and boundaries are linked directly to the transition process, those of abuse and practical difficulties are much more general in nature. Therefore properties of the category of challenge are the extent to which a challenge is *specific* to the transition process, ranging from *completely specific* to *non-specific*, and to what extent it is likely to *recur*, ranging from *unique* to *constantly recurring*. A further property of **challenges** was the extent to which they were *locality based*. This interacts with the *range of effectiveness* of social support interventions in influencing the range of options open to participants. The sub-categories of the **challenge** category will now be discussed.

Occupation

One of the main **challenges** facing the participants regarding the transition into adulthood was the finding of day placements and thinking about what to do in the future. Some participants had a much clearer idea about how they would go about choosing placements or jobs and how they would go about finding them. Others had found that choices and decisions were made for them by carers and teachers. Some seemed even unaware that these decisions and choices were being made. Such a range of experiences inevitably raises issues around control and responsibility.

P: Oh, Mrs L, she said, "you can go to different colleges if you want, or you can go Castle. Whatever you want". I said I'd go Castle.

Participant 5, Interview 1: 184-185

Participant 5 clearly felt that the decision would be made by somebody else, and that he would be informed of this at a 'review' meeting:

P: And then they send you into another place.

I: And what sort of other place do you think.

P: I don't know yet.

I: Have you talked to anybody about it.

P: No. till 'ave another interview again. Review, I mean, about a job. If they say I've behaved well 'ere - cos I was messing about 'ere and carry on being good 'ere - it's good for everybody 'ere, everybody - if they're good and they're working good 'ard, right - then they find jobs for those people

Participant 5, Interview 2: 178-185

Participant 3, on the other hand, appeared to consider himself as having much more control and influence over his coming employment prospects:

P: No. Well, you go down, and if you've got a question like - 'Can I have a careers interview then' or clear a book, or make a date with whoever you want to see. (Yes) But you've got to know the careers teacher's name to have interview. (Right). Like when another careers talk's on - to see like what I'm doing when I leave college.

Participant 3, Interview 1: 254-257

One property of occupations was *suitability*. Participants differentiated clearly between those placements that they had felt were suitable for them and those at which they had been unhappy:

P: .... Then I went to CH (Yeah) I didn't like it there. Becos' I cut , I got cut on me hands

         becos' there was blades........sharp blades. I used to go round wi' cuts on me 'ands.

Participant 4, Interview 1: 186-187

Social Connectedness

Another important challenge facing people undergoing the change from school to those

of adulthood was the difficulty of maintaining social connectedness. This was defined as

maintaining existing and establishing new social relationships. This was particularly

difficult at a time when changes in daytime occupation and living arrangements would

make this particularly pertinent.

I: What about people at school when it was actually time to leave. Were they helpful, or

         not?

P: Errr.... Not really. I mean, I were quite upset when I left school. (Yes) 'Cos I were

         missing me friends. When it got to the holidays I were really missing me friends then -

         then they all rang me up and gave me their addresses. So I gave them all me 'phone

         number. (Yes). So I gave them me address. Me 'phone number's in the book

Participant 3, Interview 1: 123-127

This issue was further complicated for four of the participants in the study who had

moved from their family homes over the course of the transition. Not only does this

reflect instability and change in the support network but is a source of **challenge** to the

individual as well.

I: How did your mum feel when you left.

P: I feel it's alright - it's up to me.

I: She said it was up to you.

P: Yes. She didn't say that. I know it's up to me anyway. She was upset and crying and I
        was a bit. 'Cos ....

I: I guess it's very difficult, actually.

Participant 5, Interview 2: 441-446

Abuse

This was defined as living in or experiencing situations that could be abusive was also
raised as one of the **challenges** experienced. Whilst not one *specific* to the transition into
the adult world, physical and verbal abuse were clearly identified as a problems which
occurred in participants' lives. This category also included experiences of bullying. One
property of abuse was *source*, which could range from someone *familiar* to someone
unknown. For example, one participant talked about the violence he had experienced at
the hands of his father:

P: My dads' er, my dad's er cracked me brother as well.

I: Cracked your brother? Did he crack you as well?

P: Yes.

I: Yes.

P: With a .... with a belt.

I: With a belt? Sounds painful.

P: It does. It hurts. (yeah) It really hurts.

Participant 1, Interview 1: 237-243

Another discussed bullying from a relative stranger:

> P: No, I weren't sad. This lad called JW, he kept bullying people 'ere and I said 'Either 'it me
>
> or bleedin' get out'. He used to pick on me at Castle College - my carer sorted it out.
>
> Participant 5, Interview 1: 301-302

Other concepts subsumed into this category were 'name-calling' and 'being made fun of', which were labelled <u>verbal abuse</u>:

> P: They got excluded a load of times, them. I got excluded once because this boy called me
>
> names and call me Mum a 'slag' and 'bitch' and 'prostitute' and then I got excluded once
>
> and I didn't do it since. For beating 'em up a little bit and these lads got excluded loads of
>
> times for messing about.
>
> Participant 5, Interview 1: 398-401

> P: .... they not 'andicap, Oh, No, not 'andicap. They can do quick writing - I can't do that.
>
> They was laughing and making fun of me.
>
> Participant 5, Interview 2: 68-70

It was clear from the interviews that <u>verbal abuse</u> was very muvh a fact of many of the participant's lives.

Practical difficulties

The participants also discussed a number of <u>practical difficulties</u> that they faced occasionally. This category was defined as consisting of the more prosaic obstacles faced

by the participants in the course of day to day activities and their difficulties in solving them. It was conceived as including diverse challenges such as having one's computer stolen, issues around travelling or the difficulty of finding the way around an unfamiliar building.

P: ...... somebody didn't lock my wardrobe properly 'cos - 'cos I went upstairs and I found my computer missing and I was asking 'im where it had gone and nobody hadn't got a clue where it was 'cos somebody had took it and hidden it and I couldn't find it. So I had to hunt high and low to look for it and .... and I couldn't - I couldn't find it anywhere 'cos - 'cos eventually I found it 'cos somebody put it in their wardrobe.

Participant 2, Interview 2: 258-262

P: Yes. 'Cos I'm a bit frightened, panicking 'cos I don't know where I am. When I'm here. I do know.

Participant 5, Interview 2: 54-55

Boundaries

The participants gave examples of the way in which some of the rules by which their social world operates have changed as participants became older. This was another area where negotiation could take place throughout these years when the participants were leaving school. These changing boundaries brought with them the properties of *responsibility* and *freedom*. For example, Participant 1 spoke of the increased *freedom* he experiences now that he is older, whilst his brother is still bound by rules relating to younger people:

P: My brother does, (yeah). He gets shouted in.

I: He gets shouted in.

P: Yes, and I don't.

I: Why

P: Cos I'm older than him see, I'm older that him, (yeah) I can stay up, I can stay up at night

        's long as I want. (yes) Cos I'm older than him.

Participant 1, Interview 1: 385-390

However, the increase in *freedom* is associated with an increase in *responsibility* that can

lead him into <u>conflict</u> with his parents.

P: Yes and he gets away with it more than me. (Yes). Little' uns get away with it and big

        'uns don't, do they (right) So they can stay away with it and big 'uns don't.

Participant 1, Interview 1: 215-216

Participant 5 also spoke of how his growing older increased his level of *freedom*.

P: Yeah, Went to, not far, went to Butlins with Castle College. I were about sixteen - but I

        didn't drink 'cos I weren't old enough. I went to Butlins sixteen, then seventeen, then

        eighteen.

I: Did you go to Butlins three years running, did you.

P: Yes, eighteen I was drinking beer, eighteen, but seventeen, I can't. I asked for a beer 'cos,

        they said eighteen, you're not eighteen. You're seventeen.

Participant 5, Interview 1: 435-439

Participant 6 talked of how the increased *responsibility* inherent in having his own flat led

him to worry (see **emotional state**).

> P: It's not easy. See when I were wi' me Dad there were no bills to worry about. Now, it's
>
>   like, worry. It's like pulling yer 'air out. You want to pull yer 'air out and you can't.
>
> I: So you've got quite a few new worries now.
>
> P: Worry, big worry.
>
> Participant 3, Interview 2: 174-177

Emotional states

Descriptions of emotional responses formed a primary aspect of participants discussion

about their responses to the challenges they came across.

> P: That's what they say at school It's wrong it's - I don't like it when they talk about your
>
>   Mum like that - I hate that.
>
> I: It can be quite upsetting can't it.
>
> P: Yeah. It get's yer angry. I like the mums, some mums yes, but I don't like them talking
>
>   about 'em. If you talk about your friends? I'm not bothered , if they talk about your
>
>   parents I do bother.
>
> Participant 5, Interview 1: 405-409

In the above example Participant 5 identifies a property of emotion, that of *intensity*,

which ranges from the *unemotional* "not bothered" to the *intense* "I hate it". Emotions

were named as playing a number of roles in the development of support networks. A

further property of emotions was their *effect upon interactions*. This extended from the

facilitation through to *inhibition* of **social support**; **emotional states** could also preclude as well as facilitate the establishment of social support structures.

Emotional facilitation

Emotions were sometimes mentioned as sequelae to **challenges** and antecedents to **social support** interventions or **self-reliant coping** responses. As such emotions sometimes played a mediating role between **challenges** and **coping strategies**. The specific nature of the role they played depended upon the circumstance. A property of **emotional states** is that of *tone* which ranges from *good* to *bad*. Negative emotional states, such as those of becoming upset or angry, often preceded participants receiving social support. In the excerpt below, for example, the participant recalls becoming distressed and discussing the issue with his mother:

P: Bit strange. Some people don't cry but I ..... tears were coming

I: When you got home, or when you rang you friends later, did you talk to any of them

        about what had happened .

P: No, I've got no friends at home. I'm sort of on me own. Me and me Mum. I talked to me

        Mum about it, she says, 'Probably why you're crying, 'cos it's strange'. In't it, 'cos it's

        strange.

Participant 5, Interview 2: 48-52

In the following excerpt the expression of emotion was followed by <u>unsought social support</u>:

P: No, they saw me crying, they saw I felt a bit strange, they said 'You'll be alright' , they

said 'do you not go to hairdressing - reception said go to hairdressers, they said - 'You go

to catering' and then showed be round - to caterers.

Participant 5, Interview 2: 327-329

Thus the participants negative feelings could play a role in mobilising **social support** either through inducing them to request help or by cueing those around into providing unsought social support.

Emotional inhibition

On the other hand, participants also cited emotions as reducing their willingness to receive social support. One participant talked of having to be in the right 'mood' to talk to a friend. As such, the *tone* of his emotional state could clearly have an *inhibitory* role on his receptiveness to support:

P: If I'm moody and that - sometimes he can't cheer me up - if you know what I mean - 'cos

I'm like - had a really bad day, stressed out. Or I've been drinking in the night and got

hangover and it's like can't cope with it. It's like - go away, leave me alone.

I: So, if sometimes if he comes and he's trying to be joking and you just don't want....

P: I just don't - I say go away I'm in a bad mood and all that stuff. Move - or I might do

somthing to yer. So that leaves me on my own.

Participant 3, Interview 1: 333-335

At these times this participant saw being on his own as the positive and preferred option. Hence his emotional state of the participant lead to the initiation of self-sufficient coping strategies rather than the seeking out of social support.

Pathways to support

Pathway to support was developed as a category that described the diverse ways in which participants accessed **social support**. Participants delineated numerous ways in which **social support** interactions occurred in response to the **challenges** with which they were faced. These included <u>initiating support</u>, <u>unsought social support</u> and <u>negative behaviour</u>. The particular **pathway to support** that was taken depended on a number of factors. These included their **emotional state** and the success or otherwise of <u>self-reliant coping</u>, as well as **contextual factors** such as the <u>location</u> that the **challenge** was occurring in, the existence of a supportive <u>social network</u> and how they judged the other person's <u>ability to support</u>. Depending upon this constellation of factors the pattern of responses could also lead through a number of complex **pathways** of <u>actively seeking support</u>, <u>passively receiving support</u> or of initiating <u>self-reliant coping</u>. These would be succeeded by alternative strategies according to the <u>success</u> or <u>failure</u> of these responses. Participants reported different combinations of these response strategies, such that a **challenge** might be met initially by either a <u>self-reliant coping</u> or a <u>social support</u> strategy but would be superceded by another strategy if it did not lead to a <u>satisfactory resolution</u> (see **consequences**).

P: While I was doing me work they were telling me .....to do things but I .....didn't

want to do em. So they said, 'See that wheelbarrow, go and get it for us (Yes) and I said

'No', and then, and then, and then, and I said to one of me friends 'Why don't you get it

yourself 'cos I am not, 'cos I'm not your slave for getting your wheelbarrow ' because I'd

already got my own wheelbarrow. (Mmmm) Then somebody pinched me wheelbarrow

and then and then they used mine...and I .. and I got a bit... mad about that because,

because I was saying to my friend 'That's my wheelbarrow. I've got that out of the

greenhouse. Out the garage'. and he er.. says 'I've got that out the garage before you so I

went to tell, I went to tell me er instructor about they ... they .... took my wheelbarrow

without asking (Yes) Like, like .... when I was like ... putting something in, they kept

tipping it out , using it and then I got like, ... a bit mad so the instructor came and told

them off and told them to get their own so they went, they went to get their own.

Participant 2, Interview 1: 273-282

In the example above the participant talks about a <u>practical challenge</u> in the form of

having 'pinched' his wheelbarrow 'pinched' by someone. This was followed by <u>self-</u>

<u>reliant coping</u> when he remonstrated with the other person. When the **consequence** of

this was no change he recalled his **emotional state** as 'mad' and that he <u>initiated</u> a search

for <u>social support</u> in the form of telling his instructor. This strategy then succeeded,

leading to a <u>satisfactory resolution</u> of the **challenge**.

