

**Social support offered to people with learning disabilities:
the service user's perspective**

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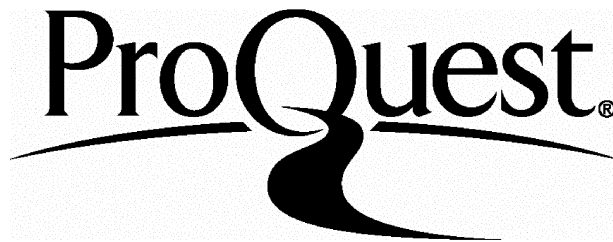
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Acknowledgements

This study relied on the support and goodwill of a large number of people. Firstly, I would like to thank all of the service users who agreed to give their time and share their experiences with me. I learned a great deal during the conversations that took place as part of this research.

Secondly, my thanks go to Dr. Chris Barker, who supervised the project and provided me with greatly appreciated support and guidance throughout its duration.

I would also like to thank Chris Jones and Judith Samuel at Oxfordshire Learning Disability Trust and Eva Jarvis at PentaHact Ltd for their enthusiasm and support for the project, as well as all the support staff and service managers who facilitated the process of meeting and talking to participants.

Thirdly, I am very grateful to Jill Bradshaw, Lecturer in Learning Disability at the Tizard Centre, for her advice regarding the communication aspects of the study, and for her help with data coding.

Finally, my thanks as always to my family and friends – my ‘social support’ – who have been there for me throughout the course of this research.

Abstract

Many studies have shown that social support is related to psychological and physical well being, with recent research placing an emphasis on the role of individual perceptions of received support. This study attempted to relate the knowledge gained from studies of social support in the general population to the experience of people with learning disabilities. To do this, individuals with learning disabilities' perspectives, with regard to the social support that they receive, was explored in three ways. Firstly, the Social Support Questionnaire (SSQ) was administered to 36 men and women to establish the size and composition of their social network. Secondly, a semi-structured interview was used to elicit perceptions of support received when feeling sad or angry. Thirdly, picture stories were used to explore whether participants were able to describe the support they would offer to others in times of emotional distress.

The results of the SSQ supported previous research, suggesting that participants viewed paid staff as their main source of social support. Analysis of the interviews found that some people with learning disabilities are able to both describe the support they have received in times of distress, and relate how they would support others. No dominant type of support emerged from individuals' reports, suggesting that people are supported in highly individualised ways that are likely to be influenced by a wide range of contextual factors.

The findings were discussed both in terms of the methodology adopted and its appropriateness for people with learning disabilities and their implications for the design of service provision.

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CHAPTER ONE: Introduction

Overview

'People with learning disabilities are amongst the most socially excluded and vulnerable groups in Britain today. Very few have jobs, live in their own homes or have real choice over who cares for them.' (Department of Health, 2001, p14).

This reference to social exclusion and vulnerability from the first learning disability National Strategy for 30 years, *Valuing People*, suggests that the objective of improving quality of life stated by community care policy developed over the last decade (Secretaries of State for Health, Social Security, Wales and Scotland, 1989) has not been achieved. Forrester-Jones *et al* (2001) suggest that while accommodation and other practical structures may have been provided in the community for people with learning disabilities, individuals' social networks and the support accessed through these networks have not received adequate attention.

The focus of the present study is on the provision and *experience* of social support for people with learning disabilities. Research has suggested that social support is related to psychological and physical well-being (Cohen & Wills, 1985; McNally & Newman, 1999; Schwarzer & Leppin, 1991; Turner, 1999). An important development concerns the emphasis that such research now places upon the role of individual perceptions of received support and related cognitions (e.g. Lakey & Cassady, 1990). Studies of social support concern phenomena taken from the general population and conceptualisations have become increasingly sophisticated. This study asks people with mild or moderate learning disabilities to talk about what they have received in terms of social support, and what they find helpful and unhelpful about the support offered to them. It is hoped that the results from this analysis

will encourage reflection on some of the assumptions made by learning disability services about what their users need in times of emotional difficulty.

The literature on social support and social networks is considerable. The following review begins with a summary of the social support literature, which has largely developed from the mental health field. This precedes a discussion of the literature on the social inclusion of people with learning disabilities. The literature is more concerned with the analysis of social networks, revealing the extent to which subjective reports from people with learning disabilities about the specific types of support they receive at times of distress has been largely ignored.

Conceptualising Social Support

There are several definitions of social support in the literature. Turner (1999, p200), paraphrasing Cobb (1976), defines social support as

'...the clarity or certainty with which the individual experiences being loved, valued, and able to count on others should the need arise'.

This definition has been selected because of its emphasis on the individual and how s/he *experiences* the support available from others.

McNally and Newman (1999) summarise the literature linking social support and health, suggesting that this relationship can be explored using two main approaches, the structural approach and the functional approach.

Structural approach to social support

Firstly, social support can be described in *structural* terms that concern the quantity rather than the quality of social relationships. An example is the presence and extent of social ties that might include marriage and family (Berkman & Syme, 1979). While the social support literature refers only to the general population, structural models are likely to have traditionally been used for describing the social networks of people with learning disabilities (Jahoda, Cattermole and Markava, 1990). Calculations of the individual's social network are direct and useful for establishing received support. Tolsdorf (1976) used social network analysis to define the main structural elements of social support as the *size* of the network and what is termed *adjacency density*. In this context, *size* refers to the number of people listed by the respondent by name and identified as having contact at least once a year, while *adjacency density* refers to the interconnectedness of the respondent's network as understood by the number of dyadic relationships operating within it.

McNally and Newman (1999, p310) convey the essence of the structural approach to social support:

'This approach is not concerned with the meaning of social relationships to the individual. It is designed to be a non-evaluative way of examining the existence and pattern of social relationships while making little or no reference to the content of those relationships'.

McNally and Newman (1999) also discuss the potential influence of the structural approach to social support. They cite a study by House, Landis and Umberson (1988), who propose that the absence of social relationships can be seen as a 'risk factor' for both morbidity and

mortality, even though counting relationships in this way ignores the subjective experiences and perspective of the respondent. However, the growing recognition of the extent to which such investigations are researcher-led casts doubt on the validity of studies that ignore interpretations of the support made by its recipient (e.g. Lazarus & Folkman, 1984), and the function of the relationship between supporter and recipient cannot be established. Similarly, it is difficult to determine the degree to which any such support offered could be considered effective. An example of a researcher-led methodology is the Self-Evaluation and Social Support Schedule (SESS) (O'Conner & Brown, 1984), which uses semi-structured interview and coding by a team of trained raters to analyse specific aspects of the respondent's social support. McNally and Newman (1999) question the practicalities involved in such a time-consuming project, although they acknowledge the potential in utility available from an organised technique that provides objective data.

Functional approach to social support

The second approach to conceptualising social support is *functional*, where emphasis is placed on the 'functions an individual's relationships are perceived to serve' (McNally & Newman 1999, p310). This qualitative focus on individual perception in social support research has grown in both popularity and credibility because of evidence from studies linking health and well being (see review by Dunkel-Schetter & Bennett, 1990).

Within the context of the functional approach, Cohen and Wills (1985) review the literature and suggest that social support can be described in two key ways. The *main effect* model describes how social support can have positive effects whether or not people are experiencing stress. The name 'main effect' is derived from the statistical main effect of support with no

stress x support interaction (Milne, 1999). Lazarus and Folkman (1984, p245) summarise the main effect model, as it would occur in practice:

'...it is usually assumed that being embedded in a social network is essential for people to feel good about themselves and their lives. ...without ongoing social relationships, much of the meaningfulness of human existence is lacking or impaired. Viable social relationships make possible identification and involvement – the opposite of alienation and anomie.'

Milne (1999) suggests that the main effect of social support is linked to physical health by either its impact on the immune system or via its influence on seeking professional help and other related patterns of health-related behaviour. He proposes that the main effect model has been thought to be most applicable to circumstances where people are receiving little or moderate levels of social support. Above this cut-off, the benefits of this model are more difficult to discern.

The second key model of social support described by Cohen and Wills in their review (1985) is the *buffering* model, where social support is considered as an intervention to protect the individual from stress. This process may be in terms of actually reducing the magnitude of the stressor, by preventing the individual from appraising a stimulus as stressful or by enhancing the individual's perception of their ability to cope. These interventions tend to be linked with a supporter relating to the individual and the stressor. A second set of interventions are linked with the individual's coping responses – for example, reducing their emotional response by taking sedative medication, or by reappraising the stimulus as being less threatening or less anxiety-inducing. Gottlieb (1983) also conceptualised social support in relation to vulnerability, suggesting that it acts as a 'buffer' or protector against the effect of stressors. The Cohen and Wills model (1985) differs from that outlined by Gottlieb (1983)

mainly in terms of its greater emphasis on cognition, i.e. appraisal processes, but also in its discussion of the specific demands posed by a particular stressor. Gottlieb's model had described a broader approach that had highlighted the individual's capacity to cope (Milne 1999).

The *buffering* model suggests that social support may prevent the appraisal of stress and/or lead to 'reappraisal, inhibition of maladjustive responses, or facilitation of adjustive counter responses' (Cohen & Wills, 1985, p313). The four suggested types of support resource, which are conceptualised on the basis of an extensive review of the social support literature, are likely to be interdependent in practice:

- *Emotional support* - an exchange between people that conveys that an individual is accepted (e.g. Cobb, 1976)
- *Informational support* – help offered to assist the individual in understanding difficult events, or knowing what to do in order to resolve a problem.
- *Social companionship* – spending time with the individual, either serving as a distraction from stressful events or thoughts, or by facilitating positive mood.
- *Instrumental support* – providing the individual with material resources such as money or other forms of aid.

The buffering model has found empirical support from studies of the general population, suggesting that *perceptions* of support may 'buffer' or mediate the relationship between stress and psychological outcome (e.g. Dunkel-Schetter & Bennett, 1990). However, this evidence has also been clouded by the possibility that social desirability can influence the ways in which respondents report their perception of social support, depending on how they want to present themselves to the investigator. Some studies have attempted to control for this

phenomenon by using specific social desirability measures (e.g. Roberts, Cox, Shannon & Wells, 1994). This is particularly pertinent to research with people with learning disabilities, who are more likely to have a potential for seeking approval during interview (Atkinson, 1988). This is just one of the many issues that need to be addressed when conducting research of any kind that involves interviewing people with learning disabilities.

Personal coping strategies

A key factor to be considered when highlighting the individual's perspective in social support is the nature of appraisal. Heller, Swindle and Dusenbury (1986) recognised the interactions between social support and coping, enabling concepts from the literature on personal coping strategies to be used in models of social support. Lazarus and Folkman (1984, p141) suggest that coping refers to

'...constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands (i.e. stress) that are appraised as taxing or exceeding the resources of the person'.

Two major forms of coping with stressors dominate the research literature. 'Problem-focused' coping involves '...taking direct action in relation to one's internal or external environment to remove or alter stress appraised as threatening' while 'emotion-focused' coping '...consists of thoughts or actions intended to alter or limit the distress that results from stress' Milne (1999, p51). These two broad categories have since been broken down into a range of sub-categories. This approach enables parallels to be drawn between social support and coping, and in practice they are considered to operate in combination (Thoits, 1986). Thoits (1986) also proposed that the coping strategies people use to deal with stress in

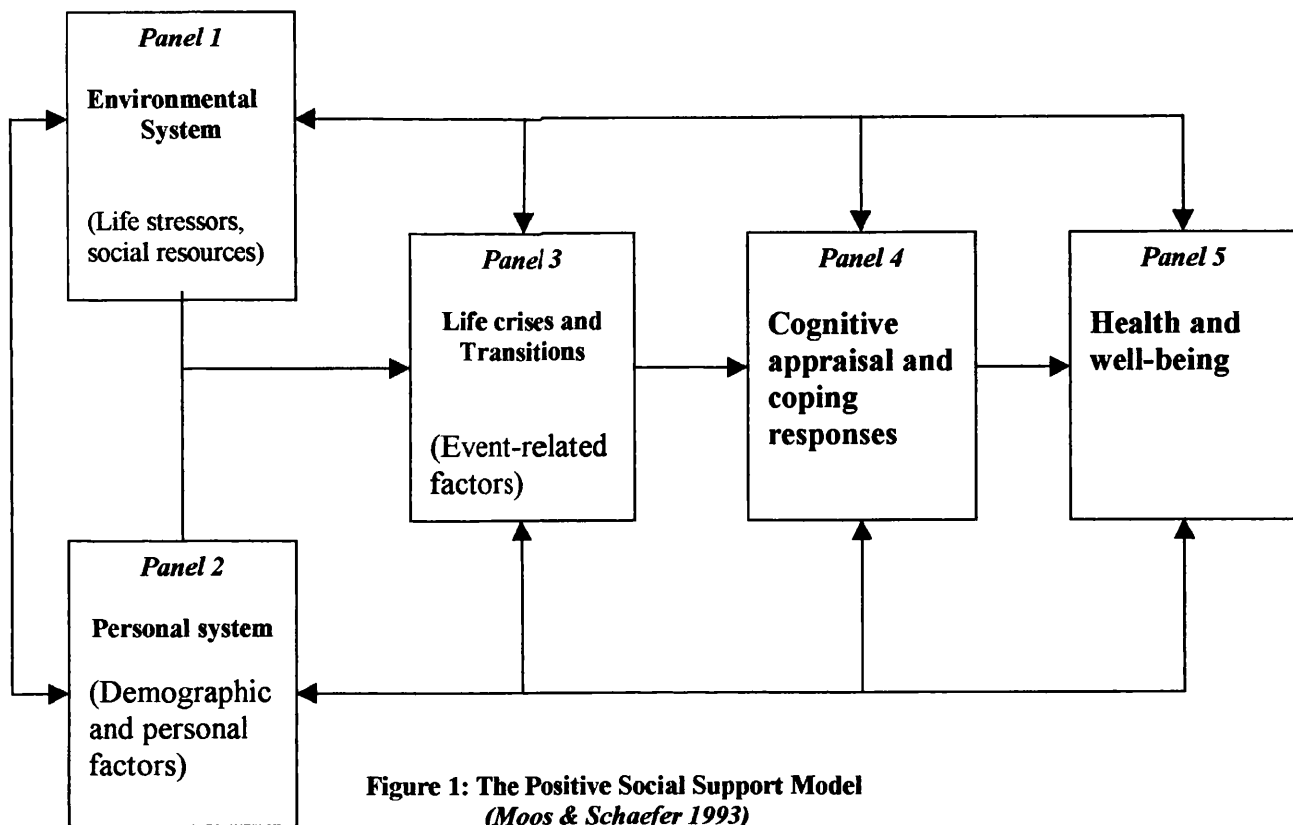
their own lives are also the strategies they use to assist others. She relabelled social support as 'coping assistance', and suggested that a range of people can serve as potential sources of social support, as long as they are able to provide the key function of suggesting alternative ways of perceiving or handling stressors.

The psychotherapy literature uses the 'core conditions' of concreteness and empathy for therapy, which influenced Thoits' (1986, p420) approach to understanding social support. She suggests that empathic understanding is fundamental to social support, and is most likely to be available to those who 'have faced or are facing the same stressors, and who have done so or are doing so more calmly than the distressed individual'. In Milne's (1999) discussion of Thoits' work, it is suggested that sociocultural and situational similarity between the helper and the helped can enhance the likelihood of the effective perception and reception of empathy.

While the above was deemed pertinent to informal help by early social support literature, later accounts have described the role of the mental health practitioner, who has 'expert knowledge in the fundamental pragmatics of life' (Smith, Standinger & Baltes, 1994). Such 'wisdom' can override the prominence afforded to sociocultural and situational factors.

Contemporary models of social support

Milne (1999) describes the evolution of models of support, an example of which is represented by the work of Moos and Schaefer (see Figure 1). A key development in such models of support appearing in the 1990s was an acknowledgement of some benefits of being exposed to stress, such as learning to use the knowledge of others appropriately and to build one's problem-solving skills.



A further development concerns the step of placing social support within a social-ecological, dynamic context, which allows the notion that reactions and adaptability to stressors can change within individuals over time. A third key characteristic of contemporary models is the recognition of the individual's active agency, emphasising the role of appraisal (Brewin, 1995, in Milne 1999).

Implications of contemporary models of social support for learning disability practitioners

Milne (1999) reviews the wide range of clinical studies that have employed contemporary models of social support and coping, using the evidence to devise a list of 5 key elements of good practice for mental health practitioners:

- A comprehensive assessment of the service user's repertoire of coping strategies
- Establishing relationships between this profile of coping with the service user's subjective appraisal of stressors
- Relating the individual's coping strategies and appraisal processes to his or her background variables, such as family and personal environment
- The importance of developing cognitive and behavioural problem-solving skills rather than focusing on emotion-focused approaches
- Encouraging an extension of the individual's coping repertoire, together with an emphasis on flexibility of their application

Applying this approach to services for people with learning disabilities needs special consideration, and each of Milne's elements are now taken in turn.

A comprehensive assessment of the service user's repertoire of coping strategies

Establishing the individual's coping strategies is likely to be a substantial piece of work taking place over time and across a variety of situations, requiring the member of staff concerned to work intensively with the same person over a long period. This is likely to be a difficult approach for those services experiencing high staff turnover, a common phenomenon in learning disability services (McBrien & Candy, 1998). Staff will also need the skills to conduct the assessment; inconsistencies in staff qualifications and background frequently observed in learning disability services (Carnaby, 1999) could lead to staff members needing varying levels of support in order to complete this work.

Establishing relationships between this profile of coping with the service user's subjective appraisal of stressors

Services are increasingly adopting an individualised approach to supporting people with learning disabilities (Emerson, 1998), with good practice guidelines recommending the use of inclusive person-centred planning (Galambos, 1996). Service-user views are being sought in a variety of ways, through augmentative communication, self-advocacy groups and a range of consultation processes (McIntosh & Whittaker, 2000). However, there has been very little discussion of service users' subjective appraisal within the context of specific incidences of distress. This may be as a result of perceived obstacles to gathering such information (e.g. because of difficulties with communication). Alternatively, it is because the emphasis placed on subjective appraisal that has emerged in the mental health field is yet to have clear impact on research and practice in services for people with learning disabilities.

Relating the individual's coping strategies and appraisal processes to his or her background variables, such as family and personal environment

Service design is increasingly incorporating background variables, particularly around interventions devised to alleviate distress (e.g. Murphy, 1994). This is a useful foundation upon which to build a strategy for social support provision, which is likely to complement existing structures.

The importance of developing cognitive and behavioural problem-solving skills rather than focusing on emotion-focused approaches

Behavioural interventions are commonplace for people with learning disabilities, particularly for those individuals presenting with challenging behaviour (e.g. Emerson, 1998). However, recent research has highlighted ways in which practitioners can work cognitively with

individuals, particularly those with mild learning disabilities (see Stenfert Kroese, Dagnan & Loumidis, 1997). Techniques such as self-instruction training aim to give people the resources to manage stressful situations when there are no staff around to provide appropriate prompts (Dagnan & Chadwick, 1997).

Encouraging an extension of the individual's coping repertoire, together with an emphasis on flexibility of their application

Skill teaching approaches for people with learning disabilities have struggled with the issue of generalisability and flexibility of application, as the individual will use many of the strategies learned only in the specific setting and for the particular task for which they were first taught (Emerson, 1998). Encouraging an extension of coping strategies for other situations at different times is likely to be a significant challenge for service providers.

Application to learning disability services

When applied to learning disability services, it is clear that the duty of care requires members of staff to provide both informational and instrumental support to service users. The characteristics of such support are likely to be described in operational policies, staff job descriptions and individual care plans, while the efficacy of these resources can usually be established by direct observation. For example, service providers may conduct audits that describe support available to a group of adults with learning disabilities sharing accommodation in the community. This description is likely to consist of the staff: service user ratio and the number of hours that members of the staff team work on each shift. Service managers are likely to calculate the ratio of staff to service users using an assessment process completed by either themselves or a care manager. The criteria for the calculation are often based on risk and safety factors (e.g. the extent to which the individual needs staff around to

prevent harm to self or others) and on the level of support needed to complete self-care tasks and tasks of daily living. It is unlikely that the calculation takes into account levels of emotional support, leading to support designs being implemented that acknowledge the level of practical help needed by an individual, but ignore the level of need on an emotional level.

This argument is best illustrated using a clinical example taken from a real case of an individual with mild learning disabilities who was supported by a local outreach project. This individual had accomplished skills of daily living and independence, and was allocated a small number of hours per week for assistance from staff with tasks such as budgeting or shopping. This approach can be challenged on two levels. Firstly, there is a danger that the hours are set in line with the constraints placed upon the service as a result of meeting the needs of other service users, rather than being determined at times led by the needs of the individual. This means that the identified tasks needing support from staff can only be completed at these times, and for example, the individual will need to be ready to go shopping between 2 p.m. and 3 p.m. every Thursday. There is little room for flexibility, particularly when factors such as staff sickness and the inevitable crises that occur regularly are also considered. For the individual in this example, this meant having to be at home at set times of day, sometimes waiting beyond the agreed time because the staff member had had to deal with difficulties arising with another service user.

In addition to these difficulties, the model can be challenged for its neglect of the *emotional* support needed by service users. This operates at a number of levels. People with learning disabilities, particularly those living alone, are at significant risk of isolation and loneliness, resulting in a greater vulnerability to mental health problems (Moss, 1999). Where support offered by services is primarily concerned with practical help at set times, it is possible that

the individual's emotional needs are not being met. The individual in the example was referred to clinical psychology for 'help with relationships'. During the assessment period, she was able to discuss in some depth her feelings about the support she received from the outreach service, commenting that while she appreciated the practical help she gained with shopping and jobs around the house, the major omission was the time to sit and talk. This individual was able to accept that staff members were not her 'friends', but her comment was 'I just want them to spend more time with me'.

The role of support in learning disability services

The social support literature described above does not appear to have been assimilated into service models for people with learning disabilities. The concept of support in the lives of people with learning disabilities has education and development at its foundation. O'Brien (e.g. 1981) has attempted to operationalise the dominant ideology of normalisation by defining five 'service accomplishments', one of which is attaining competence, i.e. 'developing skills and attributes that are functional and meaningful in natural community environments and relationships' (Emerson 1992, p14). In practice, the key values in learning disability services are competence and independence, which have gradually evolved from the normalisation and ordinary living literature (see Emerson, McGill & Mansell, 1994). Service users are actively supported throughout the day to participate as much as possible in the environments in which they live, the ideal being to enhance independence and self-worth (e.g. Saunders & Spradlin, 1991). A vast literature has emerged, documenting both the principles of effective skill teaching and the need for structured environments.

While this is proving to be an effective approach to establishing core staff skills for providing practical support to people with learning disabilities, there has as yet been little focus on

emotional or *social* support. Recent literature describes the failure of services to recognise the importance of social support for people with learning disabilities (Arthur, 1999), as well as the role its absence plays in the higher prevalence of psychopathology in this population (e.g. Lunskey & Haverkamp, 1999). In addition, service designs built upon the goals of competence and independence are at risk of treating people with learning disabilities as an homogeneous population (Carnaby, 1999). In reality there are significant differences between the needs and experiences of individuals who are in supported employment and able to use public transport with minimal help, and the lifestyle of individuals with profound and multiple disabilities. Yet the ideology of learning disability services in Britain currently provides support to people at either end of the support 'continuum' using the same principles and objectives.

Social integration and social inclusion of people with learning disabilities

Integration is the cornerstone of normalisation, 'enabling people with learning disabilities to attain that which most non-disabled people expect as of right' (Brown & Smith, 1992, p174). However, those reviewing the policy of community care for people with learning disabilities argue that in reality integration has become not much more than physically placing individuals in the local community with the assumption that social integration will follow automatically (Evans & Murcott, 1990; Carnaby, 1998). Indeed, people with learning disabilities are likely to be at risk from a range of stressors resulting from their ascribed role in society. This includes the general impact of stigmatisation, which often leads to disadvantage and limited opportunities, and for many individuals, long periods of unemployment (Edgerton, 1967). Flynn (1989) also observes that people with learning disabilities endure poverty and victimisation, as well as the positive aspects of independent living, and shows how the conditions in an individual's neighbourhood are likely to influence the extent and quality of informal support available.

The term ‘social inclusion’ has become prominent in Government policy (Department of Health, 1999a), the interpretations of which are often ‘steeped in the principles of normalisation [Wolfensberger, 1972]’ (Forrester Jones *et al* 2001). These principles are clearly observed in O’Brien’s (1987) later ‘Five Accomplishments’ for services, which underpin the majority of service provision (Cambridge, Hayes, Knapp with Gould & Fenyo, 1994):

- *Community presence* – in valued community settings
- *Choice* – in everyday matters as well as life-defining issues
- *Competence* – the experience of performing meaningful activity with whatever support is needed
- *Respect* – being part of a network of people and having a valued role in the community
- *Participation* - being part of a network of personal relationships with other people

For Forrester-Jones and Grant (1997), a network of social supportive relationships in the community can be regarded as the defining benchmark of social inclusion. This network is said to mediate social functioning, self-esteem (Smith & McCarthy, 1996) and mental health (Ell, 1996; Wall, 1998).

Szivos (1992) claims that *social* integration is essential if society is to genuinely move away from institutional approaches to supporting people with learning disabilities, and defines two main components: relationships with others and the use of community resources. While it may be possible to consider the extent to which people with learning disabilities increasingly use community resources, it is more difficult to establish the nature of community relationships. Szivos (1992) cites the work of Festinger (1954), who described a

psychological process ('social comparison theory') underpinning the formation of networks. He suggested that people compare themselves with others, feeling more comfortable spending time with those with whom they share similar interests, opinions and skills. Szivos-Bach (1993) suggests that when applied to the lives of people with learning disabilities, this theory has striking relevance. Normalisation and the strive towards the provision of 'ordinary' lifestyles (Brown & Smith, 1992) leads to people with learning disabilities being actively encouraged to live alongside and make relationships with non-disabled others. By definition, this means that people with learning disabilities are sharing their lives with individuals who have different lifestyles and experiences, mainly as a result of their more valued status in society. This in turn can leave people with learning disabilities feeling at best uncomfortable with the comparisons they make in such situations (Szivos-Bach, 1993; Carnaby, 1998).

Apart from the psychological considerations of social integration, there is evidence to suggest that people with learning disabilities have limited opportunities to meet non-disabled people socially, placing restrictions on their abilities to form social networks (Jahoda, Cattermole & Markava, 1990). Ralph and Usher (1995) argue that despite encouragement from normalisation to do otherwise, people with learning disabilities spend the majority of their time with other people with learning disabilities. While Szivos (1992) may argue against the strategy of integration in its current form on psychological grounds, Kennedy, Horner and Newton (1990, p86) also discuss its shortcomings in terms of implementation:

'Although there is extensive discussion about the importance of assisting people with disabilities to develop and maintain satisfactory social lives, there is very little empirical evidence to guide families, service providers and researchers.'

Measuring social networks in learning disability services

The term *social network* usually refers to the web of relationships attached to an individual (Barnes, 1954). Traditionally, learning disability services measure social support in purely quantitative ways, counting the number of people in the individual's social network and establishing whether network members are friends, relatives or members of staff - i.e. a structural approach (Whittington, 1993). This is within the context of the powerful assumption made by services that people with learning disabilities *want* to integrate with non-disabled others, and that integration with non-disabled others is both desirable and more valued than the formation of friendships and relationships with other people with learning disabilities. Social activity is measured by counting the number of times the individual interacts with non-disabled others within a community setting – for example, visiting the local pub or café, or going to the cinema. These data are quoted as frequencies in care plans or individual programmes, to monitor the extent of the individual's social integration (e.g. Greasley, 1995).

Ralph and Usher (1995) published a typical study. They interviewed 54 adults with learning disabilities about their social interactions over an average week, counting the number of contacts with other people and the settings in which the contact occurred. Participants were also asked to rate their satisfaction with the contact using a rating scale. The main finding was that the participants interacted mostly with other people with learning disabilities, supporting the researchers' hypothesis that social integration needs more effort and energy than physical relocation into the local community. In addition, Ralph and Usher (1995, p161) suggest that

'...more detailed studies are needed to look more closely at the quality of social interactions experienced by persons with developmental disabilities. The data reported here have focused more on the quantity of social interaction, and it may be that our efforts should be directed to improving quality rather than quantity.'

People with learning disabilities and their social relationships

Fischer (1976, cited in Forrester-Jones *et al* 2001) highlights the centrality of social relationships to our understanding of daily life:

'...people neither truly experience nor act on the environment as separate individuals; instead their experiences and actions are mediated by social networks.'

Social interaction between people occurs within a range of private and public contexts, be they work or leisure (Forrester-Jones *et al*, 2001), while the strength of social networks is thought to be directly related to health (Department of Health, 1999). For people with learning disabilities, happiness as a result of living in the community as opposed to institutional settings (Donnelly *et al* 1996) and self-esteem (Smith & McCarthy, 1996) have been linked to friendships derived from social network members. There is also evidence that different members within the social networks of people with learning disabilities tend to provide particular types of support, some of which is intuitive. For example, family members are the main providers of emotional support for children with learning disabilities (Grant, 1993).

Typically, the social networks of people with learning disabilities are smaller than those of members of the general population, contain proportionately fewer friends and tend to include a large number of service providers (Rosen & Burchard, 1990). Rapley and Beyer (1998),

reporting on an earlier study of a support to people with learning disabilities provided within a community setting (1996, p31), suggest that

'...the life experience of adults with [learning] disabilities in community-based services could be characterised as being one of 'isolation and disengagement'.'

Contacts with others were found to be few, and where they did exist, primarily functional in nature. Loneliness can be common experience for people with learning disabilities, and may be a significant risk factor for depression (Reiss & Benson, 1984), as are the low levels of social support that are available to this population (Reiss & Benson, 1985).

It is possible that the paucity of friendships experienced by many people with learning disabilities can be attributed at least in part to the ways in which services are designed. In an important study, Le Touze and Pahl (1992) found that while many participants were involved in a range of activities, this did not necessarily lead to satisfactory social lives. There was little space for participants to form relationships at their own pace, while transport difficulties meant that spontaneous meetings with friends were usually impossible. The study's conclusion is that those developing community services have a tendency to be more concerned with providing accommodation and day care, rather than acknowledging and addressing the need for supporting social relationships. This is supported by Lutfiyya (1991, p114):

'...people with learning disabilities who move out of institutions often remain grouped together, stranded in communities of their own; ordinary social networks can be largely inaccessible to them.'

The nature of friendship for people with learning disabilities

There is evidence that people with learning disabilities are likely to have few friends (e.g. McConkey and McGinley, 1990), with friendships being the least successful 'outcome' of deinstitutionalisation (Booth, Bilson & Fowell, 1990). Forrester-Jones *et al* (2001) draw three main reasons for this phenomenon from the literature. Firstly, service provision has tended to use a deficit model of need that focuses on physical care and skills rather than relationships (Amado, 1993). Secondly, people with learning disabilities still face practical obstacles when trying to access community activities, such as transport. Thirdly, people with learning disabilities are likely to take a life pathway that differs from the general population, and not by choice (Tyne, 1989). The majority of individuals make friendships and connections with others through school and other settings from childhood, and then through work and personal interests and pastimes. People with learning disabilities, however, are likely to reach adulthood still surrounded by childhood contacts and often surrounded by paid staff. Of key importance is that these relationships are unlikely to be reciprocal.

Forrester-Jones *et al* (2001) discuss the social construction of friendships for people with learning disabilities. They cite a study by Brandon and Beail (1991), who explored the relationships between nurses and residents living in a small hospital. The study argues that if friendships are defined as non-paid reciprocal intimacy, the residents had no friends. The key here is the social context; as work and leisure are combined in this environment, individuals appeared to re-define friendships as a strategy against isolation and loneliness. Atkinson (1987) found that the people with learning disabilities that she interviewed who had left hospital valued their friendships with other former residents, and also tended to extend their definition of friend to include ex-staff members, local retailers and neighbours. Atkinson

explains this 'recycling' of paid professionals and others as a result of the general lack of contacts experienced by people with learning disabilities.

For Lutfiyya (1991), friendship is a process that involves the sharing of time and experience, being individually created and changed over time. It is the development of an understanding between the two partners, each having their own perspective on what the friendship means. However, Lutfiyya goes on to say that it is the *voluntary* nature of the relationship that is the defining characteristic. Self-esteem develops from friendships because of the knowledge that another person has chosen to spend time out of affection rather than duty.

In their survey of the nature of friendships experienced by people with learning disabilities, Richardson and Ritchie (1989) highlight the importance of friendship as a source of enjoyment and self-esteem and suggest that leisure is an area of dissatisfaction for this population, an observation made by the recent Government National Learning Disability Strategy (Department of Health, 2001). The Richardson and Ritchie study (1989) argued for the need to enable people with learning disabilities to access social networks outside of those tending to be segregated and based around service provision. Conversely, Chappell (1994) raises the point that such moves are at risk of devaluing relationships formed *between* people with learning disabilities, and ultimately can damage the self-esteem of individuals.

In recent years there has been a clearer recognition of the right of people with learning disabilities to provide their perspective on issues that affect them (McVilly, 1995; Prosser & Bromley, 1998). A commitment to working in partnership with individuals using learning disability provision on a national level (Department of Health, 1998a; 1998b; 2001) has implications for the ways in which those individual are involved in evaluating the support

they receive. Involving people with learning disabilities in research is at great risk of tokenism, and care is needed if their involvement is to provide a meaningful and accurate perspective. The next section of this chapter reviews current thinking in the important area of working with people with learning disabilities as partners in research about their lives.

Involving people with learning disabilities in research about their lives

A substantial body of literature has emerged outlining some of the potential pitfalls for researchers wanting to involve and include people with learning disabilities in studies about their own lifestyles, and makes recommendations for the most appropriate ways of conducting interviews with this population. This work can be broadly divided into the two main domains of studies discussing the practical techniques proposed for eliciting accurate information from people with learning disabilities, and other papers that consider the ethical issues of consulting people with learning disabilities about sensitive topics and personal issues.

Practical issues in interviewing people with learning disabilities

People with learning disabilities are likely to have difficulties with communication as a result of impairments in cognitive skills, hearing, language, speech and social interaction (Ambalu, 1997). Awareness of these difficulties enables the interviewer to adapt the format and content of the interview in order to maximise the ways in which the individual is able to participate and ensure that the interview process is a positive experience.

Setting conditions

Prosser and Bromley (1998) provide a detailed description of the setting conditions in which to conduct interviews with people with learning disabilities. While suggesting a number of

and that their support will not be affected by the responses they give during the interview (e.g. Tizard Centre Ethics Committee, University of Kent at Canterbury, 1998).

Interview techniques

In her recommendations for healthcare professionals, Ambalu (1997, p57) provides a useful list of considerations for those interviewing people with learning disabilities, and a summary version is reproduced in Table 1. Her recommendations are supported by the research literature in this area. For example, with regard to acquiescence, Heal and Sigelman (1995) have shown that asking a 'yes/no' question to an adult with learning disabilities is likely to elicit an acquiescent response of 'yes'. 'No' responses tended to be given with 'taboo' topics. This builds on earlier research, which provided evidence to support the view that issues such as consistency of response, acquiescence and the use of closed questions need to be acknowledged (Flynn, 1986; Sigelman & Budd, 1986; Sigelman *et al*, 1981; Sigelman, Budd, Winer, Schoenrock. & Martin, 1982). Shanly and Rose (1993) used combinations of open questions, 'either/or' questions and 'yes/no' questions together with question reversal to check consistency.

Other studies have looked at ways of augmenting verbal communication. Wadsworth and Harper (1991) used line drawings to support participants in their study, and found that this appeared to increase the reliability of information over time given by people with moderate learning disabilities. Cummins (1992) suggested the use of 'faces' to depict emotions as the basis of Likert scales, while March (1992) used photographs to increase intelligibility – although comments that this in itself is not enough to ensure that the individual is responding to the same question intended by the researcher.

pointers for good practice, they also observe that many of the principles involved are similar to those recommended for interviewing children and adults in the general population. A private space that will not be interrupted is clearly needed for any interview to be conducted in a way that maintains confidentiality. However, some individuals with learning disabilities may need or request a third party to provide support, which will require input from the interviewer regarding the need for the supporter to not participate more than is absolutely necessary to avoid influencing the individual with learning disabilities. As with other interviewing other populations, a good rapport is needed with the participant to enhance their confidence. Prosser and Bromley (1998) suggest that asking the participant to choose the venue for the interview is likely to aid this process. If possible, they also recommend spending time with the participant before the interview starts.

Opening an interview with an individual with learning disabilities requires an awareness of the elements accepted as good practice for interviews with the general population such as:

- stating the purpose of the interview
- describing the type of questions to be asked
- discussion who the information is for and how it will be used
- how long the interview will take.

In addition to these important elements, interviews with people with learning disabilities need to reassure the participant that there are no 'right' or 'wrong' answers and that there is the option to refuse to respond to questions. Ambalu (1998) suggests that thought needs to be given to factors such as seating, lighting and acoustics in the event that the individual has sensory disabilities. Furthermore, Ethics Committees are also recommending that interviewers should think more broadly and state that the participant will not get into trouble

Ethical issues in interviewing people with learning disabilities

Given the range of potential practical difficulties involved in interviewing people with learning disabilities, it is important to acknowledge the power differential between interviewer and interviewee. This approach has been explored by Milne and Bull (1999), who review the body of work reporting on the application of these issues to the experience of people with learning disabilities being interviewed within the criminal justice system.

Similarly, Perlman, Ericson, Esses and Isaacs, (1994) highlight the risk of suggestibility in people with learning disabilities. However, the study goes on to argue that competency for accurate reporting should not be viewed as an intrinsic quality in the individual, but more as a reflection of the ways in which questions are asked and the subject matter to which they relate.

Aside from the ethics of interview techniques and acknowledgement of how differences in power might influence responses, there are wider issues concerning the very nature of how and why research into the private lives of people with learning disabilities is conducted.

McCarthy (1998) discusses these issues in terms of her research on the sexuality of people with learning disabilities. She argues that in order to address the abuse and unlawful activities involving people with learning disabilities that happens outside the public arena, research is needed in order to establish the extent of the abuse, to expose perpetrators and support those being exploited. McCarthy (1998) concludes that there are no areas of people's lives that should be exempt from research, but also provides a clear argument against the 'tokenistic' signing of consent forms by individuals who are unable to read, suggesting that tape recordings of the conversation about participation could be used instead.

The debate over consent continues throughout the literature about learning disability, with practice becoming increasingly individualised to meet the capabilities and understanding of each participant in specific situations (see Arscott *et al* 1998 for a useful review).

Despite these considerable difficulties, interviewing people with learning disabilities about their lives is still an essential element of assessing whether the support offered to them is meeting their needs. McCarthy states (1998, p144):

'It is now recognised that people with learning disabilities are not only valid sources of information about their lives, but that they are sometimes the best or only sources.'

This is particularly pertinent to social support research that is concerned with personal appraisal of received support. It might be argued that while the accounts of people with learning disabilities may not always be considered as 'reliable' (Perlman *et al*, 1994), this is not the most important or relevant outcome. Rather it is how the support is experienced and perceived that is of interest. Even in cases where supporters provide support with the most empathic intentions, it is possible that the support is perceived as unhelpful. This mismatch is of interest and provides important information for those leading learning disability services.

Table 1: Ambalu's recommendations for healthcare professionals conducting interviews with people with learning disabilities

- use short, simple sentences; speak more slowly; pause after each sentence
- replace jargon with commonly understood words
- check that the person understands you...
- use gesture, mime, pointing and increased facial expression if necessary
- encourage the person to use his or her communication aid, if one is used
- break explanations of procedures down into steps...
- use open questions
- use either/or questions
- avoid using questions which require a 'yes/no' answer
- be aware of difficulty in understanding the full range of tenses
- be aware of difficulty in understanding time and number concepts
- if the person's speech is difficult to understand, do not pretend that you have understood. Ask him or her to
 - say it again
 - say it more slowly
 - say it in different words
 - show you what he or she means
- watch the person carefully to check that he or she is not becoming anxious or distressed
- sum up at the end of the session and say what will happen next

Summary

The social support literature has made links between the provision of social support and mental health. The *nature* of social support has been described in both structural and functional terms, whilst the mechanism by which social support is thought to be related to mental health has been discussed in terms of acting as a moderator of stress or as a main effect. Increasingly, researchers have emphasised the role of individual appraisal of social support.

Studying the appraisal of social support by people with learning disabilities is important, for at least two reasons. Clearly it can provide supporters with crucial information about how their support is perceived. In addition, such research also has the potential to encourage staff and other supporters of people with learning disabilities to reflect on the format of the support they offer and the ability of the recipient to experience that support in the way it was intended.

Quite separately from the social support literature, research in learning disability has pursued an agenda that has had a main focus on the development of competence, independence and integration with wider society. There has been some exploration of the experience of friendships and the nature of social networks, which suggest that members of these networks are often playing a non-reciprocal role in the life of the individual with learning disabilities (Rosen & Burchard, 1990). Some might argue that the ideology underpinning service provision is still likely to devalue relationships *between* people with learning disabilities. The present study therefore aims to address some of these issues by applying models and concepts from the social support and coping literature, placing participants' perceptions at the heart of

the methodology. There are two main points that need to be made to outline the rationale for this study.

Previous research suggests that people with learning disabilities are able to identify the source of their social support. The present study builds on this important finding by exploring the ability of people with learning disabilities to talk about the *specific nature* of the support offered to them following specific incidents that result in emotional distress. In essence, this approach is adopted in line with the argument by Newton, Horner, Ard, LeBaron and Sappington (1994), who discuss the value of assessing the effectiveness of social support by looking at *what* support is available to an individual and *how satisfied* they are with this support.

This study aims to explore models of social support for people with learning disabilities, by asking a sample of people with mild or moderate learning disabilities about their experiences of social support after critical moments of distress and how they would support others.

Participants are asked to think about a recent incident where they became distressed, describe any support offered and establish the role of the supporter in their life. In addition, participants are asked to talk about how they would support *other* people with learning disabilities by using vignettes about characters that become sad or angry respectively.

Research questions

The research aimed to address four major questions:

1. Who do people with mild or moderate learning disabilities go to for support when they are experiencing emotional distress?
2. What *kind* of support is offered to people with mild or moderate learning disabilities at these times?

3. How do people with mild or moderate learning disabilities *experience* the social support offered to them after specific incidences of emotional distress (i.e. when they feel angry and when they feel sad)?
4. What kinds of social support do people with mild or moderate learning disabilities say they would offer other people after critical incidences of distress?

CHAPTER TWO: Method

Overview

Thirty-six people with mild or moderate learning disabilities were interviewed about their perceptions of social support. They filled out a structured questionnaire (the Social Support Questionnaire) and then responded to some brief vignettes which assessed what they would do or say if someone else became sad or angry, and were asked to describe the support attempts of other people when they themselves were sad or angry.

Settings

Two service providers participated in the study. A voluntary sector service provider for people with learning disabilities based in North London agreed to give access to people identified by Care Service Managers as having mild or moderate learning disabilities and using residential and outreach support services throughout North London and parts of Essex. In addition, a learning disability trust in Southern England gave permission for service users to be approached.

The UCL ethics committee and the learning disability trust's ethics committee both approved the project (see Appendix 1). Senior Management staff at the voluntary sector service provider also discussed the project at a management meeting and approved the study (see Appendix 1).