As mentioned above there were a number of possible pathways by which social support

could come to be enacted. These included <u>initiating support</u>, when the participants would

seek social support themselves, and various means by which the supportive network

might offer <u>unsought support</u>.

Initiating support

Initiating support was defined as the action by the participant of actively seeking support. This could take the form of asking for support from people within the network or people, such as policemen, perceived as having a supportive role in society more generally. As such it formed an important part of the participant's ability to use the social support network.

> I: And when people cause trouble - How do you try and cope with that.
>
> P: Just ignore it and talk to the staff they're messing about with you.
>
> I: You talk to the staff about it.
>
> P: Aye, or just walk away.
>
> Participant 5, Interview 1: 369-372

In relating accounts of social support interactions the participants did not, however, always describe these as preceded by *intense* **emotional states**. Therefore, a dimension regarding the participants' initiating of support interactions was their *emotionality*, which could range from *intense* to *unemotional*. For example, when asked what he would do when stuck with work, Participant 5 responded, "just ask for help". Hence the request for help in these situations is much more a decision responding to the participant's appraisal of the situation rather than an emotional response to the situation.

Unsought social support

Not all of the social support experienced by the participants in the study had been initiated by themselves. Indeed, some interactions, such as decisions regarding placements, were presented by some participants as being very much in the control of others. This naturally raises the property of **control** and the question of how much control the participants had over various aspects of their lives, which will be discussed later. Unsought social support could take place in the form of face to face contact with the participant. However, it also occurred about and around the participant in the form of meetings, the passing of information and the making of decisions.

> P: No, they saw me crying, they saw I felt a bit strange, they said 'You'll be alright', they
>
> said 'do you not go to hairdressing - reception said go to hairdressers, they said - 'You go
>
> to catering' and then showed be round - to caterers. You go through reception and into
>
> New Building
>
> Participant 5, Interview: 327-329

Here unsought support came as a response by the social network to the *intense* **emotion state** shown by the participant. Participants also described how unsought social support could come through *formal* procedures such as reviews and referrals to professional teams. These were seen by some participants as having an important role within their lives and in the decisions made regarding their future.

> I: How do you think it will be before you do leave here.
>
> P: Oh, I don't know yet. 'Til they tell me.

I: Until they tell you. You wait for them to tell you.

P: If I have another interview - if you have an interview like job or something else, I'll go.

            I've been 'ere in 1998 but next year is '99. Gone quick hasn't it.

Participant 5, Interview 1: 297-301

I: .... you've done quite a few things since you left school - did you choose to do all those

            things.

P: No.

I: Who made the choice, who decided that. How did you come to do those things.

P   HJ

I: HJ, right.

P: She found me the places.

Participant 4, Interview 1: 4-9

Negative behaviour

Some participants described a further process whereby socially unacceptable behaviour lead to the establishment of a greater degree of social support. This seemed to follow the pattern of individuals finding their current social support to be *inadequate* and then engaging in self-reliant coping that were deemed *unacceptable* by those around them and led to an increase in support or the institution of more *formal* supportive procedures. For example, Participant 3 described how he abstained from school until precautions were put into place with regard to the bullying he had been experiencing. This was followed by the school providing further support, which when it failed was succeeded by further withdrawal:

I: Right. So school was quite a difficult time. (Yes) How did you try and cope with the

        bullying.

P: Well, one, one incident I stopped going to school 'cos I kept getting bullied and I got

        'phone call asking why I didn't go - I told 'em it were some bullying that I got, so... so

        they tried to 'elp me - stop bullying - tried to stop it.

I: Did they manage.

P: They did - then it started again so I 'ad enough. (Right) and just left.

Participant 3, Interview 1: 41-46

Coping responses

Two broad types of coping responses were identified: self-reliant coping and social

support. The main property associated with **coping responses** was that of *efficacy*, which

determined whether the intervention lead to either satisfactory or unsatisfactory

consequences.

Self-reliant coping

This category was defined as those attempts by participants to deal with a situation by

themselves. When faced with **challenges,** participant's often did not automatically resort

to attempting to find social support. When giving accounts of the challenges they had

faced over the previous years, participants often gave accounts of themselves

endeavoring to cope by themselves before looking for social support. This should

therefore be seen within the context of the participant's *ability to cope. Ability to cope* is

a property of **self-reliant coping** which ranged from *high* to *low* and was seen as

depending upon the interaction between the individual and the situation. Types of self-reliant coping included the participant looking for things, accessing career services, thinking through problems by themselves or fighting back when being called names or being bullied:

I: What would you do now if somebody said that about your mother again or about you or.....

P: I'd just take no notice probably.

Participant 5, Interview 1: 402-403

P: I, I like working on my own sometimes.

Participant 1, Interview 1: 114

I: But in order to organise the job what would you do to organise the job.

P: Ask if there were any vacancies (Yes) and ask 'em if they need anyone.

Participant 4, Interview 1: 223-224

I: Yes. So .... did you have to think about this by yourself or did you talk to other people about it.

P: I did it by myself.

Participant 2, Interview 1: 90-91

The property of *ability to cope* is crucial to whether or not the individual selects a self-reliant coping strategy:

P: I don't fight back 'cos if I fight back I get beaten.

Participant 5, Interview 1: 236

Another aspect of coping as a strategy was on those occasions when either social support had failed or was not viable for some reason. For example, one participant, talking about the future **challenge** of finding a job after college, hypothesised that if the social support network does not find him a job in the future then he would have to find his own, thereby initiating a self-reliant coping strategy.

I: And how does that feel - looking forwards.

P: If you, if you find a job I'll be looking forward to it - but if you can't find one - I've got to start rushing around trying finding one myself.

Participant 3, Interview 1: 270-272

A further example is the absence of a support network in the locality:

I: If you feel sad like that em.. do you feel able to - what do you do when you feel sad. What do you do if you felt sad. What would you do.

P: Just walk out the house.

Participant 6, Interview 1: 297-300

Social support

The category of social support was defined as the interactive strategies aimed at alleviating difficulties arising from the challenges presented during the transition process.

Social support of course depended upon the *availability* of a *supportive* relationship. This often depended upon other intervening factors such as location and *specificity* of role. Seven types of social support were identified through the coding process: those of emotional support, social validation, practical support, academic support, material assistance, skill development and mediation.

Before discussing the typology of social support that has been developed it is important to consider the property of *range of effectiveness* which pertains to social support. Supportive relationships and roles were sometimes limited by location. Therefore, where a **challenge** occurred, if indeed it was limited to an immediate location, interacted with the support available in determing the types of support on which the participant could draw. Supportive relationships, therefore, might be *specific* to a particular location. For example, this could be either in terms of the opportunities that may be available to see friends. The effectiveness of other types of support intervention, such as whether a member of staff has the power to stop bullying or name calling outside the gates of a college or work placement, might be limited to a particular location.

P: If you're upset, people 'ere, you just talk to a member of staff who'll say 'what are you

        upset for', and you'll say 'I'm upset' and you've got to say the name. Is it in 'ere or

        outside, 'cos outside is nowt' to do with 'ere. If it's in 'ere it's like, some bullies, she can

        be a bully, N., if she hit me outside, staff can't do nothing about it. If she hit me on their

        premises, yes, 'cos it's the grounds in't it. If it's in 'ere they can do something about it. If

        it's near bus stop they can't do nothing 'cos it's outside. Same as schools. You can do

        what you want outside, you know what I mean. You can hit her but if she went and told

something I'd just go to the police, but .... if she told one of the members of staff,

they'd meet me outside, in premises or bus stop.

Participant 5, Interview 2: 276-283

On the other hand, <u>social support</u> interventions could be *universal* in that matters of location or distance did not significantly circumscribe their utility.   For example a participant talked about the <u>social validation</u> he received over the telephone from his family whilst attending a college many miles away from Sheffield:

P: Mmmm.... they, they were thinking about me and when I'm at Willsby. They

miss me and everything.

P: Yes.

I: So one way they help is to talk to you about when you're at Willsby and do you talk to

them.

P: Mm......I 'phone them, I 'phone them up on a Saturday and Sunday telling them what I'm

doing. Things like that.

Participant 2, Interview 1: 232-238

Emotional support

Considering the role played by the emotions in generating and initiating social support it should not be surprising that one of the forms of social support talked about by the participants was that of <u>emotional support</u>. Participants mentioned <u>emotional support</u> coming in the guise of making sense was one form of social support was when people in the supporting provided the participant with reassurance or explanation:

P: No, I've got no friends at home. I'm sort of on me own. Me and me Mum. I talked to me

        Mum about it, she says, 'Probably why you're crying, 'cos it's strange'. In't it, 'cos it's

        strange.

Participant 5, Interview 2: 51-52

I: And when you were upset, 'cos you left school and you had got separated from your

        friends, hadn't you. Were you able to talk about that to anybody.

P: I talked to my Mum about it. She 's helped me through it 'cos when I was missing me

        friends like 'You'll see 'em all again'. Which I 'ave done. So, she 'elped me through it.

Participant 3, Interview 1: 137-140

Another participant seemed to suggest that it was not always necessary for practical

support to deal with a problem and that it is enough for people to just talk about what is

upsetting them.

I: ... I guess there must have been times when you felt sad, what do you tend to do if you

        do feel sad.

P: Talk to someone.

I: You do.

P: Yes.

I: And who would it be.

P: Mum and Dad.

I: Your Mum and Dad generally. And what do they do to help you.

P: They talk to me, to see what's the matter.

I: And does it make things better for you if you talk to them.

P: Yes.

I: How does it make it better.

P: By talking to them about what's the matter.

I: That makes it better in itself.

P: Yes.

I: Does it matter if they do anything about it or not.

P: No.

Participant 4, Interview 2: 121-137

Social validation

An important form of social support seemed to be that of <u>social validation</u>. This was

defined as those interactions which enable the individual to develop positive relationships

and feel esteemed. 'Having fun' or 'having a laugh' were both mentioned by participants

as important and constitute activities that have a role in helping people establish social

bonds. Another example of this was the sharing of experiences.

I: Yes, and so you chose people who you thought were best together. What do you think

        about your friends you had your birthday with. What kind of things do you do with them

        that makes it good to be with them.

P: I have I have a good laugh with them.

Participant 1, Interview 1: 198-201

Another example of this type of support is the emotional attachment between a

participant and his family:

I: And, what kind of help do they give you.

P: Mmm.....they give me a lot of help, a lot of help. (Yes) Yes.

I: In what kind of ways.

P: Mmmm.... they, they were thinking about me and when I'm at Willsby. They miss me and everything.

Participant 2, Interview 1:229-232

The idea of social validation was linked by Participant 3 to feelings of belonging (see Consequences):

I: You said that when you didn't have any friends - you felt like you shouldn't be here. (Yeah) Do you still feel like that.

P: No. It's changed. 'Cos this is me second year. Know what I mean. First year. -

I: What's changed that feeling, do you think

P: I don't know, what's done it. (Yes). See, I 'ave a laugh with T. He's, he's kind 'a - I don't know if I've told you this but he's kind of a joker, if you know what I mean. He makes you laugh a lot. So....

I: And that's important, is it.

P: Yes. He makes you laugh. (Yes) So, so like if I'm down one day and grumpy and that - he cheers me up. (OK) Like, yesterday I were like, all moody and he just cheered me up by afternoon. Just made me laugh.

Participant 3, Interview 1: 318-328

Another way in which validational support was experienced was through shared activities.

I: Yes. What is it about B and G that you like.

P: I go to pub with 'em.

I: Right.

P: I 'ave a drink.

I: Right. Is that during the day, or during the night.

P: Tonight. I have a laugh with 'em.

Participant 4, Interview 2: 224-229

Finally, participants also talked about having romantic relationships. These are a further example of social validation:

P: Well, one of me friends were a girl friend. Now me 'an 'er when I were at school - me 'an 'er got together - I mean she's me girlfriend now, I still see her now. So it's people from school and college. See, she's not actually at college - I just see 'er at weekends or at night times. So I got me first girlfriend at school.

Participant 3, Interview 1: 129-132

Practical support

Practical support was offered to the participants in many different forms. Types mentioned included looking for and arranging placements. Again, as mentioned above control formed an important aspect of this. There seemed, however, to be two sub-categories of practical support: those of providing information and of giving physical assistance.

Physical assistance covers both those instances where the participant actually worked with someone to achieve an aim, such as when the participant below was searching for his computer and a friend helped look for it and also more organised *formal* support.

I: Who helps you in that kind of situation then.

P: Er... .... Me friends.

I: How do they help you.

P: Er......... they help me to find the things that have gone missing, things like that.

Participant 2, Interview 2: 192-195

P: Em... friend, friend help me. Like when, ... like when....I'm trying to pick a, pick a

log????????? up that's big, it's like it's heavy and I couldn't, I couldn't lift it(Yes) so,

.....so.... one of me friends said to me 'try and lift it yourself and see if you can do it', I

couldn't do it so some friends, so me friend helped me. (Yes) I got one end and then me

friend got the other end and we, emmm... we lifted this log on this, like this trestle thing

like that, (Yes). Then I had to like, saw through this log with a bore saw and I tried to, I

tried to ????????? difficult to cut it.(Mmmm) then me friend ???? give me a bit of

help(mmmm) give me the guide line to cut it.