Participants

Fifty-six participants were identified by their service providers and sent an information pack about the study. This pack contained:

1. An information sheet for the participant briefly outlining the purpose and nature of the research using adapted language and symbols, with a photograph of the interviewer and a consent form (Appendix 2)
2. A letter for the service user's keyworker/supporter (Appendix 3)
3. A general letter about the study (Appendix 4)
4. A pre-paid envelope addressed to the interviewer

For the present study, equal numbers of male and female participants were selected, providing the potential to explore medium to large effects of gender as the study progressed. Ensuring that there were equal numbers of each sex did not prove difficult, as the services concerned gave general information about the study to all of their service users and then approached people individually to explore their potential participation further. This initial discussion was between the potential participant and his or her keyworker. The keyworker used the written information as a basis for discussion, and asked the participant to sign a consent form and provide contact details, which were sent to the researcher. The validity of this signed consent was constantly reviewed throughout the recruitment process - which was seen as taking place right up until the research procedure began. The rate at which recruitment occurred was controlled once initial numbers grew through negotiation with service managers and their staff.

Thirty-six participants (64%) agreed to participate: eighteen men and eighteen women. They ranged in age from 24 years to 58 years with a mean age of 38.2 years. This sample size was felt to be adequate for the purposes of the study and is in the same range as that used in

similar studies (e.g. Reiss & Benson, 1985, n = 45; Newton *et al* , 1995, n = 28). For the purposes of this study, participants living alone with outreach support are described as having a ‘mild’ learning disability, while those requiring 24-hour support (living alone or with other people with learning disabilities) are described as having ‘moderate’ learning disabilities. Formal psychometric assessments to establish level of learning disability were not conducted.

Participants were contacted to arrange an interview, usually in their own home. The interview consisted of a standardised questionnaire to establish the size and composition of the individual’s perceived support network and a semi-structured interview with brief vignettes. The interview aimed to help participants identify their perceptions about the support offered to them in times of distress, as well as the help that they would offer to others in similar circumstances.

Inclusion criteria

Service managers were asked to approach service users who met the following criteria:

1. Able to give informed consent across a range of issues
2. Able to recognise concepts of ‘sad’ and ‘angry’
3. Able to think in abstract terms e.g. remembering events from the past; conditional thinking (i.e. ‘if this happened, what would you say/do?’)

Three of the participants were living with their parents, and eight were living alone. A further eight were living in a flatshare with one other person with learning disabilities, supported by an outreach team worker. Thirteen of the participants were living in a group home (see Table 2).

Table 2: Participants' living arrangements at the time of interview

Type of accommodation	Number of people living in accommodation other than participant	Number of participants		
		Men	Women	Total
Living with parents or relatives	2	3	0	3
Living alone with occasional support from relatives	0	1	0	1
Living alone with regular support from Outreach Team	0	5	2	7
Flatshare, with regular support from Outreach Team	1	2	6	8
Group home with staff support present for much of the day and night	2	2	2	4
Ditto	3	0	3	3
Ditto	5	4	4	8
Ditto	6	1	1	2
Total		18	18	36

Procedure***Reviewing consent***

Although written consent was obtained from participants in order for them to be contacted about the interview, they were also given other opportunities to withdraw from the study if they wished. During the initial telephone call to arrange a convenient time for the interview, consent was sought verbally. In addition, the interviewer gave participants opportunity to withdraw from the study at the beginning of the interview and between the main sections of the procedure (see Appendix 5).

Interview process

Venue

Interviews took place in an appropriate setting chosen by the participant, usually a living room. Where participants lived with others, arrangements were made with staff members or the other resident(s) to ensure that the room was not going to be used for the duration of the interview, and that as far as possible, the session would not be interrupted.

Overview

At the beginning of the session, participants were given an overview of the research, making reference to the information pack. If the participant agreed to continue, the SSQ was administered. This was intended to introduce the participant to the concept of support, and also help them begin thinking about occasions when support has or has not been offered.

Items were re-worded and repeated where necessary.

The semi-structured interview followed the SSQ, with participants' responses recorded verbatim for future coding. Attempts were made to adapt the style and content of questioning to match the cognitive abilities of individual participants. This involved the use of some Makaton symbols for one participant, and much re-wording of the questions for many individuals.

Interviews were not recorded to avoid participants becoming anxious about speaking in front of a machine. This also avoided issues around how the tape would be stored and ensuring material was destroyed after the study was completed. In practice, participants tended to give short answers which were easily recorded verbatim in situ. The interviewer was also able to build further rapport by using phrases like, 'That's really interesting. I'm just going to write

that down so that I don't forget it. Is that OK?' This was felt to be inclusive practice and gave participants further control over how and what was recorded.

A full interview protocol is detailed in Appendix 5.

Consent and confidentiality

Attempts to obtain meaningful consent were made at various stages throughout the interview process. The first stage concerned agreeing to complete the consent form with support from a keyworker. This would have involved initial discussion of what the interview would entail with someone with whom – hopefully – the individual had some rapport.

On receipt of the completed consent form, the interviewer then rang the individual to discuss their participation further. This was a second opportunity for the individual to withdraw from the study. Further opportunities were provided on the day of the interview itself, before the interviewer entered the premises and again before commencing the interview. The interviewer also checked for consent to continue with the interview procedure after each section had been completed.

Confidentiality was explained to participants in terms of maintaining their anonymity when recording their responses and not relating any of the content of the interview to anybody else.

This was specifically related to the keyworker and/or service manager. However, the following statement was also made:

'I will not tell people things that you tell me. BUT if you tell me something that I think might hurt somebody else, or means that you might get hurt, I might have to tell someone else. If this happens, I will tell you. I will tell you why I need to tell someone, and we can talk about WHO I will tell, and WHAT I will tell them.'

The interviewer then checked for comprehension.

'I want to make sure that you are OK with what I have just said. Can you tell me what I was just talking about?'

When the participant related the discussion of confidentiality, the interviewer listened for key elements such as 'not telling other people' and 'but you might have to tell people.... if I say something and someone might get hurt'. If comprehension seemed unclear or inaccurate, the interviewer repeated and/or reworded what was said.

Measures

In this study, the SSQ was chosen as a measure of social networks. Other possibilities for measuring social support are the tools adapted by Lunsky and Benson (1997), which have been used with this population. The 'Social Support Self-Report' (originally used by Reiss & Benson, 1985) and Harter's (1985) 'People in my life' scale enable participants to nominate supporters within set categories. However, these measures do not enable participants to nominate the sources of their support freely at will, which was a matter of interest for the present study. Therefore the SSQ, which is widely used in the adult mental health literature, but has not yet been used with people with learning disabilities, was used to map the nature and size of networks.

Semi-structured interviews were also used to explore the *experience* of support offered to participants at times of distress. Responses were coded with the following rationale in mind, as stated by Newton *et al*, (1994:399):

'[Using coding categories] is more attuned to current ideas about the relevant content of social interactions... [They can be] an informative mode of assessing the availability, type, amount and effectiveness of social support experienced by an individual in the context of individual social interactions.'

Newton *et al* (1994) identify the need for analysis of specific social interactions and recommend research focused in this way.

Social Support Questionnaire (SSQ: Sarason et al, 1987)

The SSQ is a measure of perceived available support (see Appendix 6). It was originally a 27-item questionnaire and was adapted to a 6-item version for the present study. Each item has two parts: the first establishes the number of available others (referred to as SSQN) the individual would turn to across a range of situations. For example *'Who accepts you totally, including your worst and best points?'*

The second part of the item measures the level of satisfaction (SSQS) with the perceived available support, using a 6-point Likert scale ranging from 1 = 'very dissatisfied' to 6 = 'very satisfied'.

Adapting the rating scale for people with learning disabilities

For this study it was thought necessary to adapt the Likert scale using line drawings of faces (see Appendix 7). This adaptation process was informed by procedures used by Lindsay *et al* (1997) (based on previous work by Lindsay, 1991, and Helsel and Matson, 1989) as part of cognitive therapy for anxiety disorders in people with learning disabilities.

The adapted scale comprised 6 faces (3 'happy' faces – 1 small, 1 medium and 1 large and 3 identically sized 'unhappy' faces) corresponding to the 6 ratings on the original scale. For example, the largest smiling face indicates the response 'very satisfied', while the smallest smiling face indicates the response 'a little satisfied'.

The scale was explained to participants before administering the SSQ by saying:

'I'd like to hear how you feel about the help you get from the people around you. Here is something to help you do that [presenting the rating card]. Can you see these faces on the card? This face here [points at biggest smiling face] means being really happy about something. This face here [points at smallest sad face] means being really UNhappy about something...

If I was a TINY bit unhappy about something, I'd choose this face [points to smallest unhappy face]. If I was a bit MORE unhappy about something, I might choose this face [points at medium-sized unhappy face]. Let's see if you can have a go.'

Participants were then asked two questions to assess their comprehension of the scale. First they were asked to think of two activities, one that they liked and one that they did not like, and were asked to rate their enjoyment of each. Then the interviewer asked them to rate two types of food, cabbage and ice cream. The interviewer also rated these items, as a way of engaging with participants and building rapport. Where participants chose extremities of the scale, the interviewer ensured that he chose ratings in the middle of the scale, commenting on what they indicated, to illustrate the range available. The approach taken during the interviews was informed by Ambalu's (1997) recommendations for healthcare professionals (see p34).

2. Semi-structured interview

The interview had three main sections:

- presentation of vignettes
- participants' own recent experiences of feeling sad or angry
- general discussion about the support people might need when feeling sad or angry.

Section 1: Vignettes

Participants were presented with two separate vignettes about a female or male character; female participants were presented with stories about women, and male participants were presented with stories about men. Each of the vignettes was presented using a series of four line drawings on cards accompanied by a standard narrative. The first vignette depicts a sad event, the second vignette an angry event (see reproduction of drawings in Appendix 8).

- *'Sad' vignette*

The sad vignette concerns a character called Jane/Michael, whose mother visits every Sunday afternoon. The story depicts a particular Sunday afternoon when Jane/Michael's mother telephones to say that she is unable to come, which makes Jane/Michael feel sad.

The 4 drawings are presented individually in sequence, with the following narrative:

'This is a story about a man/woman. Let's give him/her a name. [If the participant was unable to/did not want to provide a name, the default character names were 'Michael and Jane'.]

Picture 1: *Here is Jane/Michael at home.*

Picture 2: *Every Sunday, Jane's/Michael's mum comes to see her/him.*

Picture 3: *Last Sunday, in the story, there was a problem. Jane's/Michael's mum rang to say that she was really sorry, but she couldn't come and see Jane/Michael.*

Picture 4: *This made Jane/Michael feel sad [points to face]... can you see how sad s/he looks?*

- *'Angry' vignette*

The angry vignette shows Jane/Michael going to the day centre on the bus. One particular day, other people on the bus make fun of Jane/Michael and call her/him names, which makes her/him angry.

The 4 drawings are presented individually in sequence, with the following narrative:

Picture 1: *Here is Jane/Michael in her/his bedroom*

Picture 2: *Jane/Michael goes to a day centre. S/he gets there on the bus. Here s/he is waving goodbye to the bus driver.*

Picture 3: *One day, in the story, something happened on the way home from the day centre. Other people on the bus were nasty to Jane/Michael. They pointed at her/him and called her/him names.*

Picture 4: *This made Jane/Michael feel angry. Can you see how angry s/he looks?*

After each vignette is presented, the interviewer asked the following:

'In this story, Jane/Michael feels sad/angry. What would you say (what would you do) if this had happened to her/him?'

Responses were recorded verbatim.

Section 2: Relating own experiences of feeling sad or angry

After each vignette, participants were told:

'In this story, Jane/Michael feels sad/angry. Can you think of a time recently when you felt sad/angry?'

Participants were encouraged to relate the event in as much detail as possible, and were then asked to talk about any support offered to them, who offered the support and whether the support was helpful or unhelpful.

Section 3: Discussion about the support people might need when feeling sad or angry.

The final section of the interview consist of the open questions, 'What do people need when they feel sad?' and 'What do people need when they feel angry?' The interviewer asked:

'We've talked about being sad/angry. Let's think a bit about when people are sad/angry. What do you think people need when they feel sad/angry?'

During the interview, prompts were given where necessary, for clarification, for elaboration or to keep participants on topic. Sessions lasted between approximately 30 minutes and 1 hour.

At the end of the interview, there was a short debriefing session in which the interviewer asked the participants how s/he was feeling and how they had found the interview. If there was any indication of distress, the interviewer stayed with the participant until they felt calmer and also asked if there was anyone they would like to talk to about what had been

discussed. Finally, participants were given the opportunity to ask questions or add further comments.

Participants were told that everybody's ideas were going to be put together and written as a report, an adapted version of which would be forwarded to them on completion of the study.

Coding of responses to the vignettes

Each interview was allocated a total of 6 codes from a 15-category system. These correspond to the 6 responses recorded during the semi-structured interview:

1. Response to the 'sad' vignette ('what would you say/do if this happened to Jane/Michael?')
2. Response to the 'angry' vignette ('what would you say/do if this happened to Jane/Michael?')
3. Perception of the support received after an event that left the participant feeling sad ('Did anyone help you? What did they say/do?')
4. Perception of the support received after an event that left the participant feeling angry ('Did anyone help you? What did they say/do?')
5. Response to the question 'what do sad people need?'
6. Response to the question 'what do angry people need?'

The coding system was based on that used by Lehmann, Ellard & Wortman (1986), who studied the support experienced by parents bereaved after their children were killed in a car crash. Participants were asked to describe the support they received in times of distress, and the various types of support reported were then coded using a list of categories. The Lehmann

et al study was seen as a useful starting point as it concerns the support that individuals received following a particular time of feeling distress, which is the focal point of the present study.

The system published by Lehmann *et al* (1986) was used as a starting point to develop a coding system that was more appropriate for people with learning disabilities. The process of development was as follows:

1. The initial data collected during a pilot study of 6 interviews were coded by the researcher and supervisor, and new categories were developed that were not present in the original coding scheme. Furthermore, categories that were deemed irrelevant or redundant were dropped.
2. After a series of several iterations, a coding scheme was developed for the present study..
3. To ensure reliability, a third rater who had hitherto not been involved in developing the coding scheme, independently coded the entire data set. This independent rater is a female speech and language therapist/lecturer in learning disability. Individual responses were written on cards without reference to the gender of the respondent, the event to which they were linked or the emotion that the event had evoked. Identifying numbers were written on the back of the cards. Each rater then independently allocated codes using the system listed above. Comparison of the two sets of codes revealed a 91% level of agreement between the two raters. This was felt to be an acceptable level of reliability, and enabled the remaining data to be coded.
4. Some responses contained material that could be described using more than one code (e.g. 'I'd say, "go for a walk in the park...don't worry!"). These multi-category responses were checked between raters to ensure consistency. Where there was discrepancy between allocation of codes, discussion took place to reach an agreed solution.

The final set of codes used during analysis were ‘cheering up’; ‘calming down’; ‘offering to make/making a cup of tea, coffee or alcohol, or having a cigarette’; ‘self-management’; ‘offered practical assistance’; ‘giving advice (behavioural)’; ‘giving advice (cognitive)’; ‘provide opportunity to ventilate/discuss feelings’; ‘presence (“being there”)’; ‘involve in social activities’; ‘distraction/ignoring’; ‘getting someone else to help or do something for you’; ‘physical reassurance’; ‘no response offered’; ‘don’t know’ (see Appendix 9 for full list of codes with examples of raw data for each category).

CHAPTER THREE: Results

Overview

The results are presented in three main sections:

1. The networks of supporters that participants nominated on the Social Support Questionnaire as people they would go to in times of distress and their satisfaction with experience of the support available from their individual network members.
2. Responses to the semi-structured interviews, which aimed to establish (a) the types of support that participants would offer to others (using vignettes to elicit responses) (b) the types of support that participants have received after a stressful incident that leaves them feeling sad or angry (c) participants' perception of whether the support they received after these incidents was helpful or unhelpful
3. A qualitative section discussing main themes that arose from additional information provided by participants during interview, which is presented as useful context within which to consider the main findings.

The Social Support Questionnaire (SSQ)

Mapping individual social networks

Participants identified people they would go to for support in the circumstances described by each item in the Social Support Questionnaire. Overall, responses fell into five categories:

- Paid staff members
- Parents
- Other relatives (e.g. aunt; cousin)
- Friends (with learning disabilities – no friends *without* learning disabilities were nominated)
- Other – including partners and other professionals (e.g. social workers, GP)

The general prevalence of each social network membership category was established by citing the frequency as a percentage of the total number of responses recorded. The outcomes of this process are summarised for each SSQ item in Table 3.

Context to responses for each item on the SSQ

Dependable help

Four of the five men reporting 'other' sources of support and all of the four women named professionals i.e. psychiatrist, social worker, police, social worker and community nurse. The fifth man named his psychologist.

Help available when 'under pressure'

Four male participants and one female participant reported 'nobody' in response to this question. Four of the six male participants reporting 'other' sources of support listed professionals i.e. psychologist, community nurse, and GP. The two female participants referred to a partner or a local victim support organisation respectively.

Being accepted totally

Six participants were unable to give a response. Three participants gave the response 'nobody' to this question (one male, two female).

Being cared about, regardless of what is happening

Six participants were unable to give a response. For this question, 'other' refers to social worker (five responses), a partner (two responses) and God. Three men and four women gave the response 'nobody' to this question. 'Other' refers to a partner (two responses), professionals (psychiatrist or GP – two responses) and in one case, the participant's cat.

Table 3: Frequency of responses to SSQ items

	Staff member(s)	Parent(s)	Other relative	Friend	Other
Who can you really count on to be dependable when you need help?					
<i>Male participants</i>	12 (41%)	7 (24%)	4 (14%)	1 (4%)	5 (17%)
<i>Female participants</i>	14 (56%)	2 (8%)	4 (16%)	1 (4%)	4 (16%)
Who can you really count on to help you feel more relaxed when you are under pressure or tense?					
<i>Male participants</i>	7 (44%)	1 (6%)	1 (6%)	1 (6%)	6 (38%)
<i>Female participants</i>	9 (56%)	0	2 (13%)	3 (19%)	2 (13%)
Who accepts you totally including your best and worst points?					
<i>Male participants</i>	6 (38%)	4 (25%)	1 (6%)	1 (6%)	4 (25%)
<i>Female participants</i>	5 (46%)	1 (9%)	1 (9%)	1 (9%)	3 (25%)
Whom can you really count on to care about you, regardless of what is happening to you?					
<i>Male participants</i>	4 (22%)	7 (39%)	3 (17%)	0	4 (22%)
<i>Female Participants</i>	7 (39%)	2 (11%)	4 (22%)	0	4 (22%)
Whom can you really count on to help you feel better when you are generally down-in-the-dumps?					
<i>Male participants</i>	6 (38%)	2 (13%)	0	2 (13%)	4 (25%)
<i>Female participants</i>	7 (41%)	2 (12%)	2 (12%)	3 (18%)	3 (18%)
Whom can you count on to console you when you are very upset?					
<i>Male participants</i>	3 (30%)	1 (10%)	3 (30%)	0	3 (30%)
<i>Female participants</i>	10 (63%)	2 (13%)	2 (13%)	0	2 (13%)

Note: Participants often nominated more than one individual for each item, meaning that some numbers will total as more than the sample size.

Being helped to feel better when 'down-in-the dumps'

'Other' here refers to a partner (four responses) , a social worker (two responses) and the participant's cat (one response).

Being consoled when upset

Four male participants gave the response 'nobody' to this question; seven participants were unable to give a response. 'Other' here refers to a partner (four responses) and a social worker (one response).

Summary of social network membership

Table 4 summarises the prevalence of social network membership categories across the SSQ for the entire sample of participants.

Table 4: Sum of SSQ items

	Staff member(s)	Parent(s)	Other relative	Friend (with learning disabilities)	Other
Male Participants	38 (37%)	22 (21%)	12 (12%)	5 (5%)	26 (25%)
Female participants	52 (51%)	9 (9%)	15 (15%)	8 (8%)	18 (18%)
Total	90 (44%)	31 (15%)	27 (13%)	13 (6%)	44 (22%)

Note: Again, as participants were able to nominate more than one person in response to each item, the totals may exceed more than the sample size.

The data suggest that 43.9% of the individuals named by participants as people they would go to for support are paid staff members. When gender is considered separately, the percentage

is slightly higher for the women interviewed (51% versus 37%). Parents and relatives comprised a total of 28% of identified social network members. Friends with learning disabilities comprised 6% of social network members; however, the 22% of individuals forming the membership category 'Other' includes participants' partners – a total of 12 responses (6%) across the SSQ.

Satisfaction with the perceived support available

Table 5 suggests that the average rating of satisfaction with the perceived support available is 5.05, which corresponds to a rating of 'fairly satisfied' from the original scale. This is slightly lower than the mean rating of 5.38 obtained by Sarason *et al* (1983). The range of average ratings here was 4.5 to 6.0, compared to a range of 5.1 to 5.6 observed in the original study. Mode ratings for male and female participants were 6.0 for nearly all items. The one exception was a mode rating of 5.0 for male participants responding to the item '*Who can you really count on to help you feel more relaxed when you are under pressure or tense?*'

The semi-structured interview: Data summaries

The following tables present summaries of responses coded using the system described in Chapter 2. Each interview was allocated a total of 6 codes from a 15-category system. These correspond to the 6 responses recorded during the semi-structured interview:

1. Response to the 'sad' vignette ('what would you say/do if this happened to Jane/Michael?')
2. Response to the 'angry' vignette ('what would you say/do if this happened to Jane/Michael?')

3. Perception of the support received after an event that left the participant feeling sad ('Did anyone help you? What did they say/do?')
4. Perception of the support received after an event that left the participant feeling angry ('Did anyone help you? What did they say/do?')
5. Response to the question 'what do sad people need?'
6. Response to the question 'what do angry people need?'

Table 5: Satisfaction with the support perceived as available

	Male participants: Mean rating (std. dev)	Female participants: Mean rating (std. dev)
<i>Who can you really count on to be dependable when you need help?</i>	5.3 (1.4)	5.4 (1.5)
<i>Who can you really count on to help you feel more relaxed when you are under pressure or tense?</i>	4.8 (1.4)	4.8 (1.5)
<i>Who accepts you totally including your best and worst points?</i>	5.1(1.2)	5.5 (1.0)
<i>Whom can you really count on to care about you, regardless of what is happening to you?</i>	5.4 (1.1)	5.8 (0.4)
<i>Whom can you really count on to help you feel better when you are generally down-in-the-dumps?</i>	4.7 (1.9)	5.3 (1.4)
<i>Whom can you count on to console you when you are very upset?</i>	4.8 (1.6)	4.8 (1.9)
MEAN RATING A ACROSS THE SSQ	5.0	5.1

The final set of codes used during analysis were 'cheering up'; 'calming down'; 'offering to make/making a cup of tea, coffee or alcohol, or having a cigarette'; 'self-management';

‘offered practical assistance’; ‘giving advice (behavioural)’; ‘giving advice (cognitive)’; ‘provide opportunity to ventilate/discuss feelings’; ‘presence (“being there”)’; ‘involve in social activities’; ‘distraction/ignoring’; ‘getting someone else to help or do something for you’; ‘physical reassurance’; ‘no response offered’; ‘don’t know’ (see Appendix 9).

Vignettes: Support that participants would offer others

Tables 6 and 7 summarise responses elicited using the ‘sad’ and ‘angry’ vignettes respectively.

Table 6 indicates that for the ‘sad’ vignette, the highest category of response (30%) concerns offering the character in the story behavioural advice (e.g. F8: ‘I’d tell her to make another day to go and see her [mother]’ or F5: ‘You must go out for a walk’). The next highest category (18%) is ‘involve in social activities (e.g. M12: ‘...watch TV together – go out together, do something together to make him happy’).

Table 7 indicates that for the ‘angry’ vignette, the highest categories of response (19%) are again offering the character behavioural advice (e.g. M5: ‘You should tell someone’) and also distraction or ignoring (e.g. F15: ‘I’d tell her to ignore them and walk away’). The third highest category is providing the opportunity to ventilate or discuss feelings (e.g. M3: ‘...sit them down – ask them who upset them and why, comfort the person who has been upset.’)

Table 6: Responses offered by participants to character in 'sad' vignette

Response	Male participants	Female Participants	Total
Cheering up	4 (18%)	3 (11%)	7 (14%)
Calming down	0	0	0
Offering to make/making a cup of tea, coffee or alcohol; having a cigarette	3 (14%)	5 (18%)	8 (16%)
Self-management (e.g. 'I calmed myself down) and activities that do not involve others	0	1 (4%)	1 (2%)
Offered practical assistance	0	0	0
Give advice (behavioural)	8 (36%)	7 (25%)	15 (30%)
Give advice (cognitive)	1(5%)	0	1 (2%)
Provide opportunity to ventilate/discuss feelings	2 (9%)	3 (11%)	5 (10%)
Presence ('being there')	0	0	0
Involve in social activities	4 (18%)	5 (18%)	9 (18%)
Distraction, ignoring it	0	0	0
Getting someone else to help or do something for you	0	2 (7%)	2 (4%)
Physical reassurance	0	1 (4%)	1 (2%)
No response would be offered	0	0	0
Participant not able to give a response/ 'don't know'	0	1 (4%)	1(2%)

Table 7: Responses offered by participants to character in ‘angry’ vignette

Response	Male participants	Female participants	Total
Cheering up	2 (9%)	2 (7%)	4 (8%)
Calming down	1 (4%)	1 (3%)	2 (4%)
Offering to make/making a cup of tea, coffee or alcohol; having a cigarette	3 (13%)	1 (3%)	4 (8%)
Self-management (e.g. ‘I calmed myself down) and activities that do not involve others	0	0	0
Offered practical assistance	0	0	0
Give advice (behavioural)	3 (13%)	7 (23%)	10 (19%)
Give advice (cognitive)	1 (4%)	1(3%)	2 (4%)
Provide opportunity to ventilate/discuss feelings	4 (17%)	4 (13%)	8 (15%)
Presence (‘being there’)	0	0	0
Involve in social activities	1 (4%)	1 (3%)	2 (4%)
Distraction, ignoring it	4 (17%)	6 (20%)	10 (19%)
Getting someone else to help or do something for you	2 (9%)	3 (10%)	5 (9%)
Physical reassurance	0	0	0
No response would be offered	0	0	0
Participant not able to give a response/ ‘don’t know’	2 (9%)	4 (13%)	6 (11%)

Participants' reports of support they have received in times of distress

Tables 8 and 9 summarise the coding of responses participants gave when asked to talk about support they have received from others after incidents that had left them feeling sad or angry.

Table 8 indicates that almost a third of the participants were unable to give a response when asked to describe the support they received after a recent incident left them feeling sad. Those that were able to respond gave responses that were covered by a wide range codes. The highest coding recorded was being told to 'cheer up' (14%), followed by being given the opportunity to talk about how they were feeling (12%) (e.g. M18: 'They talked to me').

Table 9 indicates that a similar proportion of participants to that observed for the 'sad' incident were unable to talk about how they had been supported after an incident that had left them feeling angry (28%). The highest frequency of coding for those that did respond was being given the opportunity to discuss their feelings (15%) (e.g. F3: 'They sit me down and talk with me calmly and quietly, they ask "what are you angry about?"'). The next highest category is 'no response was offered' (13%).

Table 8: Responses offered by others to participants after incidents that left participants feeling sad

Response	Male participants	Female participants	Total
Cheering up	2 (10%)	4 (18%)	6 (14%)
Calming down	0	0	0
Offering to make/making a cup of tea, coffee or alcohol; having a cigarette	0	2 (9%)	2 (5%)
Self-management (e.g. 'I calmed myself down) and activities that do not involve others	1 (5%)	0	1 (2%)
Offered practical assistance	3 (14%)	1 (5%)	4 (9%)
Give advice (behavioural)	1 (5%)	1 (5%)	2 (5%)
Give advice (cognitive)	1 (5%)	1 (5%)	2 (5%)
Provide opportunity to ventilate/discuss feelings	3 (14%)	2 (9%)	5 (12%)
Presence ('being there')	0	0	0
Involve in social activities	0	1 (5%)	1 (2%)
Distraction, ignoring it	2 (10%)	2 (9%)	4 (9%)
Getting someone else to help or do something for you	0	0	0
Physical reassurance	1 (5%)	0	1 (2%)
No response was offered by anybody	2 (10%)	2 (9%)	4 (9%)
Participant not able to give a response/ 'don't know'	5 (24%)	6 (27%)	11 (26%)

Table 9: Responses offered by others to participants after incidents that left participants feeling angry

Response	Male participants	Female participants	Total
Cheering up	0	0	0
Calming down	1 (5%)	1 (5%)	2 (5%)
Offering to make/making a cup of tea, coffee or alcohol; having a cigarette	2 (11%)	1 (5%)	3 (8%)
Self-management (e.g. 'I calmed myself down) and activities that do not involve others	0	1(5%)	1 (3%)
Offered practical assistance	1(5%)	1 (5%)	2 (5%)
Give advice (behavioural)	0	1(5%)	1 (3%)
Give advice (cognitive)	1 (5%)	0	1 (3%)
Provide opportunity to ventilate/discuss feelings	4 (21%)	2 (10%)	6 (15%)
Presence ('being there')	0	0	0
Involve in social activities	0	0	0
Distraction, ignoring it	2 (11%)	2 (10%)	4 (10%)
Getting someone else to help or do something for you	1 (5%)	2 (10%)	3 (8%)
Physical reassurance	0	1 (5%)	1 (3%)
No response was offered by anybody	3 (16%)	2 (10%)	5 (13%)
Participant not able to give a response/ 'don't know'	4 (21%)	7 (35%)	11 (29%)

Participants' general views about what people need when they feel sad or angry

Participants were asked what they thought was generally needed by people in times of emotional distress, specifically when feeling sad or angry.

Table 10 indicates that 26% of participants felt that when people feel sad, they need someone to talk to, while 16% felt that people feeling sad would benefit from being involved in social activities. A further 16.3 % of participants were unable to answer this question.

Table 11 indicates that 17% of participants felt that people who are angry need to calm down, while a further 14% of participants said that people feeling angry need to talk to someone about how they are feeling. A third of participants (33%) were unable to provide a response for this part of the interview.

Perceptions of the utility of the support received

Participants were asked to say whether the support they received after the incidents that left them feeling sad or angry had been helpful or unhelpful.

A wide range of types of support received when feeling angry was considered 'helpful', with being given the opportunity to discuss feelings, being offered a drink and someone offering to do something on your behalf being marginally the more common responses. Only seven participants gave examples of 'unhelpful' support they had received, which includes four responses of experiencing no support at all after the incident that had left them feeling angry. Similarly, a wide range of types of support received when feeling sad was considered 'helpful', with being given the opportunity to discuss feelings, being 'cheered up', ignoring

or distraction and being given practical assistance marginally the more common responses.

Two participants felt that being told to cheer up was unhelpful.

Table 10: Participants' suggestions for responses that could be offered to people who feel sad

Response	Male participants	Female participants	Total
Cheering up	3 (14%)	2 (11%)	5 (12%)
Calming down	0	0	0
Offering to make/making a cup of tea, coffee or alcohol; having a cigarette	4 (19%)	1(6%)	5 (12%)
Self-management (e.g. 'I calmed myself down) and activities that do not involve others	0	2 (11%)	2 (5%)
Offered practical assistance	1 (5%)	1(6%)	2 (5%)
Give advice (behavioural)	0	0	0
Give advice (cognitive)	0	0	0
Provide opportunity to ventilate/discuss feelings	6 (29%)	5 (28%)	11 (26%)
Presence ('being there')	0	0	0
Involve in social activities	3 (14%)	4 (22%)	7 (16%)
Distraction, ignoring it	2 (10%)	0	2 (5%)
Getting someone else to help or do something for you	0	1 (6%)	1 (2%)
Physical reassurance	0	1 (6%)	1 (2%)
No response was offered by anybody	0	0	0
Participant not able to give a response/ 'don't know'	2 (10%)	5 (28%)	7 (16%)

Table 11: Participants' suggestions for responses that could be offered to people who feel angry

Response	Male participants	Female Participants	Total
Cheering up	1 (6%)	0	1 (3%)
Calming down	3 (18%)	3 (16%)	6 (17%)
Offering to make/making a cup of tea, coffee or alcohol; having a cigarette	3 (18%)	1 (5%)	4 (11%)
Self-management (e.g. 'I calmed myself down) and activities that do not involve others	0	3 (16%)	3 (8%)
Offered practical assistance	0	0	0
Give advice (behavioural)	0	0	0
Give advice (cognitive)	0	0	0
Provide opportunity to ventilate/discuss feelings	2 (12%)	3 (16%)	5 (14%)
Presence ('being there')	2 (12%)	0	2 (6%)
Involve in social activities	1 (6%)	1 (5%)	2 (6%)
Distraction, ignoring it	1 (6%)	0	1 (3%)
Getting someone else to help or do something for you	0	0	0
Physical reassurance	0	0	0
Would not offer a response	0	0	0
Participant not able to give a response/ 'don't know'	4 (24%)	8 (42%)	12 (33%)

Themes arising from the interviews

Some of the participants provided additional information during unstructured discussion evoked by questions from the interview. This information was recorded in order to provide useful context. It was analysed informally into three main themes:

- The role of paid staff
- Feelings of vulnerability
- A sense of isolation

The role of paid staff members

Individuals differed in how they described their relationships with staff members, but for some there appeared to be an awareness of difference, a sense of 'them' and 'us':

'How can they ever know how we feel? They haven't got a learning disability...they can help us do cooking and stuff, but they don't know what it's like to be like us.' (M5)

None of the participants referred to staff members as friends, but several referred to staff members as people there to provide emotional support:

'...they [staff] are paid to care for us'. (F3)

'I can't remember what they say...they get paid to look after us.' (M6)

'It takes about a year to trust someone...the emotional help is useful' (M2)

Some participants felt able to express dissatisfaction with the ways in which they felt staff were fulfilling their duties. For one participant, this was illustrated by a belief that there were not enough staff to provide the support needed by service users:

'Staff come up to the flat for 5 minutes...they say they'll be back in 5 minutes. They should spend more time with us. There should be more staff'. (M3)

Another participant was worried about the size of his outreach worker's caseload and how this affected the worker's ability to support him. In addition, he seemed to feel that the service overall was struggling to manage:

'I don't know about the outreach team...are there enough people? I can't get through when I ring up – they need someone to answer 'phones centrally. There might be an emergency...are they working too hard?' (M9)

All of the 10 participants who made similar comments were using outreach support services, either living alone or with another person with learning disabilities. Their support appeared to be offered at regular times, which 7 of these 10 participants found unhelpful as it meant that there was no flexibility around when they could be supported to do certain tasks such as shopping or laundry.

Vulnerability

Some participants conveyed a sense of both physical and emotional vulnerability during their interview. This was apparent in their general comments about what happens in times of difficulty, as well as from reviewing the number and role of people that they were able to identify in their social network using the SSQ. As well as reporting a small number of people available to them, the majority of the people perceived as available to provide support were paid professionals. In some cases, participants identified a small number of professionals and were living alone. The perception of being physical vulnerability is illustrated by F8:

'I feel like I want more help – to feel safe...I need some more help to get rid of my fear, I feel scared. Sometimes it gets inside me...I want to get it out, to tell people.'

Her partner, M7 suggested a way of addressing this:

'What gets me is, I never see the local bobby...I think it would be good for them to get the local bobby to come to our homes and talk about things.'

Isolation

Physical and emotional vulnerability is stemmed from the locality and nature of living accommodation for some individuals. Some participants who lived alone or with a partner conveyed a sense of physical isolation from others, which on occasion was accompanied by feelings of vulnerability. One woman, a wheelchair-user, was living with her partner on a council estate and talked about the difficulties they were having in arranging transport so that they could see their friends and family:

F12:

'Some nights, if we can't go out anywhere, we're stuck in the flat...seven nights a week.'

While some individuals gave the impression of coping very well living alone, others appeared to invest far more in their relationships with outreach support workers, describing them as their only regular contact.

Summary

This study attempted to answer four main research questions about the perceptions that people with mild or moderate learning disabilities have about support they receive in times of distress.

1. Who do people with mild or moderate learning disabilities go to for support when they are experiencing emotional distress?

The data obtained from the SSQ suggest that the largest group of people that the individuals with learning disabilities who participated in this study would go to for social support is paid staff members (44%), followed by parents and relatives (28%).

2. What kind of support is offered to people with mild or moderate learning disabilities at these times?

Responses from participants were similar for both when they were asked about being sad and about being angry. Almost a third of participants were unable or unwilling to describe the support offered to them following an incident leaving them feeling sad. Of the responses recorded, the most frequently recorded types of support were being told to cheer up (14%) or being given the opportunity to talk about their feelings (12%).

Similarly, almost a third of participants were unable or unwilling to talk about support received after an incident that left them feeling angry. Of the responses recorded here, the most frequently recorded types of support were being given the opportunity to talk about their feelings (15%) and being encouraged to ignore the situation or be distracted (10%).

3. *How do people with mild or moderate learning disabilities experience the social support offered to them at times of emotional distress (i.e. when they feel angry and when they feel sad)?*

'Helpful' responses when people felt angry varied, with being given the opportunity to discuss feelings, being offered a drink and someone offering to do something on your behalf being marginally the more common responses. Similarly, a wide range of types of support received when feeling sad was considered 'helpful', with being given the opportunity to discuss feelings, being 'cheered up', ignoring or distraction and being given practical assistance marginally the more common responses. Two participants felt that being told to cheer up was unhelpful.

4. *What kinds of social support do people with mild or moderate learning disabilities say they will offer to other people?*

Vignettes depicting characters feeling sad and angry respectively elicited a wide range of responses from participants concerning the support they would offer in the circumstances described. In the vignette portraying the 'sad' character, the most frequently recorded type of support was giving behavioural advice (30%), followed by offering involvement in social activities (18%). The character in the 'angry' vignette was also offered behavioural advice (19%), was told to ignore the situation (19%) or given the opportunity to discuss feelings (15%).

More generally, participants felt that when people are sad, they need opportunities to talk about how they feel (26%) or should be involved in social activities (16%). However, if people are feeling angry, participants felt that they would benefit from being told to calm

down (17%) or be given the opportunity to discuss their feelings. A third of participants were unable or unwilling to respond to this part of the interview.

Table 12 presents the three most frequently occurring codes from the data for responses to feelings of sadness and anger. This allows comparisons to be made between participants' accounts of support they received, the responses participants would offer as elicited by the vignettes and the responses participants gave when asked more generally about the support that people need when feeling sad and angry.

Table 12: Comparing coded responses

	Participants' report of support received after a recent incident	Support that participant would offer to character in vignette	General account of support that people need
When feeling 'sad'	<ol style="list-style-type: none"> 1. being told to cheer up 2. being given the opportunity to talk about how they feel 3. begin given practical assistance OR being distracted 	<ol style="list-style-type: none"> 1. would give behavioural advice 2. would involve in social activities 3. would offer to make a drink 	<ol style="list-style-type: none"> 1. opportunity to talk about how they feel 2. being involved in social activities 3. being offered a drink OR being told to cheer up
When feeling 'angry'	<ol style="list-style-type: none"> 1. being given the opportunity to talk about how they feel 2. no response was given by others 3. distraction 	<ol style="list-style-type: none"> 1. would give behavioural advice 2. would tell the individual to ignore it 3. would give the opportunity to talk about feelings 	<ol style="list-style-type: none"> 1. being told to calm down 2. opportunity to talk about how they feel 3. being offered a drink

CHAPTER FOUR: Discussion

Overview

This study attempted to explore the subjective experience of people with mild or moderate learning disabilities when given support in times of emotional distress. The Social Support Questionnaire (SSQ: Sarason *et al*, 1987) was used to map participants' social networks, while a semi-structured interview was used to encourage participants to give their perceptions of support they had received after incidents that had left them feeling sad or angry. In addition, participants were asked to suggest ways in which they would support others.

The findings suggested that people with learning disabilities that use services are likely to view paid staff members as their main source of social support. When asked to describe the support they have received after incidents that left them feeling distressed, participants gave a wide range of responses. It is difficult to draw clear conclusions regarding the more dominant types of support reported. The analysis has been descriptive due to the relatively small sample of participants. The most commonly reported types of support received when feeling sad were being told to 'cheer up', being given the opportunity to talk about feelings or being given practical assistance/being distracted from the stressor(s). The most commonly reported types of support received when feeling angry were being given the opportunity to talk about feelings, no response from others and being distracted from the trigger incident.

This chapter discusses the findings from the study in six main sections:

- the nature of participants' social networks and their satisfaction with the perceived support available through these networks
- participants' accounts of how they would support others in times of emotional distress

- participants' accounts of the support they themselves received following incidents leaving them sad and angry respectively
- methodological issues relating to the study
- proposals for future research
- implications for the design and delivery of learning disability services

The nature of social networks reported by people with learning disabilities

The data from the SSQ supports previous studies of social networks of people with learning disabilities (e.g. Lutfiyya, 1991; Rapley & Beyer, 1998) in that participants reported paid staff and relatives as dominant network members. The point of interest here however, is that participants gave subjective confirmation of a previously objectively measured phenomenon. While some of the participants lived with other people with learning disabilities – in two cases with a partner, and in three other cases as a flatmate with outreach support – it was still their sense that they obtained critical support from paid staff and sometimes relatives.

Friendships of any kind, with people with or without disabilities, were largely absent from participant reports. This evidence supports the literature on the social integration of people with learning disabilities, which argues that community care legislation has helped them to be physically *in* but not psychologically *of* their local community (see Bulmer, 1987; Carnaby, 1998; Myers, Ager, Kerr, & Myles, 1998). This is discussed further below (see section headed *Implications for the design and delivery of learning disability services*).

Satisfaction with perceived support generally available

The average rating of satisfaction with the perceived support available was 5.05, which corresponds to a rating of 'fairly satisfied' from the original scale. This is slightly lower than the mean rating of 5.38 obtained by Sarason *et al* (1987) in their study using participants from the general population. Arguably, one might expect that people with learning disabilities are more likely to be acquiescent, less likely to be critical of the services they use and would mostly rate satisfaction at its highest. Ratings of 4 or 5 (i.e. not the maximum ratings available to participants), although still in themselves high ratings, might reflect for some individuals a level of dissatisfaction with the support available.

Gaining the views of people with learning disabilities about the support they receive is a critical element of a quality service (Department of Health, 2001), and as such services need to establish clear mechanisms for collecting this information.

Participants' accounts of how they would support others

The findings suggest that while some individuals had difficulties with understanding the question, most of the people with learning disabilities interviewed were able to describe how they would support someone else feeling distressed. The types of support that would be offered by participants varied, but the most frequently occurring from the data for both vignettes was 'giving behavioural advice' (e.g. 'I'd tell him to go and see [his mum] instead'). This can be interpreted in a number of ways, but it is interesting to consider the possibility that participants' responses might reflect how they have been supported in the past, and/or ways in which they would like to be supported themselves. Support that is mainly behavioural and directive is arguably the more traditional – and more straightforward – approach to managing distress, and often seen as a strategy for supporting children.

Behavioural advice is concrete, and therefore more likely to be understood by people with learning disabilities, particularly if they are distressed.

Skills in supporting others have rarely been acknowledged in people with learning disabilities, nor have individuals been supported in acquiring such skills. This may in part be explained by the reluctance to accept the emotional lives of people with learning disabilities as discussed by Arthur (1999), an approach left over from institutionalisation where individuals were seen as passive recipients of care.

People with learning disabilities' perceptions of support offered to them in times of distress

Participants appeared to have more difficulty in describing the support that had been offered to them after incidents leaving *them* feeling sad or angry, with about a third unable or unwilling to give a response in each case. This might be understood in terms of cognitive demand (e.g. difficulties in remembering) but could also be linked to difficulties that individuals might have in talking about a time when they became upset. These issues are discussed further in the section outlining methodological issues below.