Participant 2, Interview 1: 265-271

An example of practical support organised through *formal* arrangements is that regarding
travel. These were mentioned by some participants as being an important form of social
support. This would evidently vary according to the capability of the individual and their
ability to travel independently.

I: How had you used to get there then.

P: I used to go on special bus. (Mmm) They used to come and pick me up bus in the

        morning.

Participant 4, Interview 1: 45-46

Information was given in a number of forms, including advice:

> P: They told me, at school, once. If you wait at school 'til you're sixteen and you leave
>
> school you can go to Castle College. What you want to be. Catering or Castle College, or
>
> mechanic. It's alright 'ere.
>
> Participant 5, Interview 2: 31-33

However, not all advice was felt to be practicable, leading as a **consequence** to

unresolved **challenges**:

> P: Well, she 'elped me through a lot of bad times. (Yes) When I were bullied at school, she
>
> 'elped me through it. (Yes). She said 'it 'em back an' all that but then - when you 'it 'em
>
> back they're going to start more, aren't they. More trouble. So you couldn't really 'it 'em
>
> back.
>
> Participant 3, Interview 1: 159-161

Information could also be obtained directly from people who were already familiar with a

particular service or situation:

> I: So, it was awful, and did you find people that managed to help you with that.
>
> P: Yes, I did, I went to, Ohhh, reception. said 'whereabouts should I be'.
>
> Participant 5, Interview 1: 5-6

P: I had to , I had to ask a friend to take me to a course, because I couldn't find my way around.

Participant 2, Interview 1:

Academic support

Participants also talked about how they were helped with academic work. This help might come from a friend or from more *formal* sources of support.

I: And has T helped you a lot to settle here.

P: Oh yes, 'e 'elps me a lot.

I: In what ways does he help you?

P: Spelling. If we've got a form from our teacher and it says some'at like, if you can't spell it what I can't spell it so he 'elps me. He says C O N I R like that.

Participant 3, Interview 1: 109-113

P: They're just like support teachers. (Right). They help you with your work. If you've got a really 'ard question they'll come up and 'elp you sort it out. (Right) So you can answer it. Don't tell you what the answer is, they give you a clue as to what it's supposed to be. So they 'elp in that kind of way.

Participant 3, Interview 1: 94-97

Material assistance

Receiving gifts and other material items were also mentioned spontaneously by two participants and seemed to indicate how they valued the way in which supporters managed their material affairs. This may relate in certain instances to the limited

socioeconomic power of people with learning disabilities and also the lack of **control** over their own finances.

> I: What was it like, getting to know your new carers then.
>
> P: Oh, it was alright, actually. They give me anything, what I want, like TV. They bought
>
>   me a computer, 1994 Super Nintendo. (Right) It's a good game - 'cos I like computers.
>
> Participant 5, Interview 2: 374-376

Skill development

Another aspect of social support mentioned as important by participants was that of <u>skill development</u>. This was conceived as when people in the <u>support network</u> enabled the participants to develop practical skills such as cookery and, as in the example below, being shown how to ride a bicycle

> P: I didn't pass it straight away. It's takes time, time. It seems over there, I came in, over on
>
>   bike again, he pushed me like that, he says, "what about the pedals". And I did them.
>
> Participant 5, Interview 1: 267-268

> P: What you do, you go to tell people and what you do is the staff - they show you what to
>
>   do - before you do it - 'cos if you don't you might bugger it up. And that's very easily
>
>   done. If they want to pay - manufacturers won't pay. What they do is show you how to
>
>   do things first and then you do it. That way it's easy to do.
>
> I: So learning new things is very important.
>
> Participant 5, Interview 1: 287-291

Mediation

Mediation was seen as an important aspect of the social support offered by some people in the participant's support network. This form of support was defined as when support was offered to enable the participant negotiate a **challenge** related to social connectedness. This included arbitration, or enabling participants to re-establish good relations with friends in times of conflict, and advocacy, the representation of the participants interests in certain situations, often more formal ones.

Arbitration was discussed by participants in relation to how certain people in their social network would encourage the participants and their friends to maintain contact with positive relationships, particularly when those relationships were in conflict.

> P: I know if he says some'at nasty - it's like - no way I'm going to say sorry. Why
>
> should I - being nasty like that. Sometimes 'is Mum, 'is Mum rings up and tells me to say
>
> sorry. Like, no way, I can't do it. (Yes). Or sometimes he 'phones up and, and we make it
>
> - we say sorry on 'phone and make up like that. 'Cos sometimes I can't face 'im and say
>
> it. So that I couldn't like do this and say sorry to 'im like. (Yes) I sometimes 'ave to
>
> 'phone 'im.

Participant 3, Interview 1: 364-368

> P: He - the Instructor said that, to my friend, that I was being a bit hard on him because I
>
> was like - shouting at him. (Right) fer - I said to him 'I don't want any help thank you' and
>
> I started shouting at him in front of him - that's why he let me do a bit panting and a bit
>
> upset 'cos he went in the living room to ..... went in the living room to cry and I just like
>
> .... just like... went in the living room and said 'I'm sorry, I didn't mean it to shout at you'

so when I said sorry - he said 'I'll help you now' 'cos I said to him 'I need some help now' - and I said 'I am sorry what I did to you' I said and he said, 'OK then'.

Participant 2, Interview 2: 359-365

P: I fell out with D, me girlfriend, then I go to me Mum and she 'elps me, like, sort it out.

Participant 3, Interview 2: 285

Another example of how **mediation** was an important was when there were difficult social situations where they felt they needed someone to argue their case. At these times advocacy was an important support provided by people within the support network. Examples where the participants were represented by their supporters in more formal settings included:

P: Me Mum and Dad said they were useless. They were doin' nowt for me.

I: And what did you think of them.

P: Not very good.

I: And so what happened. How did your Mum and Dad find out that they were useless.

P: Because they came to look 'round.

I: They went to look around again.

P: Yes. Weren't very good. I were standing there doin' nowt.

Participant 4, Interview 2: 56-62

A further aspect of the advocacy role in mediation was its protective function. Participants gave examples of carers ensuring that an environment was safe. This was particularly a pre-occupation of those who had been bullied previously and one participant who had a particularly bad placement.

I: What other ways did she try to help you.

P: She'd come down to the school, meet me after, or she would tell a teacher, what 'ave yer.

        (Yes). Stuff like that. Saying 'My son's being bullied, what you going to do about it'.

I: So she'd try and sort things out for you. Yes. And was she successful.

P: Yes. She stopped the bullying sometimes.

Participant 3, Interview 1: 164-168

I: Anything else........... So what happened when you had a fight with somebody.

P: Went and told me Mum and Dad and they're going to sort it out.

I: Who did they have to sort it out with.

P: The people that hit me. (Yes). They were going to have a word with 'em.

Participant 4, Interview 2: 151-154

In the following example Participant 4 also talked about how his parents always *checked* on the placements he was attending:

P: They come and look round and I talk to 'em.

I: What makes them decide to come and look 'round - do they.....

P: They always come and see if I like it

Participant 4, Interview 2: 95-97

Whilst advocacy was seen in a positive light by the participants the example above illustrates the dilemma for many parents.   Whilst the action of the parents is clearly supportive and protective of their son, their intervention clearly maintains him in the role

of a dependent who is incapable of deciding an issue for himself. How much protection

is necessary is clearly a difficult issue for parents and professional to decide.

Relationship properties

Relationship factors were identified as those constructs which the participants

mentioned with regard to making judgments about the relationships that they were

experiencing. These factors often affected the process of deciding upon which strategies,

either <u>self-reliant coping</u> or <u>social support</u>, to use in attempting to deal with a **challenge**.

Participants identified <u>trust</u> as being an important aspect of a positive, supporting

relationship. They also discussed <u>ambiguity</u> in relationships, the fact that different

relationships have <u>different boundaries</u> and that the persons <u>ability</u> to help in a specific

situation was crucial to their decision on whether or not to ask for help. These factors

will now be discussed.

Specificity of roles

One property of relationships was the extent to which some people might fulfil a number

of roles in an individuals network as opposed to having only a single role, or the

specificity of roles. This dimension ranged from *multiple roles* to *single role*. For

example, someone might be an agreeable companion but might nevertheless not be

entrusted with problems:

      I: What is it about D that you think you miss.

P: Talking about football and that.

I: What other things did you used to talk about with David.

P: Cricket. Football. That's it.

I: If you'd been upset at school could you - who would you talk to at school.

P: Teachers or headmaster - They'd sort it out.

I: Right. Headmaster or teachers.

P: Yes.

I: What about D. Did you ever talk to him, or not.

P: No.

Participant 4, Interview 2: 199-208

Other participants mentioned people in the support network as having a number of roles.
Participant 3 seemed to see a clear distinction between the support offered him by his
mother and that offered him by his father:

P: Well, me Dad's, me Dad's helped me with me 'omework if I got it - so that I got if for

           school then he'd 'elp me with it. But I don't get 'omework from college so it's easier 'ere

           than what it were at school 'cos I got 'omework. (Yes) And you know most kids don't

           like 'omework, do they. I bet you didn't when you were younger.

I: I still have trouble with it. So, he helped you quite a lot with your homework.

Participant 3, Interview 1: 191-195

I: OK. Are there some people you would talk to about it.

P: Yes, I tell my Mum.

I: Are there other people you wouldn't.

P: Yes, me Dad.

I: What's the difference between telling your Dad and your Mother.

P: Well, if I tell me Dad, 'e won't 'elp out. He"ll just say - if you've fallen out with her that's

       your problem. Like me Mum well she'll go, - well, I'll 'elp you out.. I'll tell you what to

       say to 'er and all that.

I: So your Mum's much better for that kind of thing than your Dad.

P: 'Cos me Dad says "It's your problem you go and see to it". And like 'how'?

Participant 3, Interview 2: 316-325

For Participant 3 the roles performed by his mother and father in his life seemed very

much separated, and this was mirrored by how he perceived their moods:

P: As in different ways with me Mum and Dad. Well, one way me Dad's kind of moody,

       you know, he's like sometimes he's in a bad mood or good mood, and me Mum's all

       happy and cheerful and that kind of way - so it's different kinds of ways.

Participant 3, Interview 1: 207-209

Ambiguity

Another property of relationships that seemed important was the degree of ambiguity.

Confusing and ambiguous relationships were mentioned by a number of participants.

Conflictual statements acknowledged that relationships are not a straightforward way of

getting support and that with relationships come problems as well as solutions:

P: R's alright

I: R, right then.

P: He teases me a lot

I: He teases you a lot. You like that then do you.

P: I don't, I don't like teasing

I: So you like him even though he teases you a lot. What's good about it then, there must be something good about it, even though he teases you a lot.

P: Sometimes he talks to me .... sometimes he talks to me in his real voice and sometimes he doesn't.

Participant 1, Interview 1: 151-158

The above example shows how, even in a relationship which is valued by the participant, there are elements that are experienced as condescending or unpleasant. In the following example, Participant 5 discusses how a relationship appears to change very quickly and for no apparent reason according to the mood of the person:

I: So it's difficult to know where you are sometimes.

P: Aye. It's confusing everybody. Next week they're me mate, next thing they're not. Two days they're me mate. Next week, if I come back you're alright. Don't know what's up with 'er. If she's in a bad mood don't take it out on other people. Tell 'er to keep to 'erself.

Participant 5, Interview 2: 582-584

Different limits

Participants recognised that social support is an aspect of relationships that have *different limits* and boundaries. This aspect of relationships was also seen in the **challenge** during these years of adapting to new boundaries.

P: Yes. It's not like he shouts at you, though, it's just like, (mmm) if I were 'aving a laugh,

       or if banged, started banging in bedroom or somthing like that (mmm) he'd .... but if

       I banged in me Mum's room she wouldn't say nowt.

I: So what would happen if you banged in your Dad's house.

P: He'd 'ave a go, he'd shout. - 'Stop banging ' and everything. He'd come and he'd start

       telling me to stop banging and shout from the living room.

Participant 3, Interview 1: 211-216

This excerpt also demonstrates how the Participant's life is compromised by the boundaries of those he is living with.

Trust

Some participants also talked about how important it was to discuss problems with certain people and not others, implying that trust was an important aspect of the relationship. It was, however, not always easy to say why that person should be spoken to:

P: Err....... cos I 'phone me Mam up and talk to 'er, I feel upset when somebody is upsetting

       me. (right) that's when ...a time when I ..'phone me Mum to tell 'er that I'm a bit upset

       'cos, 'cos I feel upset to tell 'er ..... what has happened.

I: So it actually upsets you to tell your Mum what has happened.

P: Yes.

I: But you still tell her.

P: Yes.

Participant 2, Interview 1: 173-179

Ability

There was recognition that people aren't always able to offer support and that it depended also upon how they were feeling at the time (related to <u>ambiguity</u> in relationships and issues around <u>mood</u>).

I:	What would have happened if you had. If you told your Mum.
P:	If I told me Mum - she wouldn't know what was goin' on.
I:	She wouldn't know what's going on so you wouldn't tell her.
P:	No, she'd know what was going on but she might not understand. (Right, right) Sometimes she can get in shocking mood, owt like that.
I:	Right. So some people understand more than others.
P:	Yes. A. understands. Me mother understands a bit but not all the time. She's got ????

Participant 5, Interview 2: 557-563

Other people were seen as dependable for more of the time. Thus, one property of <u>ability</u> was *stability*:

P:	.... If I 'ad any problems I just told S or A or them.
I:	Can you tell them?
P:	Yes, I'm not frightened of 'em. If I 'ad problems yes. They've told me lots of times - when they've bought new clothes, they've probably lots of times when I ..