Participants described a range of responses from others after both incidents leaving them feeling sad and incidents leaving them feeling angry. When feeling sad, the most common responses from others were reported as 'cheering up' and 'giving the opportunity to discuss feelings' (e.g. 'She sat down and we talked about it'). However, these responses were only marginally the most commonly observed, and it is difficult to draw any conclusions from a relatively small sample. Furthermore, the wide range of incidents described by participants – e.g. from specific incidents such as arguing with a flatmate to stories of feeling sad about

more general situations such as not having a partner – is likely to evoke a wide range of responses from supporters. In turn, these responses are likely to be influenced by at least some of the following factors:

- the depth and length of the relationship between the two parties
- individual personalities and mood
- the supporter's experience of supporting others, particularly those with learning disabilities
- the supporter's level of professional training and awareness
- each partner's communication skills (Bradshaw, 1998; 2001)
- the ways in which the individual with learning disabilities has been supported by that person in the past after similar or different events
- the ways in which the individual with learning disabilities has been supported by other people *apart* from the individual identified, after similar or different events

The opportunity for ventilation (i.e. being given the time and space to discuss feelings about an event or situation) has been proposed as one of the most 'helpful' forms of support, and some participants did report experiences of such opportunities. It is possible that the number of responses coded as 'being given the opportunity to discuss feelings' is an underestimation of what was offered by supporters. People with learning disabilities may find it easier to recall and/or describe the more concrete elements of the support offered to them (e.g. being offered cups of tea or being given practical assistance), having more difficulty in 'talking about talking'. Conboy-Hill (1992, p157) suggests that:

'...many people with learning disabilities have an impoverished emotional vocabulary; perhaps due to our tendency to concretise our communication with them, but perhaps in part due to the level of abstraction required to triangulate upon the meaning of words such as 'hurt', 'frustrated', 'angry' and so on.'

Similarly, while the intention of staff or other supporters may be to facilitate the ventilation of feelings, people with learning disabilities might interpret all support as advice, hearing only the components of a conversation that relate to action or behaviour.

Satisfaction with support received

Asking participants about the usefulness of support they received also elicited a range of responses with no clear pattern. Some participants were very clear that the support offered to them was what they needed, and a few individuals were able to articulate what they would have preferred in terms of support. In these cases, the comments made consisted of 'I wanted them to spend more time with me' (F3) or 'They could have talked to me.... spent time with me' (M6)

Lehman *et al* (1986) suggest that the two categories of social support described as *helpful* by those being 'supported' is contact with a similar other and opportunity to express feelings, while support described as *unhelpful* includes giving advice and encouraging recovery. More research with people with learning disabilities is needed before this same conclusion can be made about their perceptions of support offered to them. Nonetheless, it is important to note that participants in this study described receiving types of support that the Lehman *et al* (1986) study might describe as 'unhelpful' - and yet did not always see that support as unhelpful themselves.

It might be concluded that participants in this study were supported in highly individualised ways after the distressing incidents they described, with many being largely satisfied with the support offered to them. However, the mixture of responses, both between and within participants, suggests that the support process is highly complex, and needs careful consideration by those offering support.

Methodological issues

While the main aims concerned the experiences of people with learning disabilities in being supported and their capacity to support others, a further important aim was to consider the potential for using methodologies with people with learning disabilities that are commonly adopted in the social support literature. In this context, there are a number of methodological issues to discuss.

The areas focused on here are the impact of cognitive demand, consideration of psychological issues for participants and the process and impact of adapting materials. Recruitment and consent procedures are also discussed.

Cognitive demands

The selection process for the study required support workers and managers of learning disability services to identify individuals with a 'mild' or 'moderate' learning disability who would be able to identify feelings of sadness and anger both in themselves and in others.

Standardized cognitive assessments were not conducted with participants, and selection relied heavily on informants' judgements about participants' cognitive abilities.

Some participants had clear difficulties with understanding what was required of them. One way of addressing this would have been to introduce a task where potential participants are

asked to demonstrate their understanding of emotions and how they are expressed in others.

This task may include an element of identifying feelings using photographs of facial

expressions, and stories describing a situation leading to a clear emotion (e.g.

happiness/sadness/anger). Similar tasks are used to assess levels of social understanding, or

theory of mind, in children and adults with autistic spectrum disorder (see Howlin, 1998).

This approach would help to identify individuals with autism who are likely to have

difficulties with thinking about the experiences of others, and who tend to need concrete

rather than abstract information about the world. In addition, administration of a preliminary

task such as this would help to identify individuals whose skills in social understanding are

still to emerge or are at the early stages of development. (This issue is discussed further

below).

Even if participants had successfully completed a screening task demonstrating an

appropriate level of competence in identifying emotions, it is possible that the study itself still

presented considerable difficulties. The protocol used placed significant cognitive demands

on participants that need to be discussed in terms of their potential impact upon the responses

given.

Firstly, it is important to consider the abstract nature of the study protocol. Participants were

asked to think about the help that they *would* offer to an individual (who is fictional) *if* certain

events happened (which are described rather than directly observed). Most participants were

able to provide a response; the vignettes proved to be the most popular section of the protocol

with participants, and they appeared to enjoy hearing the stories and engaged well with the

task. However, two individuals initially felt that the story was depicting a real life event in

their lives, while three others began talking about the character as if s/he was real. While this

had been anticipated in part and led to the use of drawings rather than photographs to avoid participants assuming that the events related in the stories were actual, it was apparent that for some there was still confusion between the vignettes and reality. This would need to be addressed in any future research aiming to assess the ways in which people with learning disabilities might support others.

It might also be necessary to define 'helpful' and 'unhelpful' in the sense of what it might mean *for the individual* him or herself, and to consider the experience that the individual has had in differentiating between these two concepts. For example, in this study, 'helpful' for one participant describing an incident where she was being bullied might mean that her desired outcome was achieved (i.e. the member of staff told the bully to stop his behaviour), while 'unhelpful' might be someone offering to sit down and talk about how the individual was feeling. The latter might have been perceived as 'unhelpful' because the participant could not make the links between the event of being bullying and being asked to talk about it. Action might have been preferred to just 'talking'. In this context, making generalisations across populations would be very difficult.

Linked with these issues is acknowledging that participants are not likely to have been asked questions about helpfulness before, and some individuals appeared to be confused by questions asking them to give an opinion in this way. It was rare for participants to describe support as unhelpful, choosing to term it as 'OK', 'all right' or 'fine'. This may be because the support offered is generally adequate, but it may also be for other reasons. People with learning disabilities are not usually experienced at giving their opinion or perspective on matters. This might lead to them expecting there to be a 'correct' answer to the question. If participants *did* think that support offered to them was unhelpful, it is possible that they felt

unable to express this. They might feel compromised, in that they are being asked to be critical of support offered to them, which for some is the only available form of support, of any kind.

Capacity for concern

The vignettes used in this study required participants to consider the ways in which they would respond to another person experiencing distress. The main aim here was to explore one of the research questions i.e. assessing the extent to which people with learning disabilities are able to support others. This was considered important, as traditionally people with learning disabilities have been seen as passive and dependent and likely to be incapable of offering support to other people.

This part of the study made another key assumption about the cognitive skills of participants, namely that they had a developed capacity for concern. The semi-structured interview comprised questions that require the respondent to empathise with the plight of another person, and then consider how they would interact with that person if the events had actually taken place. The cognitive processes that this task demands have been investigated as part of the developmental psychology literature. For example, it has been demonstrated that around the age of 2 years, children from the general population are interested in and often concerned about the distress of their siblings and mothers. By 3 years, they respond to states of unhappiness or need as well as overt states of emotion, and indicate an understanding of what is needed to make another person happier (Dunn, 1988). In summary:

'The developmental changes show a growth from affective tuning, with relatively egocentric strategies of comfort to a comprehension of the different ways in which distressed feelings can be relieved.'

(Dunn, 1988 p105)

The process by which this development occurs is unclear. There is some consensus that the development of concern for others springs from a concern for self and the notion that concern for another person is related to a concern for oneself – as one begins to recognise the potential for one's own experience within the experience of others (Blum, 1987).

This research can also be linked with literature in the learning disability field that has emphasised the utility in describing cognitive development and interventions with people with learning disabilities (e.g. Bunning, 1997; Ware, 1996; Nind & Hewett, 1994, 2001).

While taking a developmental approach to adults with learning disabilities may appear to be in direct conflict with the principle of normalization and ordinary living, it is increasingly argued that thinking about adults in terms of their level of developmental functioning is in reality a more respectful approach. It begins with the individual and his or her understanding of the world, and considers the interventions for further development that are most appropriate to *them* (e.g. Nind & Hewett 1996; Carnaby, 2001).

Clearly, there is not a simplistic, direct line between the 'normal' development of social understanding in young children and the development of similar skills in adults with learning disabilities. It is likely that adults with learning disabilities have an uneven profile of cognitive skills, with difficulties arising in very individualised and specific areas. Difficulties in social understanding might be linked to, for example, difficulties in language and communication – where people have problems in understanding what is being said – and/or

difficulties with the ability to 'mentalise' the experience of others. Capacity for concern might also develop with having had experience at demonstrating that capacity; if an individual with learning disabilities has not had the opportunity to show that they are able to have concern for someone else's plight, that capacity may not be able to flourish. As in so many areas of life for this population, low expectations of others leading to diminished experiences are likely to have significant impact on the development of skills.

Further research might consider the ways in which social understanding develops in people with learning disabilities, particularly exploring the role of the environment and the influence of supporters in the development process.

Participating in the study also placed demands on memory skills. Individuals were asked to code their perceptions of the support offered to them as 'helpful' or 'unhelpful', but this could be problematic. Some of the events described were in the distant past, and while details of what happened were recalled with little hesitation by some, the responses of others suggested difficulties with recall. Hesitation caused anxieties, and it was important for participants to be reassured that taking time in recounting their story about a distressing incident was perfectly acceptable.

Adapting materials

It was considered important to use a standardised assessment tool for establishing the social networks of participants, but the complexity of the language used in the SSQ meant that adaptations were necessary. While attempts were made to adapt language to meet individual needs where appropriate, it is possible that the questions in the SSQ were still unclear for some individuals. The similarities between questions also caused confusion for some participants. For example

'Whom can you really count on to care about you, regardless of what is happening to you?'

and

'Who can you really count on to be dependable when you need help?'

might evoke the same thoughts, leaving participants feeling that they had 'got it wrong' because their responses were similar for both questions. Some individuals needed reassurance throughout the administration of the SSQ that it was perfectly reasonable to give the same responses for each question. It is also important to bear in mind that given the limited social networks experienced by many people with learning disabilities, they are perhaps more likely to provide the same responses to items in the SSQ. This highlights the need to ensure that the questions are asked sensitively and perhaps within the context of general conversation about what happens when help is required.

Adapting the rating scale for the SSQ

The adapted scale used as part of the SSQ to aid participants' rating of their satisfaction with support available to them (see Appendix 7) pictured happy and unhappy faces and was intended to simplify the task, but may have added further complications. While some individuals appeared able to use the scale appropriately and commented on its usefulness, others seemed confused, and wondered whether they were being asked to comment on their current mood, or the mood of the character in the vignette. In addition, it is possible that a 6-point scale was cluttered and did not enable participants to make clear judgements. The faces differ in size; the 'happy' side of the scale has 3 faces, and it could be argued that as all 3

depict a 'happy' face, the participant would be unable to distinguish between them. This issues needs to be addressed; while the original scale requires differentiation between *degrees* of satisfaction, this may not be relevant for people with learning disabilities to the same extent. Further research might consider a 3-point scale, with faces expressing 'happy', neutral and 'sad', particularly for use with individuals regarded as having moderate rather than mild disabilities.

Psychological issues

Another important area to consider as part of reviewing the methodology adopted concerns the nature of the issues being discussed. Participants were asked to think about occasions when they were upset, and recall details about the incidents that had led to this distress. While memory difficulties might explain poor recall of events, it is also possible that the emotions evoked by thinking and talking about upsetting situations partly explains responses of 'don't know' or 'can't remember'. While the interviewer gently explored such responses, it was clearly important to respect any silence, refusal to respond or shaking of the head as a possible indication of anxiety. In no cases did participants become visibly upset during the interview, and the relatively high refusal rate at the point of obtaining consent might suggest that those individuals who were very concerned about discussing their distress did not agree to participation in the study.

The consent process itself attempted to give potential participants the option to withdraw at all stages from initial contact by telephone and on first meeting and then at each stage of the research procedure. It was felt that as far as possible, efforts were made to reassure participants that their withdrawal from the study would not get them into trouble or affect the services they received in any way. The success of these attempts is clearly difficult to establish. As researchers, it is essential to be cognisant of the potential imbalances of power

present between researcher and participant, and this awareness needs to be even more acute when interviewing people with learning disabilities. In this study, it is possible that potential participants felt pressured to take part as their service manager initially approached them. The dynamics of these relationships will differ between individual service users and managers, but power imbalances are again likely to be observed. While attempts were made to encourage service managers to approach individuals with this in mind, the process was not observed. However, a more naturalistic method of approaching individuals given the time scale available for this study would have been extremely difficult to achieve. For these reasons, as much effort as possible was put into providing opportunities for withdrawal once contact had been made.

Proposals for future research

This study set out to explore whether approaches used in social support research could be applied to the learning disability population. There are indications that it is possible to ask people with learning disabilities about the support they receive, but the techniques used here need careful evaluation and revision if their effectiveness is to be maximised. The use of vignettes does appear to be useful for some individuals, but their potential could be enhanced by using vignettes that depict the individual in circumstances with which they are familiar and that relate to an incident that the individual has directly experienced. In addition, the SSQ might not be the most appropriate method for eliciting the nature of social networks for people with learning disabilities. In this case, questions often had to be re-worded and were sometimes too abstract. The use of pictures might have been helpful in encouraging less able participants to talk about their social networks, while a smaller rating scale – with perhaps three rather than five categories – may be clearer, more accurate and more meaningful. Using faces rather than numbers did appear to be a useful way of conveying levels of satisfaction.

It is important to establish that the participant group here ranged in ability from those described as having 'mild' disabilities to those with 'moderate' disabilities. Variance in cognitive ability was matched by variance in performance in the study, and future work might need to consider levels of adaptation to meet the needs of individual participants. A few participants might have been patronised by the use of 'stories' and rating scales depicting smiling faces, while others found these tools useful and necessary. Still others appeared to find parts of the interview inaccessible, and would need more creative techniques available from the researcher to enable their meaningful involvement.

Participants generally appeared to enjoy the section of the interview asking them to consider a character in a vignette and describe the support they would offer after a incident leaving him or her sad or angry. There was a sense that the 'sad' vignette was the easier of the two for participants, with only one participant unable to provide a response. Six participants were unable to provide a response for the 'angry' vignette. This may suggest that the story depicted by the 'angry' vignette was either less clear than the 'sad' vignette, or perhaps did not describe a situation that participants felt would lead to the character becoming angry. Two participants commented that the character would be 'upset' rather than 'angry', which would be a reasonable conclusion for someone being bullied, as in the story. This could be explored further by establishing participants' recognition of emotion in others, as this knowledge is clearly required before any support can be offered.

Further complications are added by considering the personal contexts of people with learning disabilities. Participants here lived in a variety of living arrangements, ranging from living alone with outreach support or living with a partner, through to being a resident in a small

group home. Consequently, the dynamics of these respective settings needs to be considered, as those living in a group home will have the physical presence of paid staff around them day and night. This is likely to contrast sharply with the experience of receiving outreach support or support from relatives, and will in turn affect the ways in which individuals perceive the support available to them. Perhaps the present study has begun to establish the great variance in living arrangements and the importance of understanding how the availability and nature of support will differ in different service settings and will be perceived accordingly by service users.

The relatively small sample size of the present study has made it difficult to draw conclusions, and future research would need to consider sampling a larger number of people. In some ways this was not anticipated, as it had been hypothesised that clear patterns of support might emerge from the data. As a consequence, statistical tests of significance (e.g. the McNemar test) were deemed inappropriate for analysis of difference between such small frequencies.

The wide range of responses recorded might also indicate that even large studies might not be fruitful for people with learning disabilities, due to the heterogeneous nature of this population. Instead, researchers – and particularly those working in clinical settings – might find it more useful to work with individuals and what is meaningful to them. Focus would be on their ability to recall and discuss how they are supported in different circumstances, with the aim of developing a profile of their views about support that they have received over time and across different situations.

Implications of the research findings for the design of learning disability support services

Many of the people with learning disabilities interviewed in this study perceived that their main source of support is from paid staff. This has implications for learning disability services, which may or may not acknowledge or reflect this phenomenon in the design of provision.

The role of paid staff

Firstly, the role of staff can be considered. While some participants reported support consisting of others sitting down with them and giving them the opportunity to talk about their feelings, this was not the most commonly recorded response. It is important to consider why this does not appear to be a strategy adopted by some support staff.

It is possible that staff do not feel competent in using 'counselling' skills, or perhaps believe that the individuals they support do not have the skills to make use of support in this way.

Alternatively, it may be the case that people with learning disabilities are not acknowledged as having emotional lives, leading to an approach to support that is based mainly on the management of behaviour. Staff training programmes are likely to benefit from the inclusion of counselling skills for frontline staff, with the ability to provide emotional support being ascribed status as a core competency in support work.

Expectations of service users

A large proportion of the people with learning disabilities interviewed here tended to name staff members as their main source of support, implying that people using services have certain expectations about those paid to support them. Further research might explore these

expectations, and give people with learning disabilities the opportunity to think about what support staff can and should offer, and whether this available support is adequate in terms of meeting their emotional needs.

The self-advocacy movement has developed significantly, and consultation with organisations such as People First and local branches of Mencap now tend to be more commonplace. Regular consultation at the service user level is considered part of good practice in both developing and evaluating models of service provision.

However, the findings of this study focus the need for consulting people with learning disabilities more specifically around the ways in which individuals are supported after critical incidents and therefore concerns consultation with service users on a micro-organisational level. The outcomes of this type of consultation are unlikely to provide useful information for overall service design, but would enable staff members and other supporters to gain feedback about the support they are offering on a service user by service user basis. In turn this might lead to more relevant and individualised care plans, become central to the approach adopted with the individual in question and hence become a key element of a person-centred service.

Expectations of supporters and service providers

Services for people with learning disabilities have undergone significant change since the advent of deinstitutionalisation, and community services have done much to improve and enhance quality of life for many individuals. Approaches to support have traditionally been informed by thinking that is mainly behavioural in orientation, although the body of literature that advocates other approaches is building. For example, psychologists are now applying systemic ideas to the support of people with learning disabilities (e.g. Dixon & Matthews,

1992; Vetere, 1993; Dale, 1996), while the psychodynamic literature is also growing steadily (e.g. Beail & Warden 1996; De Groef & Heinemann, 1999). The essence of this shift away from purely behavioural thinking towards a more person-led approach emphasises the importance of acknowledging the emotionality of people with learning disabilities. Those providing support to this population need to have an increasingly sophisticated understanding of an individual's needs. This requires thinking not only in terms of the ways in which cognitive impairment can affect daily functioning, but also in terms of how such difficulties can impact upon and affect the ability to cope with emotional distress.

There are implications for service providers, as not only are staff enablers in terms of practical tasks, but are likely to find themselves taking the role of counsellor and confidante. Whilst members of the general population using psychology or counselling services might pay for such help, people with learning disabilities are in a unique position. Supporters are paid to be with them, sometimes 24 hours a day, arriving in the lives of the people they support with little if any preparation. This is in contrast with the support experienced by the majority of the population, who are more likely to choose who they go to for support, and are likely to have built a relationship with those supporting them. Furthermore, relationships between supporter and supported in the general population are more likely to be characterised by some degree of reciprocity. Newton, Olsen and Horner (1995) support this observation. They report that the stability of social relationships between people with learning disabilities and others in the community is likely to be significantly influenced at least by the extent to which people with learning disabilities perceive this relationships as having reciprocity.

The findings here suggest that there are not clear, standardised ways of providing support to the learning disabled population. It is perhaps more appropriate to be aware of how an

individual with learning disabilities perceives a situation and through knowing them well, have some awareness of the types of support that they find most helpful. Perhaps the key here is 'knowing the person well', which suggests spending more time with him or her in a variety of situations and through a range of experiences. Spending time with someone – just 'being' with the person – is still not a valued activity in support services. It is not a task that can easily be measured or evaluated, and easily attracts criticism from peers if it is perceived that sitting with a service user is not 'real work'. Staff members therefore need the support to adjust their expectations of their own role. They need to begin seeing themselves not only as people who support and perform the practical tasks of daily living, but equally as listeners and confidantes who facilitate the development of self esteem through exploring problems and difficulties with the people they support.

Design of services to incorporate social support structures

Integration is still high on the agenda for those leading learning disability services and remains the central goal in supporting individuals (Department of Health, 2001).

Recent research has, however, argued that much is still to do, with people with learning disabilities still 'outside looking in' (Myers *et al*, 1998).

Services strive for continuing improvement and increases in quality, but are only able to work with half of the solution to social isolation for people with learning disabilities - the other half being the attitudes and levels of tolerance prevalent in wider society. Given the relative impossibility of addressing wider prejudice and lack of support for people with learning disabilities that is generally perceived 'outside' of organised provision, the role of services is arguably to act proactively as a 'buffer' against stressors. This would be in addition to taking

the more usual, reactive role in supporting individuals experiencing distress. Supporters would need to establish creative and individualised ways of assessing the impact of the support they are offering, and be reflective in their efforts if they are to ensure that their intention to be helpful is realised. Clinically, this might mean seeking feedback from the individual being supported *as soon as is possible and appropriate* after the support was offered.

In this context, the perceptions of individual are highly important; models of social support suggest that perceptions that help is available if it were needed can act as a preventive measure against mental health problems, and people with learning disabilities are not likely to be any different in this respect. The challenge lies in finding ways of understanding how individuals with learning disabilities experience the support offered to them, and then ensuring that supporters are equipped with the necessary skills to adapt what they are offering where necessary. Services therefore need to move from the rhetoric of person-centred services towards a more flexible approach that can manage the wide variation that is likely to arise from taking this highly individualised approach.

Recently, new mechanisms have been developed within social care that may encourage, perhaps even necessitate such innovation. 'Best Value' and Clinical Governance both demand accountability for provision that is evidence-based (e.g. Cambridge, 2000; Lucock, Leach & Iveson, 1999), while advances in direct payments schemes have the potential to lead to an increase in the recognition for highly tailored support.

It is also important to note that this study has only focused on individuals with learning disability that use statutory provision or provision from the voluntary sector. The integration

and social support experience of individuals with learning disabilities that are not known to services also need to be considered. In this context, further research into the social support of people with learning disabilities might consider interviewing the supporters, with the aim of establishing their intentions when supporting an individual. This will enable exploration of the communication between the individual being supported and the supporter, and will be of particular interest to those interested in teaching skills to those supporting people with learning disabilities.

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List of Appendices

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Appendix 1:

Ethics approval



The University College London Hospitals

The Joint UCL/UCLH Committees on the Ethics of Human Research

Committee Alpha Chairman: Professor André McLean

Please address all correspondence to:
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Dr C Barker
Senior Lecturer
Sub-Department of Clinical Health Psychology
UCL
Gower Street

07/04/00

Dear Dr Barker

Study No: 00/0065 (*Please quote in all correspondence*)
Title: Social support and people with learning disabilities: the service user's perspective

Thank you for letting us see the above application which was considered at the ethics committee meeting yesterday. The Committee agreed for the project to go ahead, and were particularly impressed with the clarity with which you addressed the communication with these particularly vulnerable persons.

Please note that it is important that you notify the Committee of any adverse events or changes (name of investigator etc) relating to this project. You should also notify the Committee on completion of the project, or indeed if the project is abandoned. **Please remember to quote the above number in any correspondence.**

Yours sincerely

Professor André McLean, BM BCh PhD FRC Path
Chairman

Manor House
Headley Way, Headington
Oxford OX3 9DZ

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RJ/lmp/O00.73

12 January 2001

Dr Steven Carnaby
Clinical Psychologist in Training
Oxfordshire Learning Disability NHS Trust
Slade House
Horspath Driftway
HEADINGTON
OXFORD OX3 7JH

Dear Dr Carnaby

Re: O00.73 – Social support and people with learning disabilities: the service user's perspective.

Thank you for your letter dated the 8 January 2000 addressing the concerns raised by the Committee at their meeting on the 19 December 2000. In accordance with the authority set out in the Terms of Reference, I am happy to confirm ethical approval and wish you every success with the study.

Please note:

- Ethical approval is valid for three years from the date of this letter.
- No significant changes to the research protocol should be made without appropriate research ethics committee/chairman's approval. Any deviations from or changes to the protocol which increase the risk to subjects, or affect the conduct of the research, or are made to eliminate hazards to the research subjects, should be made known to OPREC.
- OPREC should be made aware of any adverse events.
- Whilst the study has received approval on ethical grounds, it is necessary for you to obtain management approval from the relevant Clinical Directors and/or Chief Executive of the Trusts (or Health Boards/DHAs) in which the work will be done.

I should be very grateful if you could send me a copy of any publication which may arise from this study.

Yours sincerely,

Orla Bickel

pp Professor Robin Jacoby
Chairman
Oxfordshire Psychiatric Research Ethics Committee

Oxfordshire Psychiatric Research Ethics Committee (OPREC)		
OPREC No: O00.73		
Title of Project: Social support and people with learning disabilities: the service user's perspective.		
The following documents have been approved by OPREC		
	Date/Version	Approved
Protocol	19 December 2000	✓
Information Sheet for Keyworkers	19 December 2000	✓
Information Sheet for Participants	19 December 2000	✓
Participant Consent Form	19 December 2000	✓

Terms of Reference, Standard Operating Procedures and a list of members of the Ethics Committee are available from the Research & Development office on request.

INDEMNITY

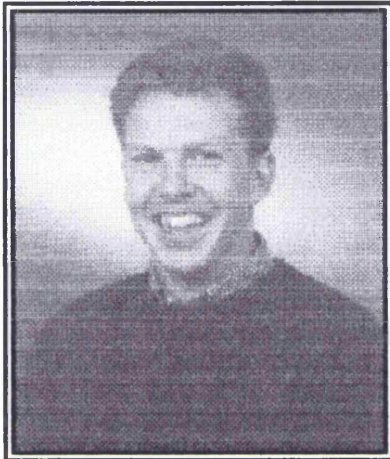
The purpose of an indemnity arrangement for a researcher is to provide legal protection in the event of a researcher led unforeseen adverse circumstance, however minimal the risk, arising during the course of a research project. The indemnity applies to the Senior Investigator in the project and automatically covers any other generally more junior colleagues associated with the project. There are various types of indemnity dependent on the circumstances of the researcher and the nature of the research project. Staff employed in the NHS Trust Hospitals should ensure that they are properly protected by the appropriate indemnity approved by the Trust Chief Executive or Medical Director.

Appendix 2:

Information sheet and consent form for participants

Information sheet and consent form for participants

Dear



My name is Steve.

I am writing about what happens when people need help.

**We all want help sometimes.
People need to know what to do to help us.**

I want to talk to lots of people about the help they get when they feel sad and upset.

**Do you want to help me do this?
I will talk to you about what happens when you get help. I will write things down, but I will not use your name.**

You will not get into trouble if you do not want to help me.

You can talk to your keyworker to find out more.

You can ring me to ask me more about this on:

[Telephone number]

From

Steve

✂.....

Please put a ✓ in the box if you want to talk to me:

 Yes

Name:

Contact Number ☎ :

Please give this form to your keyworker

Thank you

Appendix 3:

Information sheet for keyworkers, parents and carers

Information sheet for keyworkers, parents and carers

Steve Carnaby
[Contact details]

Dear Supporter,

I am currently training as a clinical psychologist at University College London. For my final year dissertation, I am conducting some research into the social support needs of people with mild or moderate learning disabilities.

The project involves talking to service users about the support they have received in the past and the help they think they might need in the future. I enclose an information sheet about what the project will entail, which also discusses confidentiality, consent issues and how the findings from the research will be used.

I would be very grateful if you could talk to the individual or individuals for whom you are keyworker about whether they would like to participate in the project. I have also enclosed an explanatory letter for potential participants, which includes a consent form. Please return completed consent forms to me at the above address using the stamped addressed envelope, and I will get in touch to make an appointment for the interview.

Please do not hesitate to give me a ring if you have any questions.

Many thanks for your help

Best wishes

Steve

Appendix 4:
General information sheet

Appendix 4:

General information sheet

<p>Social support and people with learning disabilities: PROJECT INFORMATION SHEET</p>

Background

Social support is important to everybody. Evidence is emerging to suggest that having the kinds of support that we need can act as a buffer against stress and maintain our sense of well being.

Why the need for research?

It is very difficult to describe what social support is. It could be making someone a cup of tea, saying the 'right thing' or suggesting ideas for how to deal with a difficult situation. However, it is likely that the key to ensuring that people have the support they need is to ask them about their experiences of help they have received in the past and what they thought about it.

About the project: What will people be asked to do?

This research project hopes to ask a sample of 36 people with mild or moderate learning disabilities to tell us more about what they need from supporters in times of difficulty. Only people who are able to give consent and sign a consent form will be contacted to arrange an interview time and venue. The interview lasts about an hour and will invite participants to think about the help that they have received in the past and what they thought about that help. Did the help that was offered work? Are there things that supporters could say or do differently that would increase the effect of their help?

What happens to the findings?

The findings from the research will not be fed back to [the organisation's] management on a 'case-by case' basis. All names will be kept confidential, and the results will appear as themes and key areas. The intention is to help providers of support have a clearer understanding of the *types* of help that service users want. I will write a summary report available for all staff to read, as well as an appropriately adapted version for people who use [the organisation's] services. It is also possible that the final report could be made into a resource for service users, enabling them to more clearly request the kinds of support they prefer.

Appendix 5:
Interview protocol

Appendix 5:

Interview protocol

1. Before meeting each participant

The interviewer speaks directly with the participant on the telephone. This conversation refers to the written material made available by the individual's keyworker.

Interviewer: 'Hello. My name is _____. I think [keyworker's name] talked to you about me. I'm talking to lots of people about the help they get when they are upset. Do you remember?'

Pause.

[If yes, continue. If no, provide a full explanation. If the response is still no, say you are sorry to have troubled the person and terminate the phone call]

'I think [keyworker's name] showed a piece of paper with my photo/picture on it. Then s/he talked to you about my work. You signed the piece of paper and said that I could ring you. Do you remember?'

[f response is yes, continue. If no, suggest that you will talk to the individual's keyworker again and get back in touch.]

The interviewer asks whether the individual is interested in taking part in the study. If s/he agrees, a meeting time and place are arranged. If the response is no, participation in the study is terminated.

2. On meeting the participant.

Interviewer: 'Hello _____. My name is _____. We talked on the phone and said that we'd meet today.'

Invariably, this is unnecessary, as participants are often very aware of the interview taking place that day, and/or had been prepared by their keyworker.

Interviewer: 'Do you remember this? [shows adapted material with interviewer's photograph – see Appendix 2] I'm doing some work about the help that people get when they are upset. I'm talking to lots of people and asking them what happens when they get upset and who helps them.'

Pause.

[If the person says yes, continue. If no, suggest that you could talk about the form with the person, or you could come back another day after they have talked to someone about it. If the person seems at all unsure, emphasise the option of coming back another day]

3. Checking consent

Interviewer: 'I write down the things that people tell me. That helps me to remember what they have said. I don't use their names. When I have talked to everybody, I'm going to put all of their ideas together to see if we can find out how to make sure that people get the help that they need.'

Pause.

'I want to check that this makes sense. Can you tell me what we've been talking about?'

When the participant recounts the discussions, the interviewer listens for key elements such as 'helping people' 'getting upset' 'writing things down' and 'not using names'. Elements are reiterated where necessary to ensure comprehension.

Interviewer: 'You won't get into trouble if you don't want to talk to me. Do you want to talk to me about what happens when you get upset?'

If the participant says no, terminate participation. If the participant says yes, the interviewer says:

'That's great. Here's my notepad. I'm going to write down things that you tell me, but I'm not going to use your name. That will help me to remember what you have said. Is that OK?'

4. Explaining confidentiality

If the participant agrees:

Interviewer: 'I will not tell people things that you tell me. BUT if you tell me something that I think might hurt somebody else, or means that you might get hurt, I might have to tell someone else. If this happens, I will tell you. I will tell you why I need to tell someone, and we can talk about WHO I will tell, and WHAT I will tell them.'

Pause

'I want to make sure that you are OK with what I have just said. Can you tell me what I was just talking about?'

When the participant relates the discussion of confidentiality, the interviewer listens for key elements such as 'not telling other people' and 'but you might have to tell people.... if I say

something and someone might get hurt'. If comprehension seems unclear or inaccurate, the interviewer repeats and/or rewords what was said.

5. Administer the SSQ

Explain the scale to the participant.

Interviewer: 'I'd like to hear how you feel about the help you get from the people around you. Here is something to help you do that [presenting the rating card]. Can you see these faces on the card? This face here [points at biggest smiling face] means being really happy *about something*. This face here [points at smallest sad face] means being really *UNhappy about something*...

Pause.

If I was a TINY bit unhappy about something, I'd choose this face [points to smallest unhappy face]. If I was a bit MORE unhappy about something, I might choose this face [points at medium-sized unhappy face]. Let's see if you can have a go.'

Participants were then asked two questions to assess their comprehension of the scale:

Interviewer: 'OK...Let's see if this card makes sense. I'm going to ask you some questions, and see if you can use the card to tell me what you think about the things that I ask you.'

Pause. Check and explain if necessary.

'Do you like watching Neighbours on TV? Show me what you think about Neighbours using this card'

Pause. Check and explain if necessary

'Do you like going shopping? Show me what you think about going shopping using this card'

Pause. Check and explain if necessary.

'OK. Well done. Let's think about food now. Do you like ice cream? Show me what you think about ice cream using the card.'

Pause.

'What about cabbage. Do you like cabbage? Show me what you think about cabbage using the card.'

The interviewer also rates these items for him/herself, as a way of engaging with participants and building rapport. Where participants chose extremities of the scale, the interviewer

ensures that s/he chooses ratings in the middle of the scale, commenting on what they indicated, to illustrate the range available. The approach taken during the interviews was informed by Ambalu's (1997) recommendations for healthcare professionals (see p34).

6. Semi-structured interview

Interviewer: 'Now I'm going to show you some stories. [Place the drawing for the first vignette in sequence on the table in front of the participant].
'This is a story about a man/woman. Let's give him/her a name. [If the participant was unable to/did not want to provide a name, the default character names were 'Michael and 'Jane'.]

Picture 1: Here is Jane/Michael at home.

Picture 2: Every Sunday, Jane's/Michael's mum comes to see her/him.

Picture 3: Last Sunday, in the story, there was a problem.
Jane's/Michael's mum rang to say that she was really sorry, but she couldn't come and see Jane/Michael.

Picture 4: This made Jane/Michael feel sad [points to face]... can you see how sad s/he looks?

Pause

'In this story, Jane/Michael feels sad. What would you say (what would you do) if this had happened to her/him?'

Shall we do some more?

If the response is no, terminate the interview.

'In this story, Jane/Michael feels *sad*. Can you think of a time recently when *you* felt sad?'

Record responses verbatim.

Interviewer: Did anyone help you?... What did they say?... What did they do?

Interviewer: Shall we do some more?

If the response is no, terminate the interview.

Interviewer: OK. Here's the second story.

[Place the drawing for the second vignette in sequence on the table in front of the participant].

- Picture 1: Here is Jane/Michael in her/his bedroom
- Picture 2: Jane/Michael goes to a day centre. S/he gets there on the bus. Here s/he is waving goodbye to the bus driver.
- Picture 3: One day, in the story, something happened on the way home from the day centre. Other people on the bus were nasty to Jane/Michael. They pointed at her/him and called her/him names.
- Picture 4: This made Jane/Michael feel angry. Can you see how angry s/he looks?

‘In this story, Jane/Michael feels angry. What would you say (what would you do) if this had happened to her/him?’

Record responses verbatim.

Interviewer: ‘Shall we do some more?’

If the response is no, terminate the interview.

Interviewer: ‘In this story, Jane/Michael feels *angry*. Can you think of a time recently when *you* felt angry?’

Interviewer: Did anyone help you?... What did they say?... What did they do?

Well done. Shall we do some more?

If the participant says no, terminate participation.

7. Discussion about the support people might need when feeling sad or angry.

Interviewer: ‘We’ve talked a lot about the help that people get when they are upset. We’ve talked about being sad or being angry.

‘What do you think people need when they feel sad?’

Record responses verbatim.

‘What do you think people need when they feel angry?’

7. Debriefing

Interviewer: 'We've done a lot of talking. We've talked about things that might be a bit hard to talk about. How are you feeling?'

If the participant is showing any signs of distress, stay with him/her until s/he seems calmer. Provide opportunities for him/her to talk more if appropriate. If the distress continues, ask whether s/he would like to talk to/telephone/see anybody. Make arrangements as necessary.

Appendix 6:

The Social Support Questionnaire (SSQ)

Appendix 6:

The Social Support Questionnaire (SSQ) (Sarason *et al* 1983)

Name.....

Age:

Sex:

Date:.....

Instructions

- The following questions ask about people in your environment who provide you with help or support. Each question has two parts. For the first part, list all the people you know, excluding yourself, whom you can count on for help or support in the manner described. Give the person's initials and their relationship to you (see example). Do not list more than one person next to each of the numbers beneath the question.
- For the second part, circle how satisfied you are with the overall support you have
- If you have no support for a question, put a ✓ against the words 'No one', but still rate your satisfaction. Do not list more than 9 person per question.
- Please answer all questions as best as you can. All your responses will be kept confidential.

Example

Who do you know whom you can trust with information that could get you in trouble?

- No one
- | | | |
|-------------------|--------------------|----|
| 1. T.N. (brother) | 4. T.N. (father) | 7. |
| 2. L.M. (friend) | 5. L.M. (employer) | 8. |
| 3. R.S. (friend) | 6. | 9. |

How satisfied?

6 = very satisfied	5 = fairly satisfied	4 = a little satisfied	3 = a little dissatisfied	2 = fairly dissatisfied	1 = very dissatisfied
-----------------------	-------------------------	---------------------------	------------------------------	----------------------------	--------------------------

(1) Who can you really count on to be dependable when you need help?

- No one
- | | | |
|----|----|----|
| 1. | 4. | 7. |
| 2. | 5. | 8. |
| 3. | 6. | 9. |

(2) How satisfied?

6 = very satisfied	5 = fairly satisfied	4 = a little dissatisfied	3 = a little dissatisfied	2 = fairly dissatisfied	1 = very dissatisfied
--------------------	----------------------	---------------------------	---------------------------	-------------------------	-----------------------

(3) Who can you really count on to help you feel more relaxed when you are under pressure or tense?

<input type="checkbox"/> No one	1	4	7
	2.	5.	8.
	3.	6.	9.

(4) How satisfied?

6 = very satisfied	5 = fairly satisfied	4 = a little dissatisfied	3 = a little dissatisfied	2 = fairly dissatisfied	1 = very dissatisfied
--------------------	----------------------	---------------------------	---------------------------	-------------------------	-----------------------

(5) Who accepts you totally, including your worst and your best points?

<input type="checkbox"/> No one	1.	4.	7.
	2.	5.	8.
	3.	6.	9.

(6) How satisfied?

6 = very satisfied	5 = fairly satisfied	4 = a little dissatisfied	3 = a little dissatisfied	2 = fairly dissatisfied	1 = very dissatisfied
--------------------	----------------------	---------------------------	---------------------------	-------------------------	-----------------------

(7) Whom can you really count on to care about you, regardless of what is happening to you?

<input type="checkbox"/> No one	1	4.	7.
	2.	5.	8.
	3.	6.	9.

(8) How satisfied?

6 = very satisfied	5 = fairly satisfied	4 = a little dissatisfied	3 = a little dissatisfied	2 = fairly dissatisfied	1 = very dissatisfied
--------------------	----------------------	---------------------------	---------------------------	-------------------------	-----------------------

(9) Whom can you really count on to help you feel better when you are feeling generally down-in-the-dumps?

<input type="checkbox"/> No one	1	4	7.
	2.	5.	8.
	3.	6.	9.

(10) How satisfied?

6 = very satisfied	5 = fairly satisfied	4 = a little dissatisfied	3 = a little dissatisfied	2 = fairly dissatisfied	1 = very dissatisfied
-----------------------	-------------------------	------------------------------	------------------------------	----------------------------	--------------------------

(11) Whom can you count on to console you when you are very upset?

<input type="checkbox"/> No one	1	4.	7.
	2.	5.	8.
	3.	6.	9.

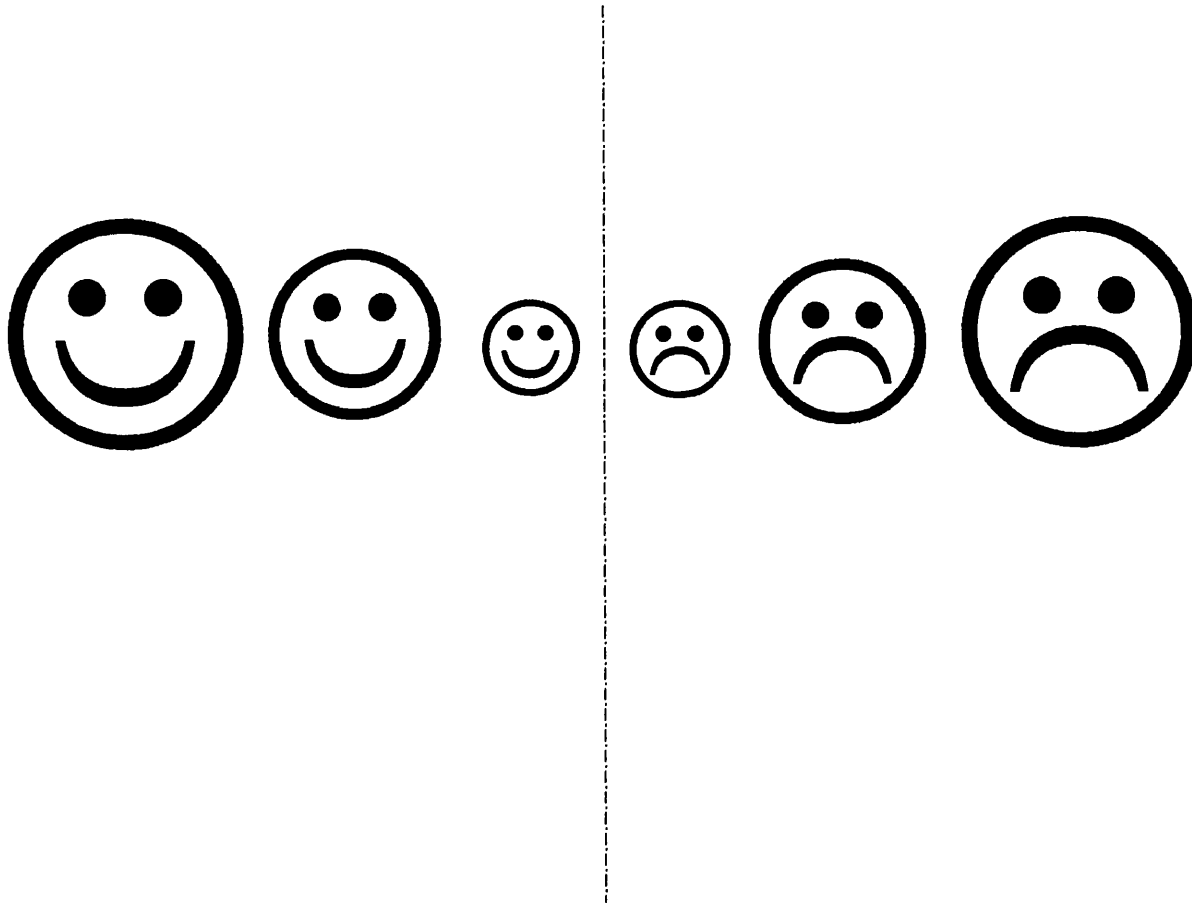
(12) How satisfied?