Participant 5, Interview 1: 582-586

Whilst Participant 5 suggests above that his trust in his carers is related to their *capability* in looking after his material needs, Participant 6 indicated that for her the experience of *intimacy* was more important.

> I: Can you tell me what it is about H that makes to talk to her rather than anyone else.
>
> P: Sometimes she gives me a hug - I feel alright with H.
>
> I: Sometimes what...
>
> P: I put my arms right round her.
>
> Participant 6, Interview 2: 54-57

Context

The relationships were modified by the context in which occurred. **Context** was defined as those factors in the accounts of the participants that appeared to modify the nature of the **relationship properties**. Three were identified: network, identity and control. Identity was an important aspect in that the degree to which an individual identified his or her self with a particular social group, or saw a particular social group as being attractive, then this affected not only how readily they were prepared to turn to certain people for help, but also who was likely to be valued within the social network. The extent of the network affected the relationships in so much as the more developed the network the more there appeared to be specifity of roles within it. Finally, the level of control that participant's considered themselves to have in their lives seemed to affect the dependence they placed upon the relationships,

Identity

Identity was conceived as a sub-category which covered those factors of the individual which the participants attributed to themselves, both in their own eyes and those of others. The possibility that these was socially induced by broader community attitudes cannot be ruled out. As such it influenced how participants responded and related to the network around them. It had three aspects: *ability*, *gender* and *race*.

Ability

This aspect was conceived as a dimensional range from *disabled* to *normal*. One participant in particular made a number of remarks about having special needs and about how this made him different.

> P: What you do 'ere. This is like a training scheme like. You learn to work in 'ere and then if you can't be good 'ere, and you can't be good, it's not 'cos of good, 'cos of good, you work 'ere 'til they find you a job. (Right). proper one. Not with 'igh 'opes like normal people. I think it's for special needs. They didn't tell you, I think it's for special needs.
>
> Participant 5, Interview 2: 173-176

This participant's awareness of difference related to his experiences of abusive people, labelled as 'normal', and the need to meet people who are not abusive. Being 'disabled' was perceived by this participant as something which could not be overcome and as a *permanent* aspect of his identity.

P: They'd help you, everybody here. I 'ad difficulties right enough (OK). I am disabled but I

can't 'elp that.

Participant 5, Interview 2: 599-600

This contrasted with his experience of behavioural difficulties, which were seen as *changeable*:

P: 'Cos I was naughty.

I: Because you were naughty at first.

P: Yes. At me Mum's an' all. Oh, about all sorts of things. Getting in trouble - with coppers.

I: Right, when you were at your Mum's.

P: Yes. Police come to 'ouse. Me Mum were upset. That's why - I needed to learn to behave

meself.

Participant 5, Interview 2: 457-462

Hence another dimension of identity is *permanence.* This 'disabled identity' was also expressed in the way the participant related to the interviewer, with a distinction being perceived between the interviewer and the participant:

P: 'Cos, 'cos, there it's got a very big room, the class (Right), smaller than that, a bit bigger,

no, a bit smaller, and er......... there's a big table and you know what I mean. (Yes). You're

normal to me, yes Your normal. (So), some was laughing and some was not.

Participant 5, Interview 2: 86-88

In contrast, another participant labelled many of his experiences as 'normal'. This represents the other end point of the property.

P: It's good enough. It is. So....... I'm really got everything - it's just like a normal 'ouse like.

        So it were all done. All waterpapered when I moved in, so I didn't 'ave to do that.

Participant 3, Interview 2: 135-136

There was a marked contrast with the 'disabled' endpoint of the property in how this participant related himself to the interviewer.

P: So like, if you've got friends where you work now, it would be the same like wi' you if

        you didn't see your friends.

I: Sure, yes, absolutely. Yes.

P: It's just same.

I: Entirely, I guess whenever we move on from somewhere we tend to leave a lot of people

        behind, don't we.

Participant 3, Interview 1: 142-147

Race

This aspect was mentioned by a black participant. She appeared to be saying that she felt *uncomfortable* having a brown face and that white faces were better.

P: I thought - all white people.

I: They're all white people.

P: Yes. I don't like brown.

Participant 6, Interview 1: 141-143

The interviewer was not able to ascertain why this was. Although this may have been partially due to abusive experiences at home, the possibility that it was socially induced by broader community attitudes cannot be ruled out.

Gender

One participant mentioned gender as being an important facet of the social network. This was perhaps linked to a troublesome relationship between himself and his mother, but also appeared to be linked with issues of authority:

I: Right. How have they helped you calm down.

P: Just did it. 'Cos I need a man, like me Mum said to me - I needed a man behind me back.

I: Do you think that's good.

P: Yes. 'Cos you don't mess with a man.

Participant 5, Interview 2: 469-472

For Participant 5 masculine gender was also linked to independence of action, an important consideration given the lack of independence in many lives of people with learning disabilities:

P: Oh, men like to do it theselves, don't they.

Participant 5, Interview 2: 513

Control

One of the most important issues regarding the **context** within which social support operates regarding people with learning disabilities is the level of control which they exert over their own lives. This was seen in a number of ways, including the control by carers of the individual's money and the control over decisions affecting the lives of the participants, particularly with regard to daytime activities. Control manifested itself in two forms: control over decisions and control over resources. The key property in control was to the extent to which it was *internal* to the participant and to what extent *external*. For example, in the quote below the participant is talking about a decision which resulted in him leaving his home and moving to a different part of the country, a decision of which he was apparently unaware and had no direct influence:

I: .... But, sounds like it was quite an important decision, deciding what to do after school. (Yes) Can you remember how that decision was made.

P: Err......No.

I: No. Can you remember who made the decision. Who decided.

P: Errrr.............Nobody made the decision. No.

I: OK. So nobody decided that you'd go to Wheelsby. College. No. Who first told you about it.

P: Me Mum.

I: Your Mum first told you about it.(Yes) How did she know about it?

P: She told me when I got the funding for W. That's when she told me.

I: So she told you when you got the funding. And what did you think when she told you that about the funding.

P: I were amazed.

Participant 2, Interview 2 10-22:

Similarly, Participant 5 discussed how his carers take responsibility for his money:

I: Who sorts your money out.

P: Them (They sort it out) - I get no money only £16 a month (Mmm) some'at like that.

           They do it - they put it in me bank

Participant 5, Interview 2: 480-482

Often changes occurred due to circumstances beyond the <u>control</u> of the individual, such as the leaving age for school or a college closing down:

I: And why did you leave College.

P: Because it shut down - it were closing.

Participant 4, Interview 1: 68-69

Another participant was much more able to take <u>control</u> of the <u>decisions</u> in his life, even in the face of opposition from people within his support network:

P: I thought for meself. I mostly do everything for meself these days.

I: Yes. Did your parents give you any ideas what to do after school.

P: I did it all meself.

I: What about your teachers, did they.

P: They, they - they didn't recommend college, but I did. They didn't think it were a good

           idea.

I: What did they think would be a good idea.

P: They didn't really say. They just said college isn't a good idea. I though I could anyway,

        even though you're saying I'm not. So .... I took college up.

I: Sounds like, it was your decision and it was in the face of a few people.

Participant 3, Interview 1: 75-83

The above examples of decisions being taken, sometimes without the knowledge of paricipants, by others is an example of the stimatisation that people with learning disabilities face. They are sometimes viewed as unable to make life decisions and choices. These choices are then made by the carers and professionals supporting the person with learning disabilities. Under conditions such as these, social support must operate in a very different context to that of less socially disadvantaged people.

Social network

Supportive relationships and interactions occur within the context of the social network. Two aspects appeared relevant during the coding process to the provision of social support; those of stability and conflict within the network. Stability as a category was associated with loss and change.

Stabilty

Another important factor during the interviews was change within the social support network. This is particularly pertinent at a time of transition as the participants in leaving school or college were often leaving institutions, staff and, in some cases, friends with

whom they had been familiar for a long time. In their place they were moving into services which were hitherto unknown.

> P: It weren't easy - becos' I didn't know anybody. (Mmm) but some people from my school, came 'ere. But they weren't my friends. You know what I mean. They're still not. So I had to find some more, other friends.
>
> I: What was it like when you first came and you were alone.
>
> P: It were kind of quiet. I didn't feel that I were supposed to be in college. (Right). I were supposed to be 'ere but I didn't feel like I should 'ave been. 'Cos there were no one to talk to and no friends. (Yeah) So it's gone from there.
>
> Participant 3, Interview 1: 301-307

There were two properties associated with this factor. The first was that of *completeness*, the second *permanence*. The *completeness* of the loss is a dimension that extends from *complete* to *partial*. The most striking example of complete loss was when Participant 1 talked about the death of his grandfather and his uncle in terms of loss:

> P: Yes. My err .... I lost my Grandad, J M (yeah) our Grandand (yeah) He died (mmm) Of a heart attack.
>
> I: Right, yeah.
>
> P: I lost my Uncle S (yeah). He had a heart attack as well
>
> Participant 1, Interview 1: 312-315

These losses of two close relatives had evidently had quite an impact upon the participant. There can be no more final loss than the death of someone dear.

Other participants gave a number of examples of *partial* losses when they talked about the loss of friends that ensued leaving school. Often this loss was experienced as more ambiguous. There was an awareness of their continued presence but also a feeling of loss associated with lack of daily contact that followed:

I: What would you say was the hardest thing about leaving school. Was it a hard thing to do.

P: Yes. 'Cos of me friends. 'Cos you 'ave to split up from yer friends, don't yer. When you go back every day you see yer friends more than what you do when you're not at school. So me friends gave me the 'phone numbers and the addresses so I could go and see them.

I: So that you could see them outside school.

P: Yes. But that were the 'ardest part of it, not seeing 'em.

Participant 3, Interview 1: 62-67

A similar type of loss followed when somebody in the support network stopped engaging in an activity that had previously been shared with the participant.

P: Oh and my grandad used to go fishing as well. My Dad used to go fishing (yeah) but he's retired. My brother....

I: Your brother goes fishing

P: Yes but he's retired as well

Participant 1, Interview 1: 484-487

Such a loss seems as though it may be particularly important to people with learning disabilities due to the lack of resources they control and the effect that such movement may have upon their own ability to participate in activities. Another example of this was

that by the end of the interviews four of the participants in the study had moved away from their family home, either into a college, a council flat or in with carers. Losses such as these can be a source of challenge to the individual.

Another property associated with change was that of *permanence*. This property had dimensional range from permanent to temporary. The example above of the participant's relatives dying is an example of a permanent loss. Other changes were for a short period of time only:

P: We got a one that's coming back here.

I: You've got?

P: An instructor. We've got an old instructor coming back here.

I: An old instructor coming back here.

P: Yes. P.S.

Participant 1, Interview 1: 335-339

Conversely, other aspects of the participants support networks remained remarkably *stable*. Familiar faces were mentioned by participants as enduring features within the social support network and, as such, were testament to the stability of some aspects of the participants social support networks. However, familiar faces were not necessarily *friendly* faces. Thus this category has the property of *friendliness* with dimensional ranges from *friendly* to *unfriendly*.

I: ....who is important to you. Who would you say is the most important to you.

The person   closest to you.

P: At the moment er P, who comes from Sheffield.

I: Comes from Sheffield?

P: Like S, or like L, I err, like 5 or 6 people from Sheffield.

Participant 1, Interview 1: 130-133

I: C. Is he someone who works here or lives here, what does C do then.

P: He's a friend who went to the same school as me.

Participant 2, Interview 1: 158-159

However, such stability was not necessarily a good thing and the value of the existence of

familiar faces depended very much upon the nature of the relationship the participant had

with those people. Below is an example of a participant who met people from his school

at college but these weren't people who he felt friendly towards and therefore were not an

important part of his social support network. The following is an example at the other

end of the friendliness dimension.

P: It weren't easy - becos' I didn't know anybody. (Mmm) but some people from my school,

         came 'ere. But they weren't my friends. You know what I mean. They're still not. So I had

         to find some more, other friends.

Participant 3, Interview 1: 301-303

Conflict

Another property of the social network was the level of *conflict* within the support

network. Conflict impeded the effectiveness of supportive relationships and could also

stem from supportive interventions. *Conflict* was that of *involvement*, or how much it

involved the participant. As such it could either be *third party* or if the participant was involved, *first person*.

Third party conflict involved people within the social network other than the participant. Such conflict could impede the effective collaboration of the network in supporting the individual.

> P: He were the one at 'ome. It's me Dad who brought me up. 'Cos me Mum and Dad are separated. (Right) Divorced.
>
> I: So do they live in different houses now.
>
> P: Well I still see them both - but I live wi' me Dad most. (Right) I just stop wi' me Mum weekends.
>
> Participant 3, Interview 1: 184-186

First person conflict within the network took two forms. Firstly, there were occasions when there was a disagreement between the individual and others regarding what to do in a particular situation. Sometimes these disputes would take place over boundary issues. This had implications regarding individuals asserting themselves and managing the conflict.

> P: He gets away with it but I don't. (yes) I'mmm, I'm his big brother
>
> I: You're his big brother.
>
> P: Yes and he gets away with it more than me. (Yes). Little' uns get away with it and big 'uns don't, do they (right) So they can stay away with it and big 'uns don't.
>
> I: So that's how you feel about it so that's what happens.

103

P: Yes.

I: So what sort of things does he get away with.

P: He blames t'on me.

Participant 1, Interview 1: 213-220

The following excerpt is a rare example of a Participant who found himself in conflict with his father and still asserted his own voice. This may have been aided by the fact that mother and father were separated and that there had been a model of conflict available to him in previous years:

P: I told me Dad first. He said "No" but I said I were leaving anyway.