6 = very satisfied	5 = fairly satisfied	4 = a little dissatisfied	3 = a little dissatisfied	2 = fairly dissatisfied	1 = very dissatisfied
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Appendix 7:
Adapted Likert scale

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Adapted Likert scale



Appendix 8:

Line drawings for vignettes:

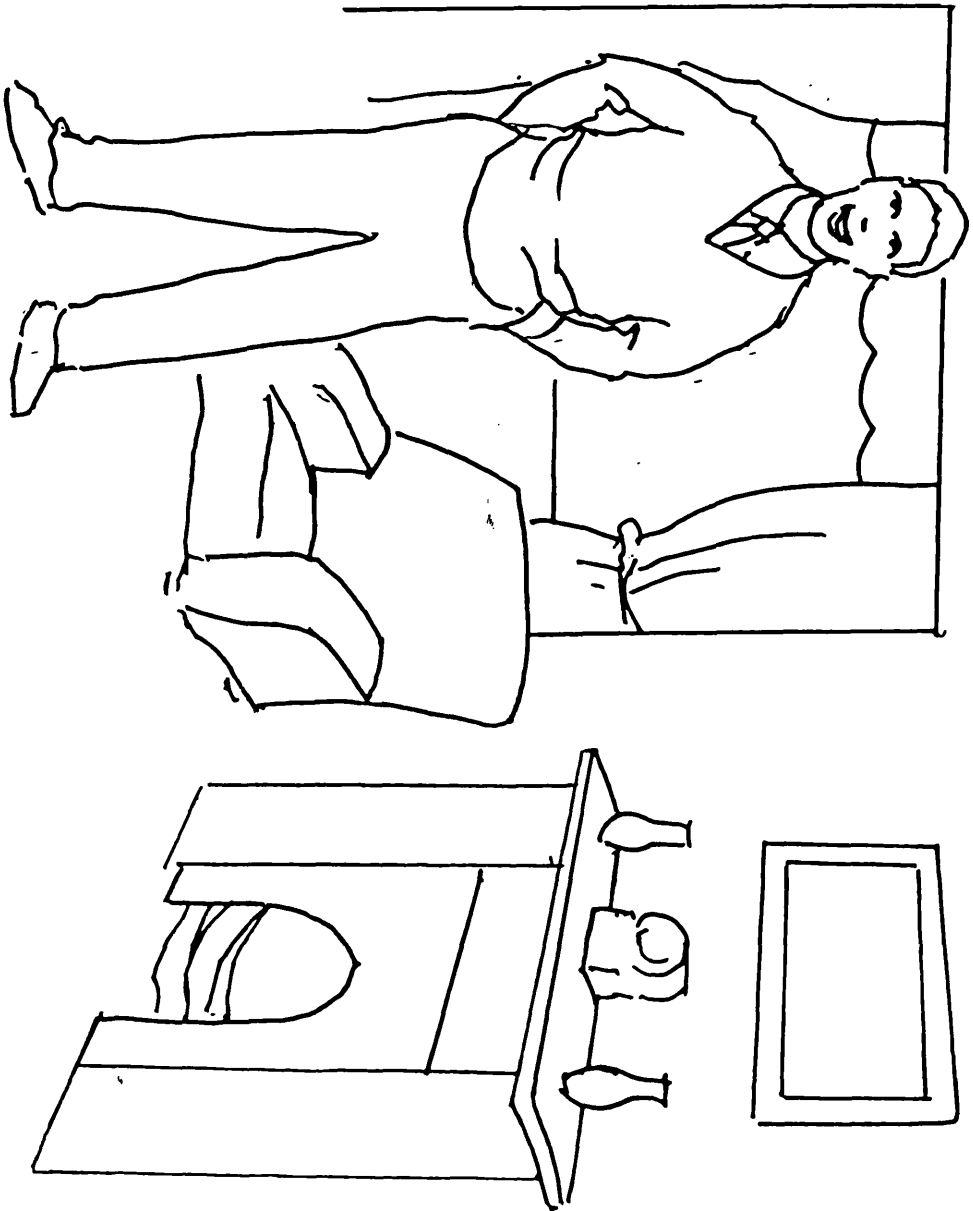
Pages 133 - 136: 'Sad' vignette – Female character

Pages 137 - 140: 'Sad' vignette – Male character

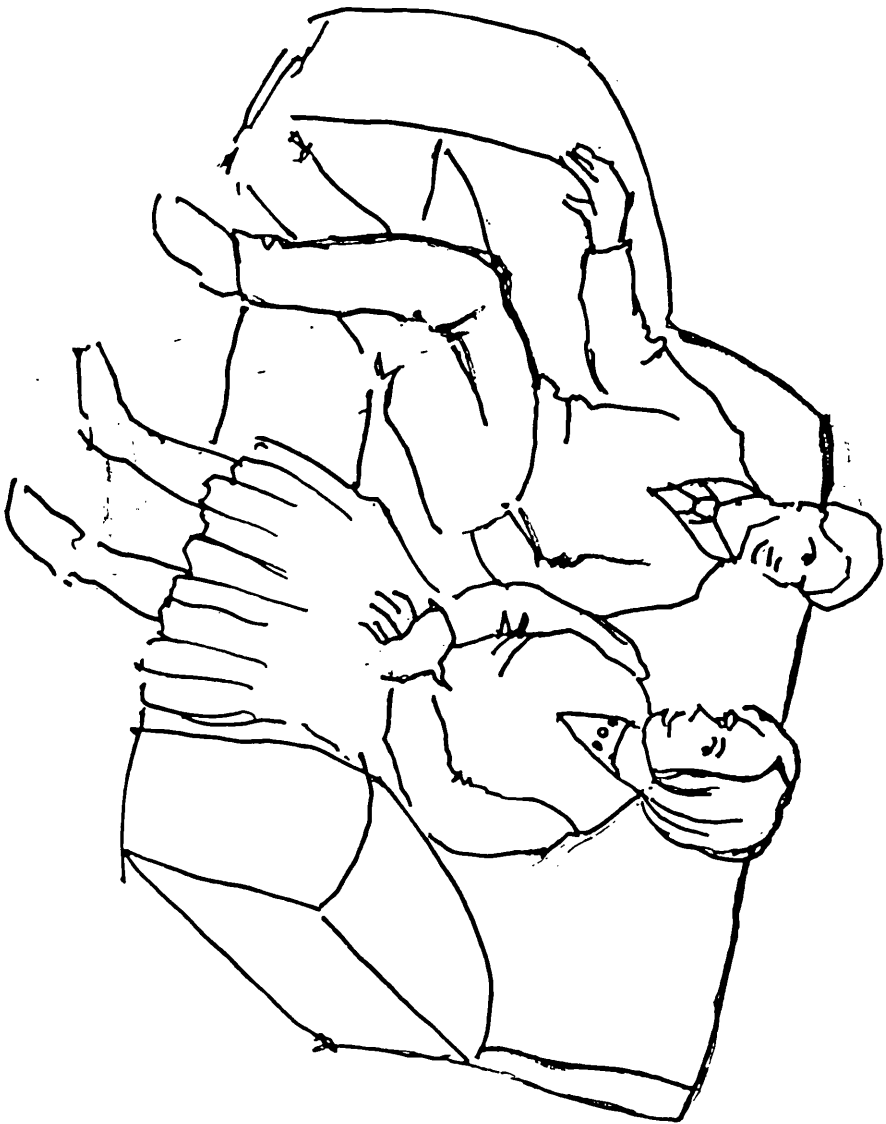
Pages 141 - 144: 'Angry' vignette – Female character

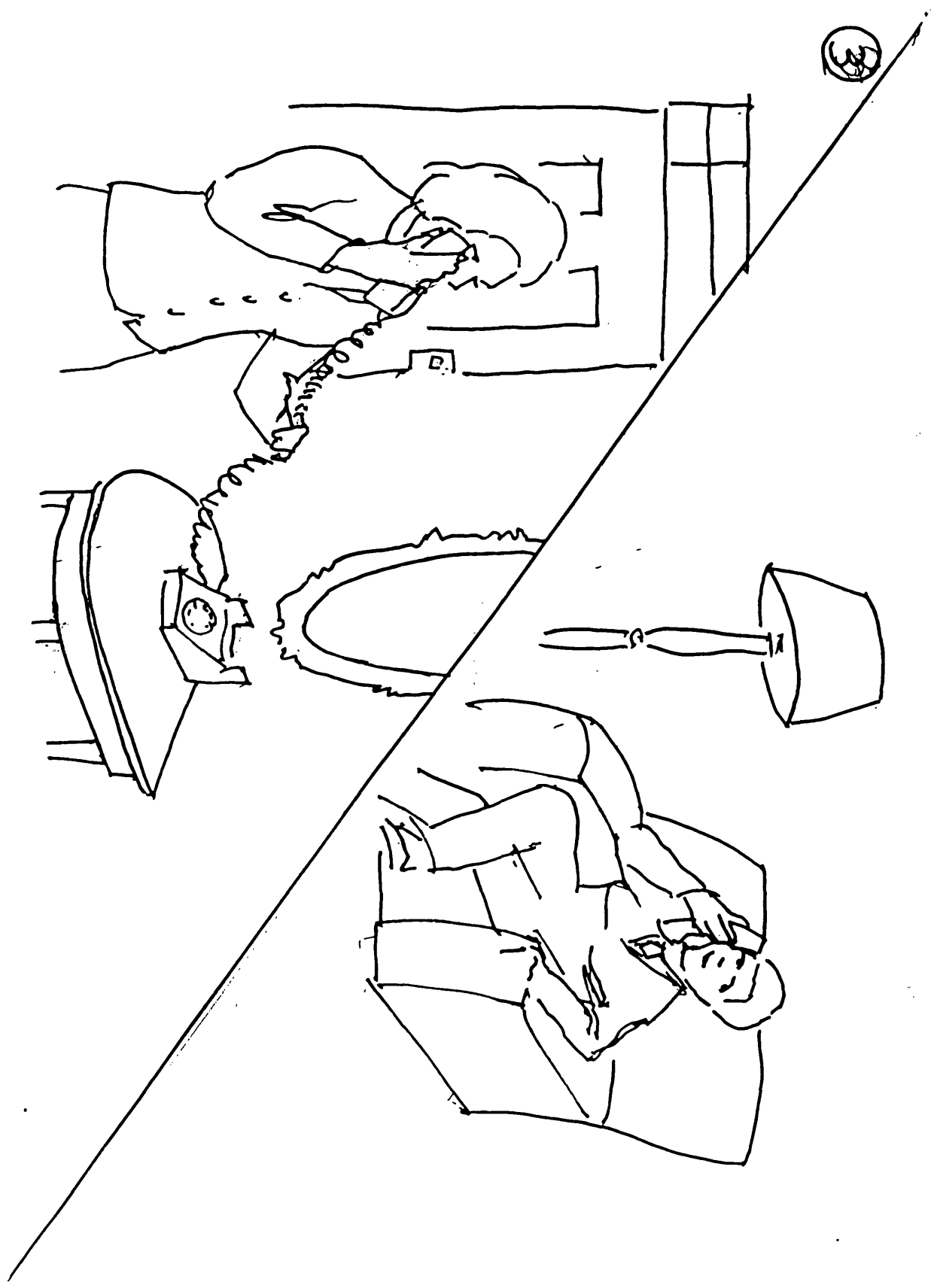
Pages 145 - 148: 'Angry vignette – Male character

1

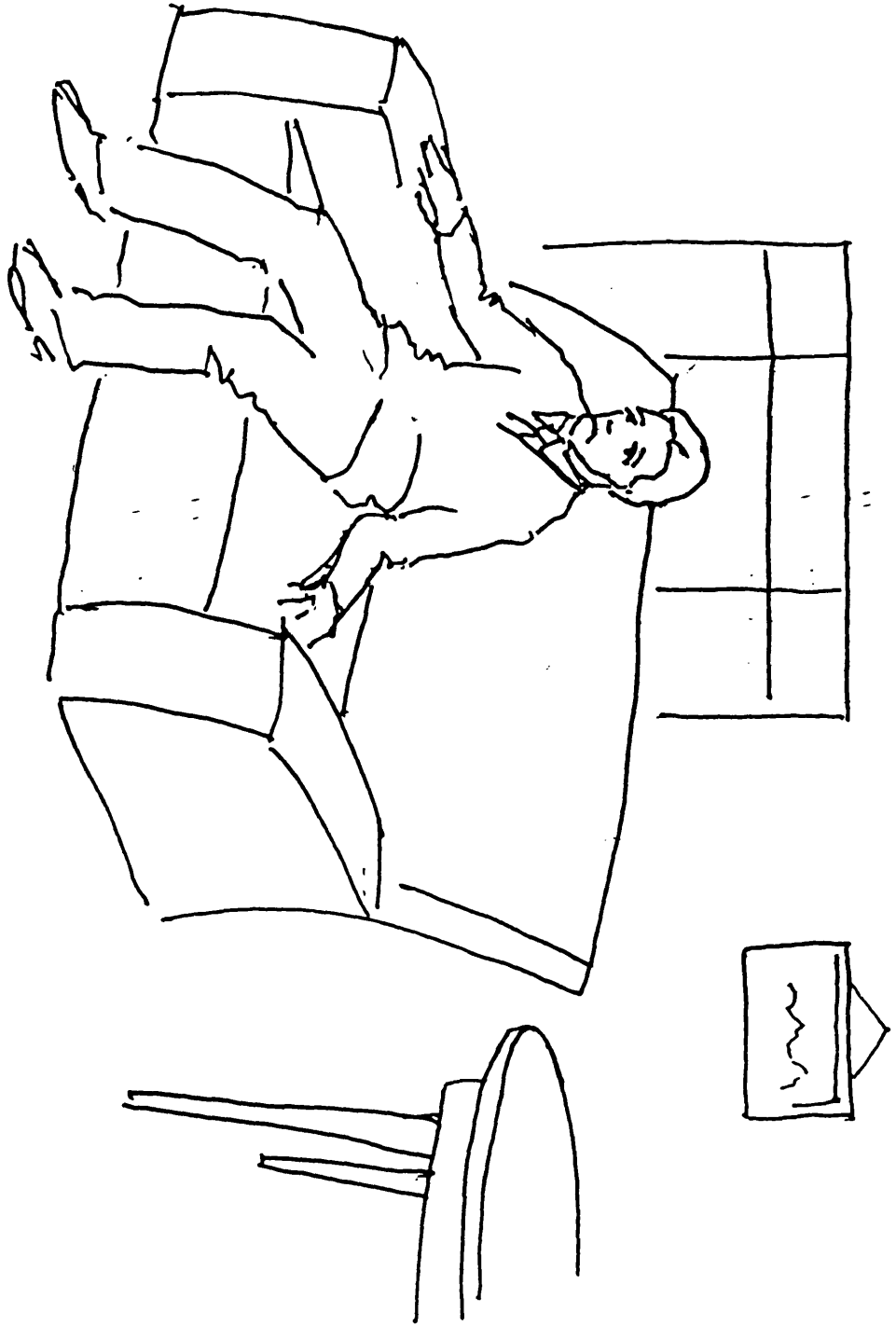


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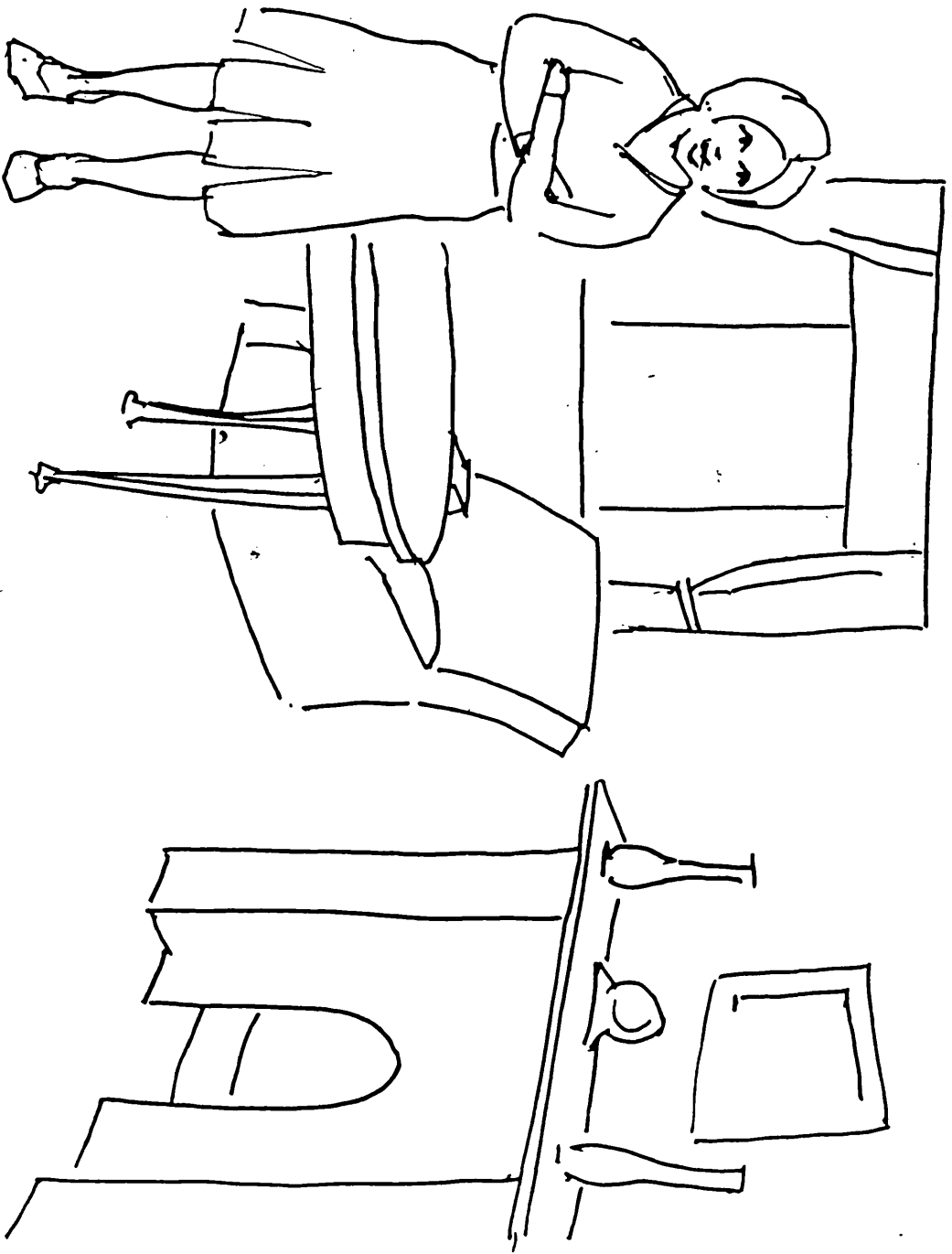