I: So, he disagreed with you.

P: Yes.

I: Was it easy to make your own mind up, when your Dad disagreed, or.....

P: Err..... I kind of argued with it but he finally come to my decision.

Participant 3, Interview 2: 23-27

Indeed, the same participant was able to identify sources of conflict in a number close relationships. This, as has been noted above, may have been related to his experience of his parents marital relationship, or it may have been due to his level of independence and his therefore greater ability to survive a conflictual situation:

P: Yes, arguments. And we just don't talk to each other for a day, something like that. We're still friends but .... still going out with each other but we've just 'ad an argument.

Participant 3, Interview 2: 282-283

There was one example of conflict being seen as having a beneficial effect. In the following example the participant seemed to view conflict as helping to lay down boundaries.

I: Right. How have they helped you calm down.

P: Just did it. 'Cos I need a man, like me Mum said to me - I needed a man behind me back.

I: Do you think that's good.

P: Yes. 'Cos you don't mess with a man.

I: And does A.

P: Yes. If I mess about he says 'Behave yourself'. That means - don't mess about. (Right).

        And now, I don't mess about no more, used to, not now. Can't now ????

Participant 5, Interview 2: 469-475

A more negative example in which conflict arises was presented by the same participant. This consisted of conflicts between himself and his mother taking place as a result of his emotional difficulties.

I: What about if you've had a bad day at school, a bad day at college, and you get home and

        somebody asked you how it is. What do you do.

P: I used to take it out on me Mum.

I: You used to what.

P: I used to take it out on me Mum.

I: Did you.

P: Aye. She said 'Don't take it out on me, what's up wi' yer'. I lost match at school - well

        that's your fault.

Participant 5, Interview 2: 538-545

Managing social networks

An important group of constructs were those pertaining to the **management of social networks** and <u>relationships</u>. The category was named **managing social networks** and was based upon a number of strategies that were identified during the open coding process. Aspects of the **management of social networks** included <u>establishing ties</u>, <u>maintaining contact</u>, and <u>social strategies</u> were identified by participants as important to the management of their social relationships. The failure of these different strategies could lead to isolation or negative conflictual relationships which would add to the **challenges** facing the individual. For example, Participant 5 spoke of the possible problems involved in failing to negotiate the social world:

I: What was it like trying to meet people.

P: It's alright. What's your name - making friends, 'cos if you don't make friends at here or Castle College or anywhere, you don't very good. They'll say "oh, he's a bit funny in't he".(Yes) "he's not talking to us". That's why - that's why I ???? bit funny isn't it.

I: Yes, so it's important to make friends is it.

P: Yes. It's not important but it's nice to make friends 'cos if, if, ... I came 'ere first time they'd used to have them stickers up without letters up with them sticker things - if I didn't talk to nobody 'ere they'd say - "oh, he's a bit funny like, he causes trouble, don't 'e".

I: Right, and you don't want to be known as someone who causes trouble.

P: No, 'cos if he causes trouble I can get done from the ?? It's nice to talk to people, yes.

Participant 5, Interview 1: 346-355

Establishing ties

Establishing ties was identified by participants as an important aspect to **managing their social support network**. Indeed, meeting new people was described by participants as important, particularly with respect to the manner in which relationships validate shared experiences and give a sense of belonging (see Social validation above). Some participants seemed more comfortable than others at this type of activity and participants differentiated between occasions when they took an active role in this and other occasions when their own role was more passive. A property of establishing ties, therefore, was *pro-activity*, with ranges from *active* to *passive*. For example, Participant 2 described how he had *actively* made friends at his new placement:

I: T, L and G. How did you get to be friends with them.

P: Err....When I started at Willsby I just sat and talked to them about things.

I: So they're people that you can talk to.

Participant 2, Interview 1: 175-177

Participants also spoke of less active ways in which social networks become elaborated. These included an individual introducing his or her self to the participant and introduction via a third party.

P: Well, I didn't know anybody when I first come here. (Yes). Becos' I were just sat in a

        corner, on me own, working away, no one talking to me. (Sure). Then T come and he

says 'Have you got any friends', and I say 'No not 'ere'. So he says 'I'll be your friend

then'. And it's been going on from there. (Right) And we've been friends every since.

Participant 3, Interview 1: 101-104

P: What is was. Why I met A and S 'cos there were this C who lives in my road, S's sister.

She said to me 'Do you want to see me sister', and I said,'Oh, yes' and we went to her

sister's 'ouse. That's 'ow I met 'em.

Participant 5, Interview 2: 410-412

Establishing ties was also affected by the **emotional state** of the participant. This

appeared to be particularly the case for one participant who told of feeling guilty and

disloyal to previous friends. These were seen as emotional *inhibitors* to establishing ties.

P: Well, when I first met T I were like, - no, I can't be his friend - I've got other friends at

other places. (Yes). It didn't feel right with 'im being - it felt to me like I were knocking

me other friends out. (Yeah) - I didn't want to know him - so I weren't all that good. You

know what I mean. It were like I were leaving me other friends out. (Mmm) So that's way

it went.

Participant 3, Interview 1: 311-314

Maintaining contact

Maintaining contact was defined as attempts by participants to keep in touch with friends

or family members when a change in situation had altered the nature of their relationship.

Examples of this were when participants mentioned paying or receiving occasional visits to or from friends or telephone calls to friends and family.

P: 'Cos ..... after a bit, me friend, me friend at me old school gave his telephone number to me.... so I can contact him and talk to him (Right) to see if he were alright and things like that.

I: So you came to an arrangement and do you 'phone him up.

P: Yes.

I: And who's idea was it that you took his 'phone number.

P: Err...... me friend's idea.

Participant 2, Interview 1: 103-108

Maintaining contact was clearly an important issue for the participants, so much so that it sometimes influenced decisions they made in their lives such as where to go for daytime occupations and whether or not to accept a new carer:

P: They maybe going to   .... I wanted to stay at Sheffield - they were maybe going to send me to Leeds. If I'd been going to them other carers I'd be in Leeds by now.

I: Right, right. I can understand that.

P: I wouldn't stand that - I'd miss me Mum a lot. 'Cos Leeds is quite a long way.

Participant 5, Interview 2: 404-407

Special occasions

Special occasions were mentioned by participants as being conducive to the experiencing of *positive* relationships with others and of maintaining contact with people seen less regularly.

> I: What happened on your birthday.. Who was there.
>
> P: There was about ten of us. (yes.) There was myself, A (yes) K, M, K, S, S is a member
>
> of staff P, R, member of staff and myself. That's ten.
>
> I: So there's you, seven of your friends and a couple of members of staff.
>
> P: Yes. and then we went to Macdonalds for tea from there went bowling (yeah) and off out
>
> for a drink.
>
> Participant 1, Interview 1: 190-195

Social strategies

Participants also mentioned a number of social strategies important in maintaining cohesion within their social network. These included gratitude, apologies, arguing and helping others. For example, in the excerpt below the participant responded to the unsought social support proffered by his friend by protesting, followed by apologising when he realised he had upset his friend, after which he compromised in order to settle the situation and maintain a positive relationship.

> P: He -- the Instructor said that, to my friend, that I was being a bit hard on him because I
>
> was like - shouting at him. (Right) fer - I said to him 'I don't want any help thank you' and
>
> I started shouting at him in front of him - that's why he left me a bit panting and a bit
>
> upset 'cos he went in the living room to ..... went in the living room to cry and I just like

.... just like... went in the living room and said 'I'm sorry, I didn't mean it to shout at you'

so when I said sorry - he said 'I'll help you now' 'cos I said to him 'I need some help now'

- and I said 'I am sorry what I did to you' I said and he said, 'OK then'.

Participant 2, Interview 2: 359-365

Participant 3 noted how difficult it can be manage such relationships:

P: .... it's 'ard to make it up - 'cos you feel right idiots - arguing with your best friend.

(Right) How am I going to say sorry, and ....(Mmmm) Well, you've probably done it.

(oh) - You can't make it up - you feel guilty for shouting at 'im. (Yes). You know what I

mean. It's really 'ard making it back up when you've 'ad arguments.

Participant 3, Interview 1: 352-355

Consequences

The final major category within the analysis was that of **consequences**. These could be

consequences to either <u>self-reliant coping</u> or to <u>social support</u> interventions. The

consequences ranged from *satisfactory* to *unsatisfactory*.

Satisfactory

Satisfactory conclusions to **coping** interventions took a variety of forms. This is

consistent with the diversity of strategies and **challenges** that occurred. Participants

mentioned a number of incidents in terms of carers 'sorting it out'. These were seen as

examples where coping strategies had succeeded, indicating a positive end to the coping

process and a resolution to the challenge:

P: ..... He used to pick on me at Castle College - my carer sorted it out.

Participant 5, Interview 1: 302

Another example of a satisfactory consequence was the feeling of belonging that one participant found after making friends at college. In the excerpt below the participant recalls how his parents help him to resolve an issue regarding a broken plug:

P: ..... My Mum and Dad told the staff that the plug cost a lot of money and they had to

pay a lot of money to that person who broke it to go and buy me a new one (Right) for

my computer. 'Cos that person who had broken it, was the person who didn't... want it

to.... didn't ask me my permission to use it.

Participant 2, Interview 2: 231-234

Satisfactory consequences were seen as an end to the coping process described in this analysis.

Unsatisfactory

Three types of unsatisfactory coping were identified: ambivalent conclusions where the intervention resolves the initial **challenge** but in a way that leaves new problems for the participant, **refusal** by someone within the support network to help and **undermining** support. Examples were given by individuals where coping strategies were found to be inadequate or advice was poor. In these cases the participant would often return to trying

to find a way to cope. In the worst cases, however, these unsatisfactory consequences could lead to new challenges.

Ambivalent

One example given of an <u>ambivalent</u> **consequence** was that which arose for Participant 3 when he was experiencing bulling at school. The measures taken by the <u>support intervention</u> stopped the bullying but led on to difficulties between himself and his girlfriend:

P: So they were always there, in case I got bullied.

I: Sure, yes, yes. And what did that feel like, having....

P: At times, I didn't want them near. (Yes). 'Cos when I were with my girlfriend it's like –

          she were like, 'what are they doing 'ere'. And I'm like – they stuck with me all the time –

          and going around with 'em all around me. 'Cos she weren't quite happy about it.

Participant 3, Interview 1: 177-181

In this case the ambiguity led to conflict between the participant and his girlfriend, which is illustrative of how a social support intervention may have unforeseen negative consequences as well as positive ones.

Refusal

It was noted that people requested for help were not always forthcoming. Participant 2 talked about how people had ignored his requests for help:

P: Er ....sometimes .... sometimes they 're........sometimes they are a little bit helpful but

        when they're not, they're like, they're not helping me right. Like... like... they say I'm not

        helping enough. Like I go, like I'll go and do something else. Like, like ... like they don't

        help me..... They, like they just walk off..... Like....like they walk off and go with

        somebody else and things like that so that's what, that's what, that's what they did.

Participant 2, Interview 1: 322-326

P: People haven't been helpful.

I: OK. What makes you say that. Do you feel people have made things difficult do you

        think. They've not done as much as they could, or what.

P: Mmm, they didn't ..... they didn't - in a way they didn't explain to me part of the course?

        Because they were saying it a bit too quickly and mmm... and like they weren't listening

        what I was saying but they just carried on, just like talking to one another. That's all.

Participant 2, Interview 1: 193-198

Undermining

At other times when help was offered it was felt to be undermining skills which the

participant felt able to perform. These were examples where unsought support had been

offered but had not been wanted by the individual. This then lead into a process of

refusal by the recipient and the withdrawal of the supporter:

P: If I work in the canteen, right, if I'm cooking in the canteen, in cafe, I can do it myself

        and I practice - I done it meself - like them others. D says 'Can you make it, want any

        'elp'. I say ' I don't want any 'elp. I can do it meself'. If I work in the cafe and I'm making

som'at in there - I say I'll put that on a plate - I can make omlettes - I make an omlette - I

put it on plate.

Participant 5, Interview 2: 516-522

P: I said 'No, no - I'll be alright, I've got it under control' - so, so he just like ....went in room

in a huff and - and - and this lad ... just like got up out of chair, and - and he said .....

Participant 2, Interview 1: 354-356

Another participant gave an example of the negative pattern of interaction that can

proceed when unwanted social support is offered:

P: I just, I just ignored 'em when they come. They didn't like it. Teachers didn't like me

ignoring 'em.

I: What did they say when you ignored them.

P: They said 'Oh, we're talking to you'. I said,' No we're not, I'm trying to get on with me

work and you're like disturbing me'. So she says 'Oh, I'll leave you alone then'. And she

did.

Participant 3, Interview 2: 496-504

As can be seen from the above excerpts, such interaction patterns, if poorly handled can

lead onto increased conflict between the person with the learning disability and their

support network. This once again leads to further **challenges** which the participant must

come to terms with in the transition to their adult lifestyle.

Selective coding

As may be observed from the above account, the coding that has taken place of the data has been at the level of open coding the interview transcripts and axial coding which aims to explicate the relationships between these categories and their properties. As recorded in the Methodology section of the thesis, a third level of coding exists which is that of selective coding. In this the core category is chosen to explicate the story line. This research project has, however, stayed at the level of open and axial coding as there has not been enough time to move further into the area of selective coding.

However, whilst examining the nature of the relationships outlined above the author did bear in mind the need to develop a core conceptualisation of the research. Further analysis of the data would therefore have moved in the direction of the construct that currently seems most accurate with regard to the model described above, that of **negotiating**.

The category of negotiation might have been developed in three ways. Firstly, in the sense that it can mean to find your way around issues and problems. This sense encapsulates the approach to the challenges thrown up during the course of the transition process. The participants need to negotiate these through the use of coping strategies. As such, a property of the core category might be *outcome* with ranges from *successful* to *stuck*. Secondly, the concept of negotiating describes how the process the participants undergo in establishing their place in their social network. They negotiate their identify through their interactions with their peers and others around them. As change takes place

within their own lives and those of the people around them they need to use social management skills to maintain contact with familiar faces and establish new ties. Finally, **negotiation** is a key theme of transition. As people with learning disabilities grow older they, like all adolescents, begin to argue for control over decisions and areas in their lives which remained out of their reach as children.

Discussion

As reviewed in the Introduction, previous research has established the role of life events and transitions in the mental health of different populations and the role of social support in mediating these changes. Research has specified typologies of social support and other important aspects of social support including the dichotomy between perceived and actual social support. However, few studies have examined the process of social support or the views of people with learning disabilities on social support. This study therefore aimed to develop an understanding of how people with learning disabilities experience social support during the period after leaving school when they enter the adult services and begin the transition into adult life. It has drawn on the perceptions of young adults with learning disabilities and attempted to identify those factors which define the process of social support. An additional aim of this work has been to make explicit the properties and dimensions of these factors as experienced by young adults with learning disabilities.

A number of significant issues to understanding the nature of social support for people with a learning disability were identified. Support interventions were examined in the context of the intervening factors and social context within which they occur and relationships were traced between these contextual factors and the coping process. The pathways to support and their implications represent an addition to traditional theories of social support. These issues and the consequent theoretical and clinical implications will now be discussed. In addition, the research methodology and process will be evaluated.

Theoretical implications

Through the process of the analysis of the transcripts the study has uncovered a number

of factors which are not addressed in previous research on social support. These included

the different courses to supportive interactions that occur. In addition the research also

identified features of relationships that were important to the participants. Issues

pertaining to the social networks of people with learning disabilities were also identified

and the difficulties that arise when conflict occurs within the support network. These will

now be discussed in comparison with previous research.

Typologies

Numerous analyses of social support have been made (Barrera and Ainlay, 1983; Barrera,

1986). For example, Barrera and Ainlay's (1983) analysis produced four factors:

directive guidance, *non-directive support*, *positive social interaction* and *tangible*

assistance. A number of overlaps exist between this typology and that elaborated

through the research process and described in the Analysis above. This is perhaps to be

expected as the original conceptual analysis by Barrera and Ainlay formed the basis for

the interview schedule used by the author. For example, *directive guidance* is similar to

the categories of both **academic** and **skill development**, which perhaps could have been

merged together into a single category. Similarly, the category of *non-directive support*

resembles that of **social validation**. Although the categories of **academic, social**

validation, skill development, practical support and **emotional support** do not

correspond exactly to those of Barrera and Ainlay's analysis, it is interesting to note that the same basic types of support are applicable to both those with and those without learning disabilities.

The one major difference between the two typologies of social support interventions if the category of **social mediation** which appears in the current report. This describes supportive interactions whereby the individual is either represented by a supported in the role of advocate or receives advice and guidance regarding social relationships. This distinction may reflect the very different nature of the two samples; Barrera and Ainlay's (1983) sample consisting of college undergraduates as opposed to the current study's sample being drawn from the learning disabilities. The differences between the two sampled groups are multiple. The sample in Barrera and Ainlay's report are likely to be more eloquent, less likely to have communication difficulties and occupy a higher social status than the participants in the current study. For these reasons this type of support may be less relevant to their needs. Alternatively, people from such a background may be unwilling to disclose social support in an area that is assumed to be one of their strengths. However, the category of **social mediation** may be more relevant to the support needs of socially disadvantaged groups, such as people with learning disabilities, the elderly or people with enduring mental health problems.

The support process

An important distinction noted within this study were the different **pathways** to supportive interventions. Much research into social support has not studied the pattern of

interactions that lead to the delivery of support. The differing effects that these may have upon the context in which the support occurs, the self-image and self esteem of the recipient and the subsequent development of the individuals abilities and relationship with his or her social network have therefore often been ignored. This study found that the method of attaining support had crucial implications, particularly when support interactions were misplaced in either timing or outcome. If the individual **initiated** a search for social support then the ability to identify those who are going to be supportive is crucial to the satisfactory conclusion of the support seeking behaviour. If an individual asks people who are not prepared to offer support then they are likely to suffer an adverse experience of **refusal**. Although not demonstrated in this study, it might be conjectured that this might lead to a withdrawal from the tendency to seek out support when it is needed and lead to a dependence upon support needs being provided by those who are alert to the needs of the individual.

The second pathway was that of support being offered by someone in the individual's social network. This too entailed risks, in that such support was not always positively received and could be seen as **undermining** either the individual's sense of independence or their social role. This finding supports that of Bolger, Kessler & Shilling (1989, cited in Coyne & Bolger, 1990) who in a diary study found that participants did not associate social support with positive emotional states. Instead, Bolger et al. found that support was much more positively received when it was unnoticed. Finally, the third pathway to support was the least adaptive in that it necessitated the individual protesting in one form or another until the support network or services responded.

Thirdly, participants also talked about the relationship between social support and **non-cooperative behaviour**. This was an example of what may go wrong when support isn't forthcoming in that participants described a process of disengaging from services until either adequate support or an alternative was provided. The findings related above supports that of Krause and Liang (1993) who found when older adults initiated requests for support they were perceived as burdensome, resulting in a perception of being burdensome and a lessening of the quality of social support available to the individual. This study suggests that the ability to perceive who is prepared and able to give support is an important quality necessary to the successful utilisation of the support network.

Relationship Factors

Previous studies have delineated concepts of intimacy in an attempt to understand the nature of supportive relationships (Barrera, 1992). For example, Lin (1986) described three levels of supportive relationships: the community, the support network and intimate loving relationships. Similarly, Barrera (1987), responding to a paper regarding a social support intervention, proposed that the intervention had failed due to a lack of intimacy. Such analyses suggest that supportive relationships are one-dimensional and that the key factor is that of *intimacy*. The current study clearly identifies a number of other aspects to supportive relationships. Whilst **trust** was an important factor it was clearly moderated by how **dependable** a person who provides the support was perceived and the **specificity** of roles which they might be called on to fulfill. Participants clearly indicated that some types of support would be support by some members of the network but not

others. Whilst some times this was at the discretion of the participant this factor was also defined by what roles the supporter was able or felt inclined to give.

Network

The study also enabled the clarification of the aspects of **social network** which affect contextually the possibility of supportive interactions. Much previous research has been dedicated to the enumeration of social support networks. Studies have tended to examine support structures from the point of view of the main carers of the person with the disability (e.g. Grant, 1993). These have shown that support networks of people with learning disabilities tend to be quite small, with many people within the network taking on a number of roles. Whilst this has been generally borne out in this study there has also been evidence of people with the **specific** support roles as being important to the participants.

Much has been made in previous research of the way the support networks of people with learning disability constrict as they become older and family members and friends leave through either death or relocation (Grant 1986, 1993; Clegg and Lansdell-Welfare, 1995). Again this is supported in the current research in that **loss** was one of the main themes associated with **social networks**. This has been elaborated to demonstrate how changes in patterns of activity and changes of location can result in **partial** changes affecting their quality of life. However, the notion that people with learning disabilities passively accept their shrinking resources is challenged by the finding in the current research project that people with learning difficulties view **establishing new ties** as an important aspect to

effecting a successful transition into new services. This was associated quite strongly with obtaining a 'sense of belonging' and feeling part of a service.

Conflict

The role of **conflict** in **social networks** has not been considered in previous research. This was found to have implication for the implementation of support strategies, which have different **consequences** for the participant in different areas of his life leading to **ambivalent** outcomes. For example, they might lead into **conflict** with or between the people to whom the individual looks for support or they might solve one problematic area of someone's life but cramp their style in another. Effective **management** of conflicts within social support systems is an important aspect of **maintaining contact** with positive and supportive **relationships**.

Conflict over **boundaries** was also identified as pertinent to the provision of **social support** at the time of transition. This was sometimes overcome by the **management strategies** but at other times lead to the curtailment of the individuals activities. How such **conflict** was dealt with depended upon the **identity** of the individual and the level of **control** that they were able to exert over their lives.

Effects of having a learning disability

This study did not set out to make a comparative analysis of social support between learning disabilities and other populations. However, the author noted that certain conceptualisations raised issues around disability and the social conditions and social

functioning which can result from being considered to have a learning disability. The categories of **control** and **identity** most pertinently raised these issues in the current analysis.

Lack of **control** over both **decisions** and of **resources** was clearly indicative of the status that people with learning disabilities have both in their own families and within society generally. This finding complements that of Heyman and Huckle (1993) found that of the twenty families in their study eleven adopted the shared danger avoidance pattern, two were in conflict and seven the shared risk taking strategy. The lack of control over both resources and decisions that is experienced by people with learning disabilities further disables some of them in preventing their taking a greater part in the transition from adolescence to adulthood. As one of the aspects most associated with this transition is the adoption of greater responsibility for our own lives, this might be seen as a key ommission. Whilst clearly some people with learning disabilities might not, due to cognitive difficulties, be able to take control over such things, the complete avoidance of discussion of these subjects with some people with learning disabilities is a sensitive yet important issue about the roles of family and other carers within the person's network which might merit either family work or access to an advocacy servicce.

Similarly, **identity** played a crucial role for participants in determining how they positioned themselves within their social network and how much **control** they attempted to exert over their lifestyles. Social comparison (Festinger, 1954) formed an important aspect of participant's identities, particularly when related through **abusive** situations as

exhibited by experiences of name-calling. Clearly, there may be a reciprocal relationship between **identity** and **abusive** situations, as indeed there would appear to be between **identity** and the level of **control** that an individual has in his or her life. These issues illustrate some of the socially constructed aspects of identity.

Clinical implications

The research clearly identifies a number of implications for clinical work with individuals who are on the point of leaving or have left school. Participants described the many roles social support plays in ensuring a successful school to adult life transition. However, they also recounted how the transition process could lead to the **dislocation of social support relationships** and the curtailment of effective **social support**. Moreover, **challenges** associated with the transition were associated with **intense emotional states**. Therefore, support would clearly be important to these people to enable them to overcome the challenges they are facing. In working with these people clinicians need to be aware of the changes in support network that go hand in hand with the transition process.

The clinical implications of the current study might be drawn primarily on two levels: those interventions aimed at setting up and enabling social support interventions and those aimed at enabling people with learning disabilities to either establish their own or access more effectively pre-existing support networks. In addition to these, in some cases, as mentioned above, advocacy or family and systemic work might be indicated within those support networks where there is a great deal of **conflict**.

Social Support Interventions

As mentioned in the introduction, Monaghan and Soni (1992) suggested that community teams should be sensitive to the changes taking place in clients lives so that support can be implemented when such changes have occurred. Unfortunately, Monaghan and Soni made no specification regarding what form that support should take and, as the present study has shown, there are many types of support and different factors may affect the appropriate and success or failure of each. Current examples of social support interventions include befriending schemes and advocacy work (e.g. Wurr, 1998). Other social support interventions have looked at the influence of social support in conjunction with various training strategies (e.g. Lassner, 1991; Dadds & McHugh, 1992).

The analysis presented here suggests that such support interventions need to be carefully designed in order to avoid what have been described as the toxic effects of victimising support (Wortman, 1984). As noted earlier, support interventions can be experienced by people with learning disabilities as **undermining**. This raises the issue of the qualities that are required of supporters in order that they be effective. It would seem to suggest that supporters need to be sensitive to the needs and feeling of recipients in order to provide valued support. Moreover, it is vital that support network are responsive to the people with learning disabilities when appropriate requests for support are initiated.

It was **difficult to say** for some participants why some people should be referred to others in the social network. This lack of specification may lead to difficulties with befriending

schemes. However, people with learning difficulties do sometimes need help with **establishing new ties** or **maintaining contacts**. These might be accounted for by providing better opportunities for social contact, both before, during and after the transition process which would add greater **stability** to an otherwise changing **social network**. Such contacts might also be guided by the individuals perception of their own identity, it being important that the individual feels comfortable relating to the people with whom they are socialising. This raises difficult questions about services specific to people with learning disabilities and the principles of normalisation proposed by Wolfenberger which guide current professional practice.

It is important to consider the implications for the broader system when considering social support interventions. It has already been noted in this report that **conflict** can curtail the effectiveness of certain social support activities. It is possible therefore that support interventions introduced by professionals working with young adults with learning disabilities will lead to conflict with other aspects of the support network. This seems to be particularly the case with advocacy interventions, especially if this is a role which people within the social network already see themselves as fulfilling.

Research process

This was the authors first experience of qualitative research and, as such, was very much a learning experience for him. An immediate issue for the author was his familiarisation with the research techniques that he ahd chosen to use and the strengths and weaknesses

of this approach. However, the research process also through up further challenges in the forms of the acquisition of appropriate supervision and ethical dilemmas that arose during the research process. These issues will now be discussed.

Qualitative Interviewing

The interviewer discovered the process of qualitative interviewing to be a challenging, energising and at times frustrating experience. During the initial interviews the researcher found himself anxious to follow the interview guidelines and sample questions that had been prepared prior to the research commencing. However, as the research proceeded confidence was gained in following the narratives begun by the participants and facilitating the explanation of their personal experience of the transition process and the help and support which they had received during it. Overall, the interviewer found that participants tended to respond much more clearly and fully to questions grounded in their own experience than to more abstract questions generated through knowledge of research or through the interviewers own hypothesising.

As noted in the Methodology section of this report, when research was originally planned it was decided to interview the participants on two occasions due to the sensitive nature of some aspects of social support. This would also allow the interviews to be shorter in length, an important factor for those participants with shorter attention spans. In practice it was found that issues such as abuse were very quickly disclosed, leading to ethical questions about the correct response by the interviewer. This is perhaps evidence of how people with learning disabilities live what Bercovi (1981) has described as a 'goldfish

bowl' existence, and how accustomed they become to discussing their lives with unknown professionals.

However, whilst participants appeared to be prepared to talk about issues in an open way it can only be assumed that the above analysis is a partial account of social support. This is due to issues of trust and the question of how much the participants are comfortable in telling their researcher.

Supervision

This being the author's first practical experience of qualitative research the study was the initiation of an intense learning process regarding the use of qualitative methods. Anxieties around date coding methods were allayed through the attendance of qualitative research methods group, where peer supervision was available lead by a member of the academic staff at the university who was experienced in the use of qualitative methodologies. This was particularly helpful as neither the academic supervisor nor the field supervisor were experienced in qualitative research methodologies themselves.

Ethical Issues

Concerns were raised by the ethics committee to whom the research proposal was submitted regarding the effects that research interviews might have upon the emotional state of individuals interviewed, particularly as the interview would touch upon difficulties they were experiencing in their lives and key relationships. It was agreed

therefore that the interviews would be in a place familiar to the participant and that the interviewer would ensure that someone familiar to the participant would be available for the participant to talk to should he or she become distressed.

A further ethical concern for the interviewer was regarding how he should respond to any disclosures of abusive behaviour which might occur during the interview. This was particularly relevant as two of the participants disclosed having been the victims of abusive incidents during interviews. The author discussed these incidents with his academic supervisor and it was decided that two courses of action should be followed. Firstly, that social services should be contacted in order to ascertain whether they were aware of this. Secondly, the participants were asked again for their permission to use the information in the research.

Evaluation of the Study

It has been questioned whether research using qualitative approaches can be evaluated using the same criteria as would be applied to a quantitative study. This section will therefore consider the strengths and weaknesses of the study with particular reference to the sampling issues, methodology, ambiguity and interpretation, and the criteria by which the study might be evaluated.

Sampling Issues

One of the weaknesses of the study was that due to limitations of available time and resources there was insufficient time to allow for the proper interplay between theory generation and further data sampling. Strauss and Corbin (1990) suggest that further data collection should be guided by the categories generated in the initial coding process and hypotheses and questions which arise from this.

A further issue with the sample is that all participants were currently in day placements. The author is aware through his own clinical work of the difficulty involved in finding suitable day time placements for people with learning disabilities. There may be significant and important differences between the support of individuals with and those without daytime occupations.

However, attempts were made to contact individuals via a range of agencies in order to try to meet participants with a range of abilities and who had undergone a variety of experiences in both their schooling and through the decisions that were made with regard to the transition process. The aim of this was to incorporate the variety of experience of participants with a range of abilities in order to clarify the relationship between social support and these factors.

Self report methodologies

The methodology as used here was fundamentally one of self-report. This is to say, it relies upon the participants giving reasonably honest and accurate accounts. Clegg and

King (1998) have asserted that questions elicit answers in the form of stories but no link can be assumed between these stories, reliable memories and real events. However, the current author takes the view that it is the presumption of this link which makes self-report methodologies important and worthwhile. One of the strengths of the research methodology is the primacy it gives to the discourse of the individuals themselves who agreed. This is particularly important when researching people with learning disabilities as this sector of the population has for long been classified and stigmatised by professionals.

However, one problem with interviews is the primacy that they place upon verbal communication and that they only allow us to conceptualise those things which the participant may express. It is dependent upon the eloquence of the participants to put into words those aspects of social support which are important to them. Coyne and Bolger (1990) have assert that the self report paradigm is prone to the limits of the individual's ability to conceptualise and what they think is happening. This is a general criticism of the methodology. However, there are obvious implications for interviewing those of the population who have serious communication difficulties. Nevertheless, the free flowing nature of the interview technique allowed the interviewer and participants to join in an exploration of the issues which would have been much more difficult if a more structured format had been adopted.

A further limitation of the self-report methodologies is that this research paradigm can not take into account of those factors of which the participant is unaware or unwilling to

discuss (Coyne and Bolger, 1990). Although by interviewing twice the researcher attempted to build rapport with participants and to encourage an open discussion of the issues which have been important to them during the previous few years.

Ambiguity and contradiction

One of the questions which arises over this type of textual analysis and which was found at times to be problematic is that of ambiguity and interpretation. Thus, what participants said had to be clearly seen in the light of the context in which it was said. At times participants would also contradict themselves during the interviews. When ambiguities and contradictions were noticed by the interviewer during the course of the interview he would attempt to clarify the participants responses by asking further questions, rephrasing questions, reflecting back answers or prompting the participant by offering choices or closed questions. This encouragement of further description and elaboration of responses enabled the interviewer to check for consistency or responses, to ensure that he understood what the participant had meant in reply and that the participant had understood the meaning of the interviewer's question. The flexibility of the interview approach was therefore extremely helpful in ascertaining this participant group's concerns and beliefs about social support.

Every effort was made during the interview to avoid unjustified assumptions about the participants responses. Nevertheless, in the succeeding process of transcribing and analysing the data ambiguities and contradictions in the participants' responses emerged of which the interviewer had been unaware during the interview. In these instances the

interpretation of the text was guided by the level of description and depth of contextual evidence in the participants' contradictory responses. For example, when one participant was asked who had helped him after he left school replied no one before describing a number of positive and supportive relationships.

Validity

As described above, attempts were made during the coding process to check the validity of the concepts generated through negative case analysis and by remaining close to the data in order to maintain a 'fit' between concepts, as described above. Through the generation of the core category the aim has been to integrate these at a further level of abstraction.

The author has been open about the assumptions that were made at the start of the research process and difficulties encountered in the process of interviewing the participants and coding the date so that readers may make judgements as to the role played by these in the research process. Further, it is hoped that the documentation of evidential links presented in the Analysis section of the report will enable readers to judge for themselves some of the evidence for the categories delineated.

Further directions

This study has analysed the beliefs of people with learning disabilities about the importance of social support. Due to the time limited nature of the research it was

possible to only interview the participants twice, often within a very short space of time. Bercovici (1981) and Withers (1998) both noted how participant's accounts changed during subsequent interviews. One aspect of future research which would be useful would be multiple interviews throughout the course of transitions so that the change in support and lifestyle may be more fully delineated. Such a research project would also allow the participants to become used to the interviewer thereby prompting greater understanding between the two of them and enabling researchers to explore the changes in social support which occur over time.

As mentioned above, the sample for the research consisted only of people who had a day time placement. This raised the question of what happens to those people who disappear from services and are left without adequate day services that they need. Such a result may change the nature of peoples relationships with those who support them, making greater demands and changing the quality of the relationship. Alternatively, some families may choose to say clear of specialist services. Again, this may reflect differences in **networks** and **identities**.

Finally, an area which appears to merit further attention is that of how different aspects of the individual might affect social support structures. We have already seen that issues such as ability and how one interacts with the people around are crucial factors in deciding what support will be made help of and which social circles someone feels comfortable in. However, the self-report methodology only accesses those aspects of the support process that individuals are comfortable talking about. Observational studies

would therefore be useful in further delineating individual aspects which are important to

the support process, such as communication, social skills and mental health issues, and

would complement the analyses already made.

References

Antonovsky, A. (1974) Conceptual and methodological problems in the study of resistance resources and stressful life events, in Dohrenwend, B.S. & Dohrenwend, B.P. (eds.) *Stressful life events: Their nature and effects*, New York: Wiley

Antonovsky, A. (1979) *Health, stress and coping*. San Francisco: Jossey-Bass.

Atkinson, D. (1988) Research interviews with people with mental handicap, *Mental Handicap, 1*, 75-90

Barrera, M. (1986) Distinctions between social support concepts, measures and models, *American Journal of Community Psychology, 14 (4)*, 413-443

Barrera, M. (1991) Social support interventions and the third law of ecology, *American Journal of Community Psychology, 19 (1)*, 133-138

Barrera, M. & Ainlay, S.L. (1983) The structure of social support: A conceptual and empirical analysis, *Journal of Community Psychology, 11*, 113-143

Bercovici, S. (1981) Qualitative methods and cultural perspectives in the study of de-institutionalisation. In Bruininks, R.H., Meyers, C.E., Sigford, B.B. & Lakins, C. (eds.)

Deinstitutionalisation and community adjustment of mentally retarded people, Washington D.C.: AAMD

Brown, G.W. & Harris, T. (1978) *Social origins of depression: A study of psychiatric disorder in women.* London: Tavistock

Bryman, A. (1988) *Quantity and quality in social research.* London: Unwin Hyman

Card, H. (1983) What will happen when we're gone?, *Community Care, 28,* 20-21

Carter, E. & McGoldrick, M. (eds.) (1982) *The family life cycle: A framework for family therapy.* New York: Gardner

Cassel, J. (1976) The contribution of social environment to host resistance *American Journal of Epidemiology, 104,* 107-123

Chalmers, A.F. (1982) *What is this thing called science: An assessment of the nature and status of science and its methods.* Milton Keynes: Open University Press

Chung, R.K., Langeluddecke, P. & Tennant, G. (1986) Threatening life events in the onset of schizophrenia, schizophreniform psychosis and hypomania, *British Journal of Psychiatry, 148,* 680-685

Clegg, J.A. & Standen, P.J. (1991) Friendship among adults who have developmental disabilities, *American Journal on Mental Retardation, 95 (6)*, 663-671

Clegg, J.A., Standen, P.J. & Jones, G. (1996) Striking the balance: a grounded theory analysis of staff perspectives, *British Journal of Clinical Psychology, 35(2)*, 249-264

Cobb, S. (1976) Social support as a moderator of life stress, *Psychosomatic Medicine, 38*, 300-314

Cohen, S. & Wills, T.A. (1985) Stress, social support and the buffering hypothesis, *Psychological Bulletin, 98*, 310-357

Cohen, S. & Syme, S.L. (1985) *Social Support and Health.* New York: Academic Press

Cooke, D.J. & Hole, D.J. (1983) The aetiological importance of stressful life events, *British Journal of Psychiatry, 143*, 397- 400

Coyne, J.C. & Bolger, N. (1990) Doing without social support as an explanatory concept, *Journal of Social and Clinical Psychology, 9 (1)*, 148-158

Coyne, J.C. & Smith, D. J. (1991) Couples coping with a myocardial infarction: A contextual perspective on wives distress, *Journal of Personality and Social Psychology, 61*, 404-412

Coyne, J.C. & Smith, D. J. (1994) Couples coping with a myocardial infarction: Contextual perspective on patient self-efficacy, *Journal of Family Psychology*, *8*, 13-54

Denzin, N.K. & Lincoln, Y.S. (1994) Introduction: Entering the field of qualitative research, in Denzin, N.K. & Lincoln, Y.S. (eds.) *Handbook of qualitative research*, Thousand Oaks, California: Sage

Deutscher, I. (1973) *What we say/ what we do*. Glenview, IL: Scott, Foreman & Co.

Deiner, E. (184) Subjective well-being, *Psychological Bulletin*, *95*, 542-575

Dunn, C. (1996) A status report on transition planning for individuals with learning disabilities, *Journal of Learning Disabilities*, *29 (1)*, 17-30

Duvall, E.M. (1977) *Marriage and family development*. Philadelphia: Lippincott.

Edgerton, R.B. (1967) *The cloak of competence*. Berkley: University of California Press

Edgerton, R.B., Bollinger, M. & Herr, B. (1984) The cloak of competence: After two decades, *American Journal of Mental Deficiency*, *88*, 345-351

Ell, K. (1993) Social networks, social support and coping with serious illness: The family connection, *Social Science and Medicine*, *47(2)*, 173-183

141

Erikson, E. (1950) *Childhood and society*. New York: Norton.

Eurelings-Bontekoe, E.H.M., Diekstra, R.F.W. & Verschuur, M. (1995) Psychological distress, social support and social support seeking: A prospective study among primary mental health care patients, *Social Science and Medicine, 40 (8)*, 1083-1089

Felce, D. & Perry, J. (1995) Quality of life: Its definition and measurement, *Research in developmental disabilities, 16 (1)*, 51-74

Firth, H.& Rapley, M. (1990) *The process of friendship: issues and strategies for people with learning disabilities*. Kidderminster: BIMH

Flynn, M.C. (1987) Independent living arrangements for adults who are mentally handicapped, in Malin, N. (ed.) *Reassessing community care*. London: Croom Helm.

Grant, G. (1993) Support networks and transitions over two years among adults with a mental handicap, *Mental Handicap Research, 6*, 36-55

Ghaziuddin, M. (1988) Behavioural disorder in the mentally handicapped: The role of life events, *British Journal of Psychiatry, 152*, 683-686

Glaser, B. & Strauss, A. (1967) *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine

Goldberg, K., Magrill, L., Hale, J., Damaskinidou, K., Paul, J., & Tham, S. (1990) Protection and loss: working with learning-disabled adults and their families, *Journal of Family Therapy, 17*, 263-280

Goodyer, I., Kolvin, I. & Gatzanis, S. (1985) Recent undesirable life events and psychiatric disorder in childhood and adolescence, *British Journal of Psychiatry, 147*, 517-523

Gore, S. (1981) Stress-buffering functions of social support: An appraisal and clarification of research models, in Dohrenwend, B.S. & Dohrenwend, B.P. (eds.) *Stressful life events and their contexts*. New York : Prodist

Gollay, E., Freedman, R., Wyngaarden, M. & Kurtz, N.R. (1978) *Coming back: The community experiences of de-institutionalised mentally retarded people*. Cambridge, Ms. Anderson: Abt.

Halpern, A. (1992) Old wine in new bottles, *Exceptional children, 58*, 202-211

Halpern, A.S., Close, W.D., & Nelson, D.J. (1986) *On my own: The impact of semi-independent living programs for adults with mental retardation*. Baltimore: Brookes.

Hanley-Maxwell, C., Whitney-Thomas, J. & Mayfield Pogoloff, S. (1995) the second shock: A qualitative study of parents' perspectives and needs during their child's transition from school to adult life, *JASH*, *20*, 3-15

Heal, L.N. & Sigelman, C.K. (1995) Response biases in interviews of individuals with limited mental ability, *Journal of Intellectual Disability*, *34 (4)*, 331-340

Heller, T., Berkson, G. & Romer, D. (1981) The social ecology of supervised communal facilities for mentally disabled adults: VI. Initial social adaptation, *American Journal of Mental Deficiency*, *86*, 43-49

Henwood, K. & Nicolson, P. (1995) Qualitative research, *The Psychologist, 8 (3)*, 109-110

Henwood, K. & Pidgeon, N. (1992) Qualitative research and psychological theorizing, *British Journal of Psychology*, *83*, 97-111

Henwood, K. & Pidgeon, N. (1995) Grounded theory and psychological research, *The Psychologist, 8 (3)*, 115-118

Heyman, B. & Huckle, S. (1993) 'Normal' life in a hazardous world: How adults with moderate learning difficulties and their carers cope with risks and dangers, *Disability, Handicap and Society, 8 (2)*, 143-160

Holmes, T.H. & Rahe, R.H. (1967) The social readjustment rating scale, *Journal of Psychosomatic Research, 11*, 213-218

House, J.S. & Kahn, R.L. (1985) Measures and concepts of social support, in Cohen, S. & Syme, L. (eds.) *Social support and health*, San Diego: Academic Press

Hutchinson, D. (1983) Sexuality and the handicapped: some observations on needs and attitudes, *Educare, 18*, 27-30

Kaufman, S. (1984) Friendship, coping systems and community adjustments of mildly mentally retarded adults. In Edgerton, R.B. (ed.) *Lives in process (monograph)*. Washington DC: American Association on Mental Deficiency.

Kielhofner, G. (1979) The temporal dimension in the lives of retarded adults: a general problem of intervention and interaction, *American Journal of Occupational Therapy, 33 (3)*, 161-168

Krause, N. (1995) Assessing stress-buffering notes a cautionary note, *Psychology and ageing, 10 (4)*, 518-526

Krause, N. & Liang, J. (1993) Stress, social support, and psychological distress among the Chinese elderly, *Journal of Gerontology, 48*, 282-291

Landesman-Dwyer, S. & Berkson, G. (1984) Friendships and social behaviour. In Wortis, J. (ed.) *Mental retardation and developmental disabilities: An annual review (Vol. 13)*. New York: Plenum Press

Lassner, J.B. (1991) Does social support aid in weight loss and smoking interventions? A reply from a family systems perspective, *Annals of Behavioural Medicine, 13 (2)*, 66-72

McConkey, R., Walsh, J. & Mulcahy, M. (1982) Mentally handicapped adults living in the community: A survey conducted in and around the city of Dublin, *Mental Handicap, 11*, 90-93

Monaghan, M.T. & Soni, S. (1992) Effects of significant life events on the behaviour of mentally handicapped people in the community, *British Journal of Mental Subnormality, 38*, 114-121

Morningstar, M.E., Turnbull, A.P. & Turnbull, H.R. (1995) What do students with disabilities tell us about the importance of family involvement in the transition from school to adult life?, *Exceptional Children, 62*, 249-260

Myers, J. (1975) Life events, social integration and psychiatric symptomatology, *Journal of Health and Social Behaviour*, *16*, 421-427

Orford, J. (1995) Qualitative research for applied psychologists, *Clinical Psychology Review*, *75 (Jan)*, 19-26

Parkes, C.M. (1972) *Bereavement: Studies of grief in adult life*. London: Tavistock

Pope, C. & Mays, N. (1995) Reaching the parts other methods cannot reach: An introduction to qualitative methods in health and health service research, *British Medical Journal*, *311*, 42-45

Richardson, A. (1989) Letting go: a mother's perspective, *Disability, handicap and society*, *4*, 81-92

Romer, D. & Berkson, G. (1980) the social ecology of supervised communal facilities for mentally disabled adults: III. Predictors of social choice, *American Journal of Mental Deficiency*, *85*, 243-252

Rook, K. (1984) Promoting social bonding, *American Psychologist*, *39*, 1389-1407

Russell, P. (1996) *Rites of passage: Transition to adult life for young disabled people.* Council for Disabled Children.

Sinason, V. (1992) *Mental handicap and the human condition.* London: Free Association Books

Schloss, P.J. & Schloss, C.N. (1985) Contemporary issues in social skills research with mentally retarded persons, *Journal of Special Education, 19,* 269-282

Schreurs, K.M.G. & de Ridder, D.T.D. (1997) Integration of coping and social support perspectives: Implications for the study of adaptation to chronic disease, *Clinical Psychology Review, 17 (1),* 89-112

Strauss, A. & Corbin, J. (1990) Basics of qualitative research: Grounded theory procedures and techniques. London: Sage

Strauss, A. & Corbin, J. (1994) Grounded theory methodology: An overview, in Denzin, N.K. & Lincoln, Y.S. (eds.) *Handbook of qualitative research,* Thousand Oaks, California: Sage

Szymanski, E.M. (1994) Transition: Life span and life-space considerations for employment, *Exceptional Children, 60,* 402-410

Taylor, S.J. & Bogdan, R. (1981) A qualitative approach to community adjustment, in Bruininks, R.H., Meyers, C.E., Sigford, B.B. & Lakins, C. (eds.) *Deinstitutionalisation and community adjustment of mentally retarded people*. Washington D.C.: AAMD

Thoits, P.A. (1982) Conceptual, methodological, and theoretical problems in studying social support as a buffer against life stress, *Journal of Health and Social Behaviour, 23*, 145-159

Thoits, P. A. (1986) Social support as coping assistance, *Journal of Consulting and Clinical Psychology, 54*, 416-423

Thompson, S.C. (1992) Individual and interpersonal influences on the use of cognitive coping, in Turnbull, A., Patterson, J.M., Behr, S.K., Murphy, D. L., Marquis, J.G. & Blue-Banning, M.J. (eds.) *Coping, families and disability*. Baltimore: P.H. Brookes

Thomson, G.O.B., Ward, K.M. & Wishart, J.G. (1995) The transition to adulthood for children with down's syndrome, *Disability and Society, 10 (3)*, 325-340

Thorin, E., Yovanoff, P. & Irvin, L. (1996) Dilemmas faced by families during their young adults' transitions to adulthood: A brief report, *Mental Retardation, 34(2)*, 117-120

Todd, S., Evans, G. & Beyer, S. (1990) More recognised than known. The social support and visibility of people with developmental disabilities, *Australian and New Zealand Journal of Developmental Disabilities, 16(18)*, 207-218

Tracy, E.M. & Whittaker, J.K. (1987) The evidence base for social support interventions in child and family practice: Emerging issues for research and practice, *Children and Youth Services Review, 9*, 249-270

Turpin, G., Barley, V., Beail, N., Scaife, J., Slade, P., Smith, J.A., & Walsh, S. (1997) Standards for research projects and theses involving qualitative methods: suggested guidelines for trainees and courses, Clinical Psychology Forum, October, 108

Vaux, A. (1988) *Social support: Theory, research and intervention.* New York: Praeger

Vaux, A. (1991) Let's hang up and try again: Lessons learnt from a social support intervention, *American Journal of Community Psychology, 19 (1)*, 85-90

Whitcher, S.J. & Fisher, J.D. (1979) Multidimensional reactions to therapeutic touch in a hospital setting, *Journal of Personality and Social Psychology, 37*, 87-96

Wills, T.A. (1985) Supportive functions of interpersonal relationships, in Cohen, S. & Syme, S.L. (eds.) *Social support and health.* Orlando, Florida: Academic Press

Withers, P. (1988) When "clever" means "happy": Disability, desire and distress, *Clinical Psychology Forum, 114*, April

Wortman, C.B. (1984) Social support and the cancer patients: Conceptual and methodological issues, *Supplement to Cancer*, 2339-2360

Zetlin, A.G. & Murtaugh, M. (1988) Friendship patterns of mildly learning handicapped and nonhandicapped high school students, *American Journal of Mental Deficiency, 92*, 447-454

Appendices

Appendix I: Participant information sheet

<u>PARTICIPANT INFORMATION SHEET</u>

THE VIEWS OF YOUNG ADULTS WITH LEARNING DISABILITIES LEAVING

SCHOOL OR COLLEGE

OF THE IMPORTANCE OF SUPPORT NETWORKS

Why have I been asked to take part in this study? Leaving school is quite a difficult

time for many young people. Some manage to cope with the change better than others.

What will it involve? I will come to talk to you for about an hour about how you found

the change of leaving school, who was able to help you at the time and what sort of help

you found most useful.

What if I do not wish to take part? It is up to you whether you choose to take part or

not and you can choose not to take any further part.

Will the interviews be tape recorded? The interviews will be tape recorded.   The

interviews will then be typed up, but only including information which will not lead to

people being recognised.

What will happen to the tapes? The tapes will then be wiped clean.

What will happen to the information from the study? The information and analysis

from the study will be used in the write up for a doctoral dissertation. All information

will be treated confidentially.

What if I have further questions? You should contact Adrian Ierna on 0114 271 6935

Appendix II: Interview Protocol

First interview

Reintroduce myself and project

Tell the client who I am &:

I want to talk to you about what happened when you left school at 16 and found new things to do. I think its really important to know how you think your family, friends and all the other people you know helped you.

.... There are no right or wrong answers. Everybody finds it difficult. What I'm interested in is how you found it/ felt ...

... I'm interested in how you feel other people have helped you, because one of the biggest changes when you leave school or college as you grow up is the loss of familiar faces, such as friends and teachers you were at school with, and the meeting of new friends and people as you start new things in life ...

... it would be good to understand what was useful so that when we try to help others going through the same thing we can make better job of it....

Grounding the interview in the transition process

I imagine over the past few years, as you've got older, there must have been a few changes in your life. Can you tell me what some of the really big ones have been?

Can you tell me where it was you went to school?

Leaving school:

What's been best...

What's been most difficult...

Was it far, how did you get there?

What sort of things do you do now?

How did you find out about them?

When did you start?

What do you do when you are there?

Getting an idea who is in the support network.

When people go through changes like you they often find themselves getting help from

different people. Who are the people you think have most helped you?

Did you have help from people at school?

Did your family help you?

Do you have friends who helped you?

Are the people who help you now different from the people who helped you before?

What was it like trying to get to know new people/ helpers?

Was there anybody you've just talked about who was very helpful?

Types of help

People help us in many different ways. Can you tell me about some of the ways in which the people we've just talked about have helped you?

How did .... help?

Practical help

Often people need all kinds o different help when starting something new, whether it's being given a lift to work or college, being show around, somewhere new. What kind of help did you get?

Were you shown around the new college/place of work?

What was it like making new friends?

Close interview

Thank you for taking the time to talk to me today. You told me a lot of interesting things about people have helped you. I'd like to have a chance to think about some of the things we've talked about and then comeback and see you in ... weeks time. Will that be alright?

Is there anything you want to ask me?

Second Interview

Re-introduction

Last time we met you told me a lot of helpful things about how you've been helped in the last few years since leaving school. After we talked I had a think and I was left with

some ideas that I am not quite sure about.... Some things that I would like to know more about .....

Decision making

When someone leaves school there are a lot of difficult choices to make. Sometimes we feel like we need a lot of help choosing what to do... where to go....

Did you need help?

What help can you remember getting?

Who decided when you would leave school?

Who decided where you would go?

Who talked to you about it?

How did it make you feel?

Emotional support

When a lot of change is going on in our lives we feel a lot of different things. Some of them make us happy. Some of them make us feel a little afraid. And some of them make us sad. I guess there must have been times over the past few years when you've felt like that.

How did you feel....

Have you ever felt...

What do you do when you feel happy/sad, would you talk to someone if you felt like that?

Would you talk to anybody?

Why did you choose to talk to ….?

Would you talk to anybody?

Coping with change in the support network

Sometimes people have a friend or two that they get on very well with when they're at school. Did you have a best friend?

Who were they?

What was it you like about them?

How did you feel about leaving them?

Were there people you were sad to leave behind?

Do you still see your friend?

What did you do when you felt sad about it?

Unhelpful support

Sometimes people try to help when their help isn't really wanted.

e.g. kitchen

I wonder if things like this happen to you?

What happened?

In what situations?

Could you let the person know that you didn't want their help?

How did you try to deal with the situation?

What was it like?

Concluding comments

We've talked about a lot things over the past 2 hours or so. I wonder thinking back over the past few years, who would you say have been the most helpful people?

Can you tell me in what way you think they have been able to help you?

Are there some problems in life which people can't get any help with. I wonder if you've had any of these?

Thank you very much for your help and time. This has been very useful and I think your answers will help us understand what kind of support people need when they are leaving school. Are there any questions you would like me to ask me.