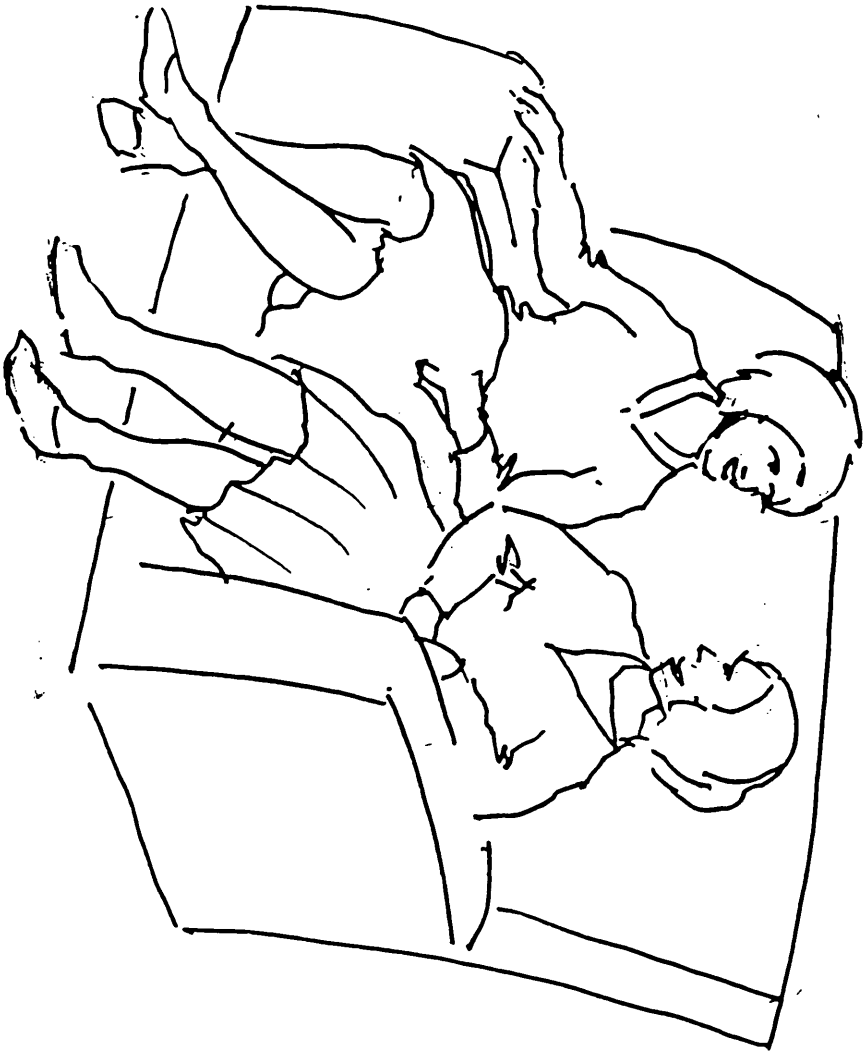
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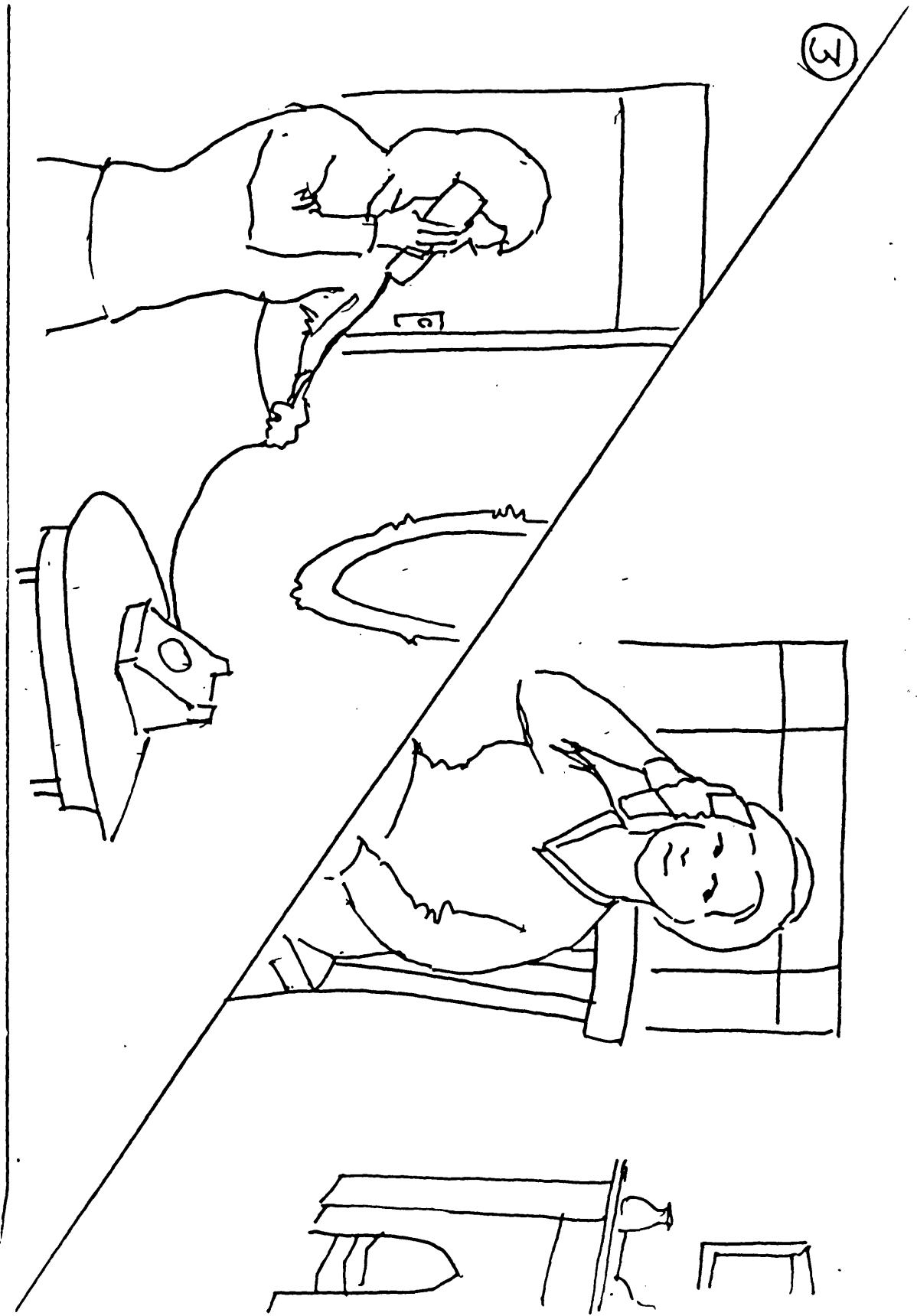
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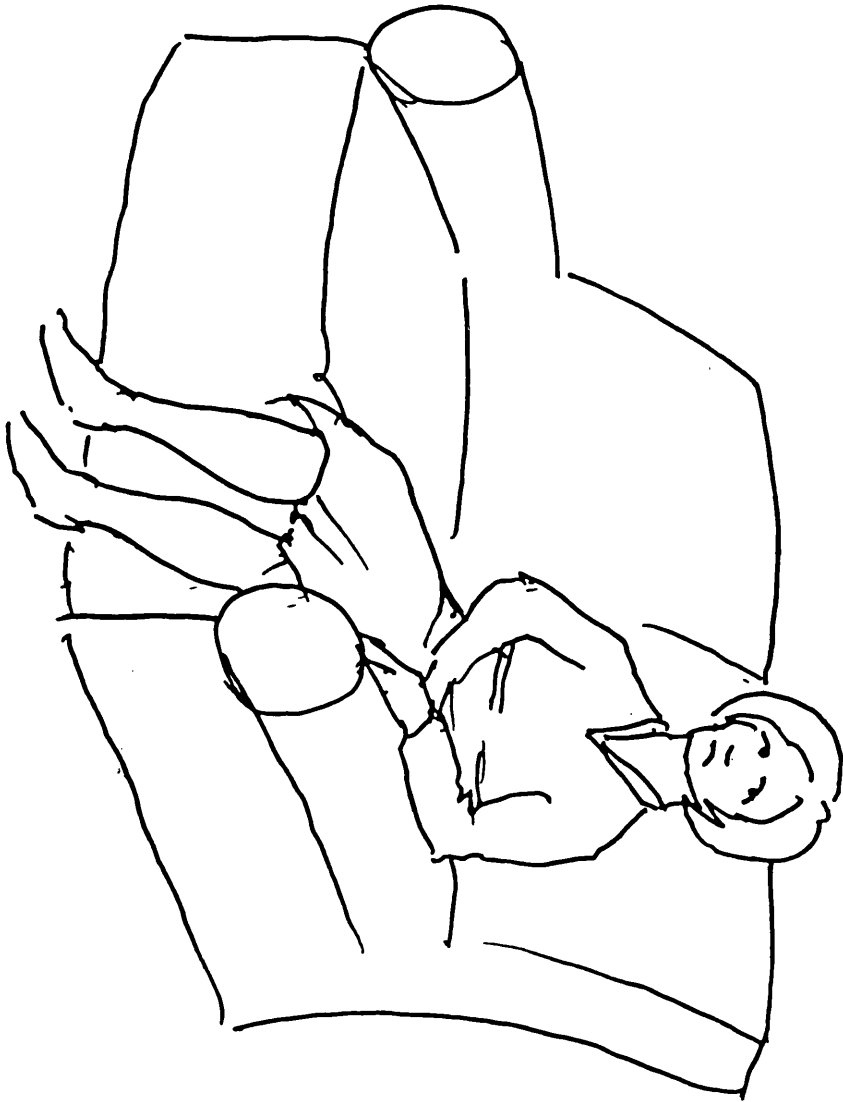
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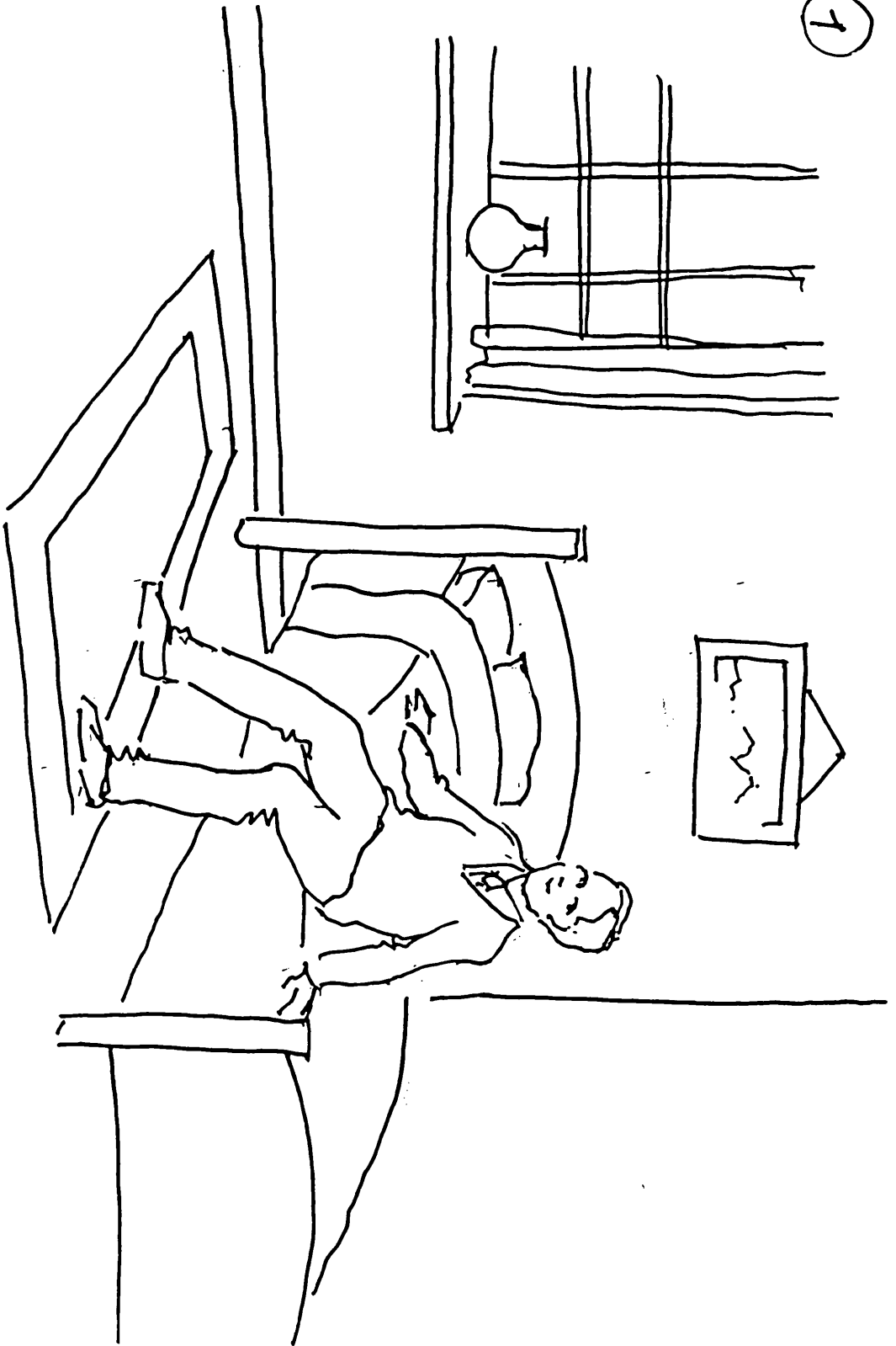
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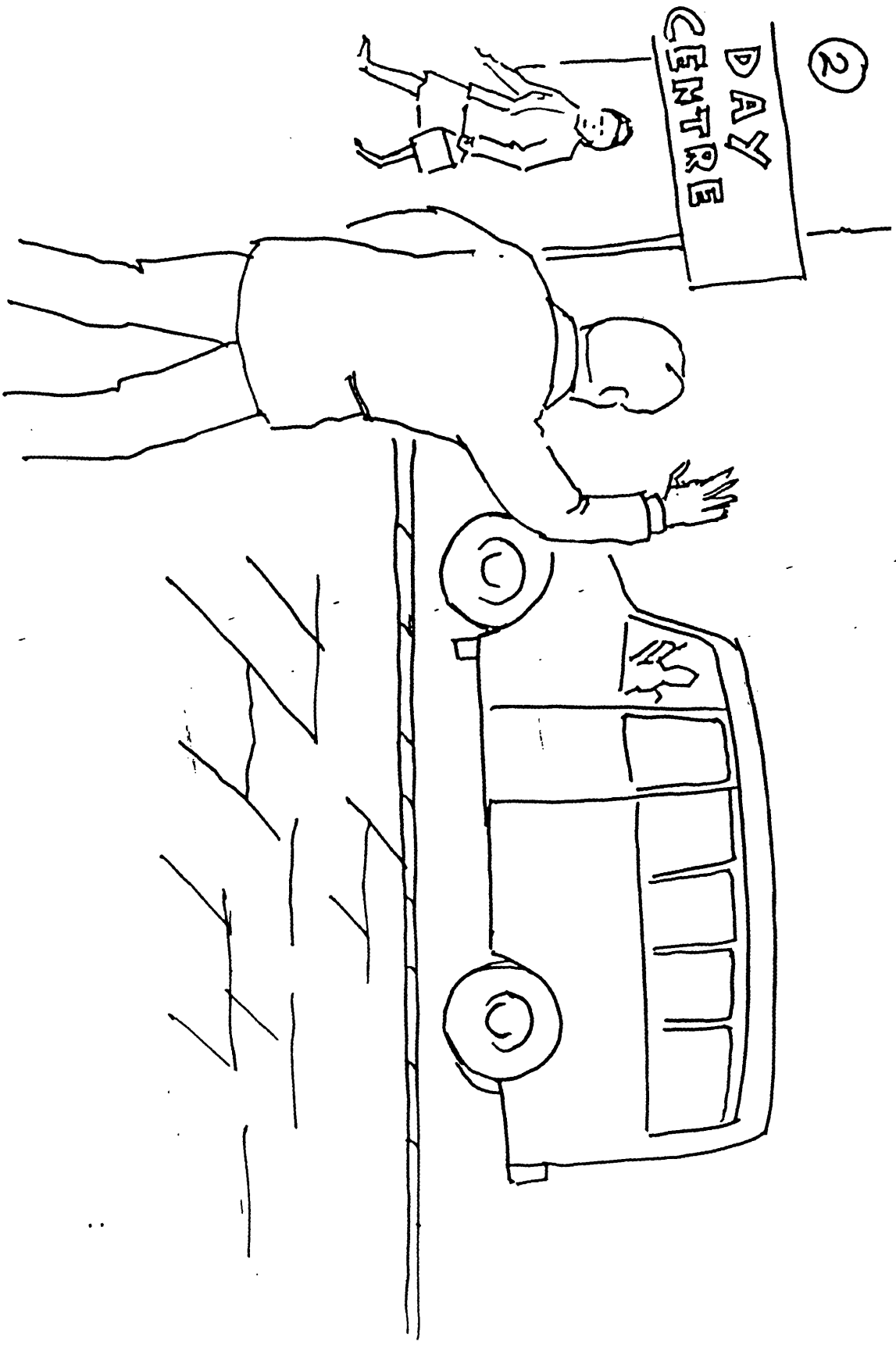


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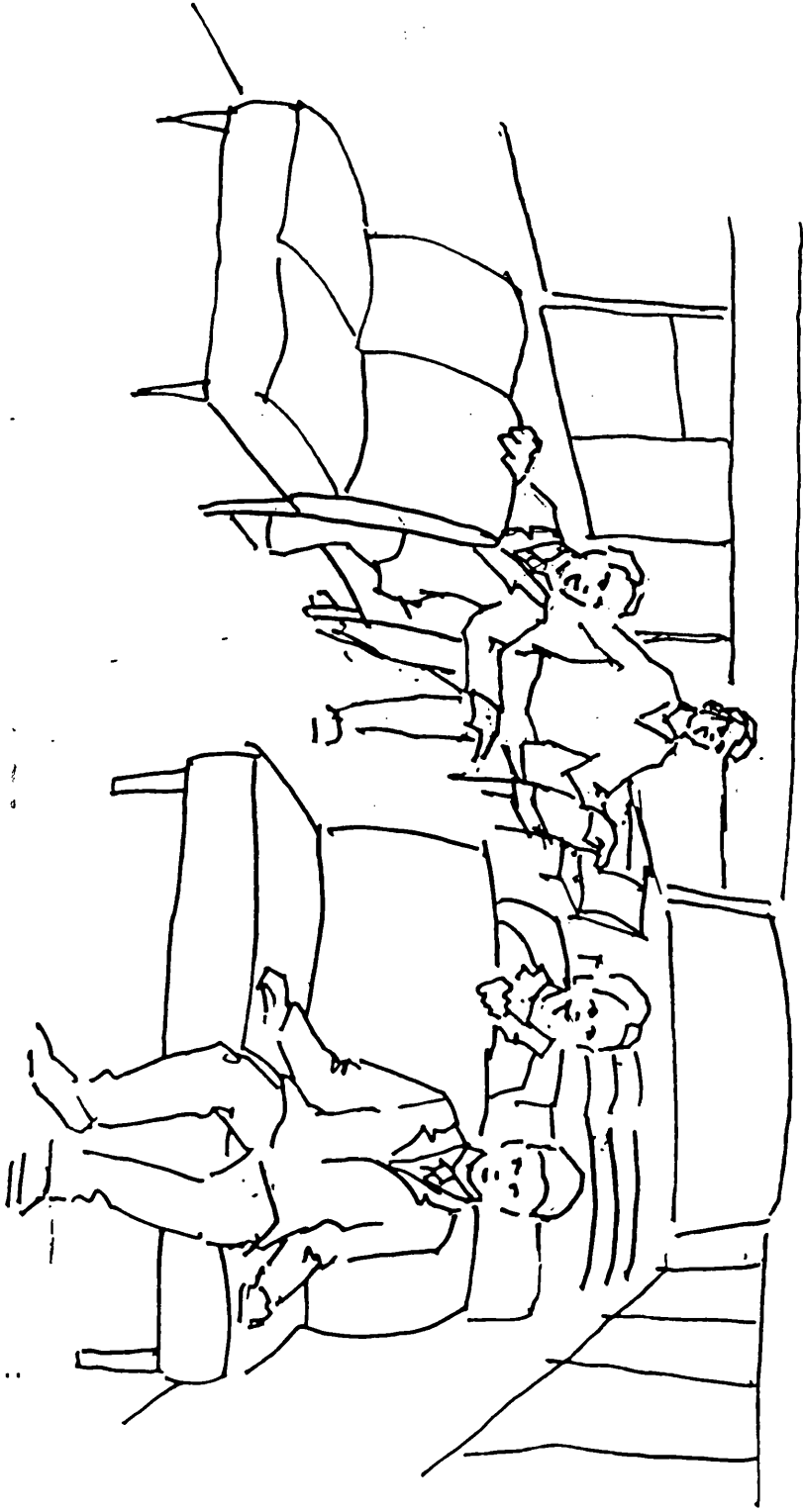


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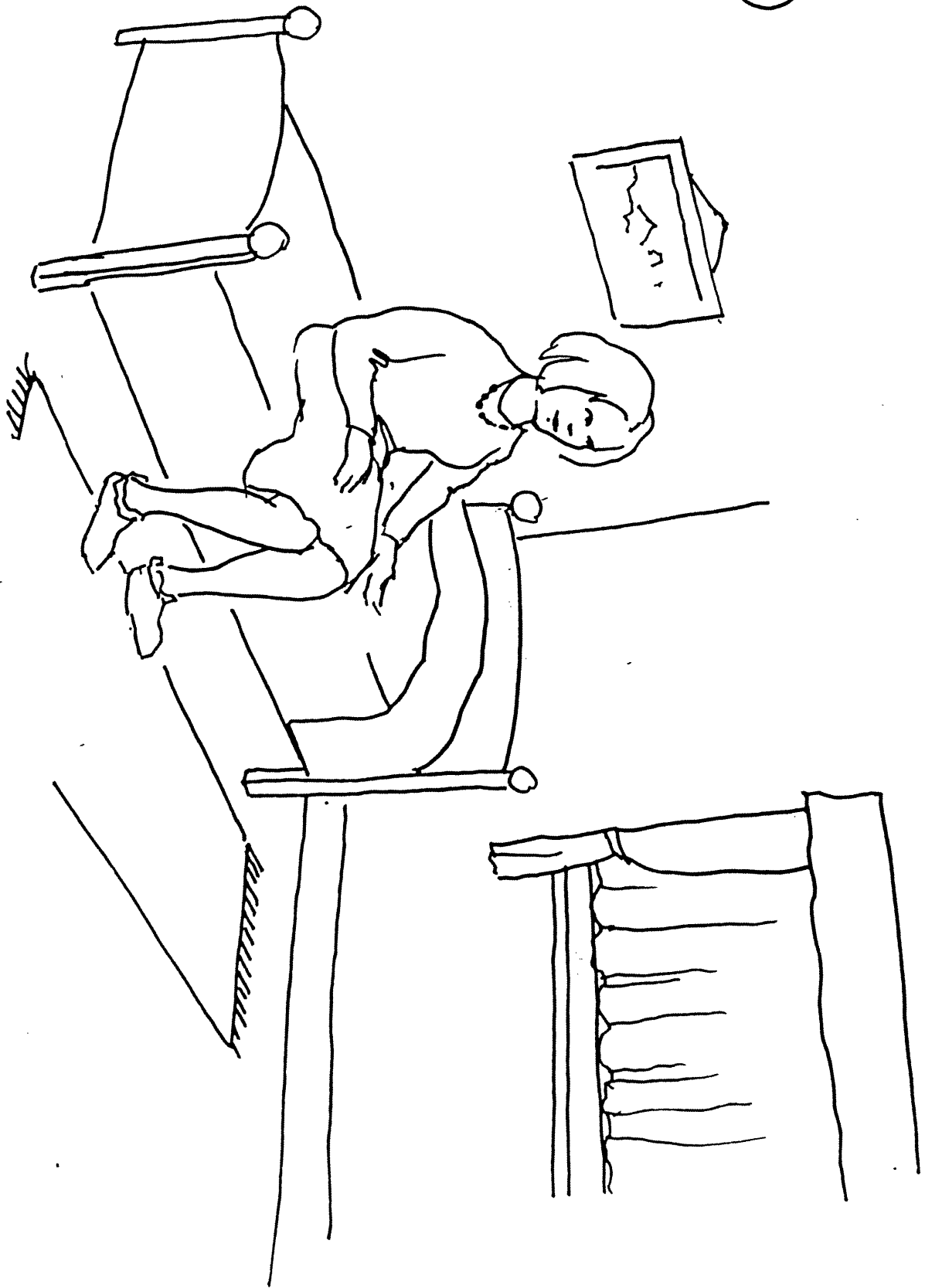
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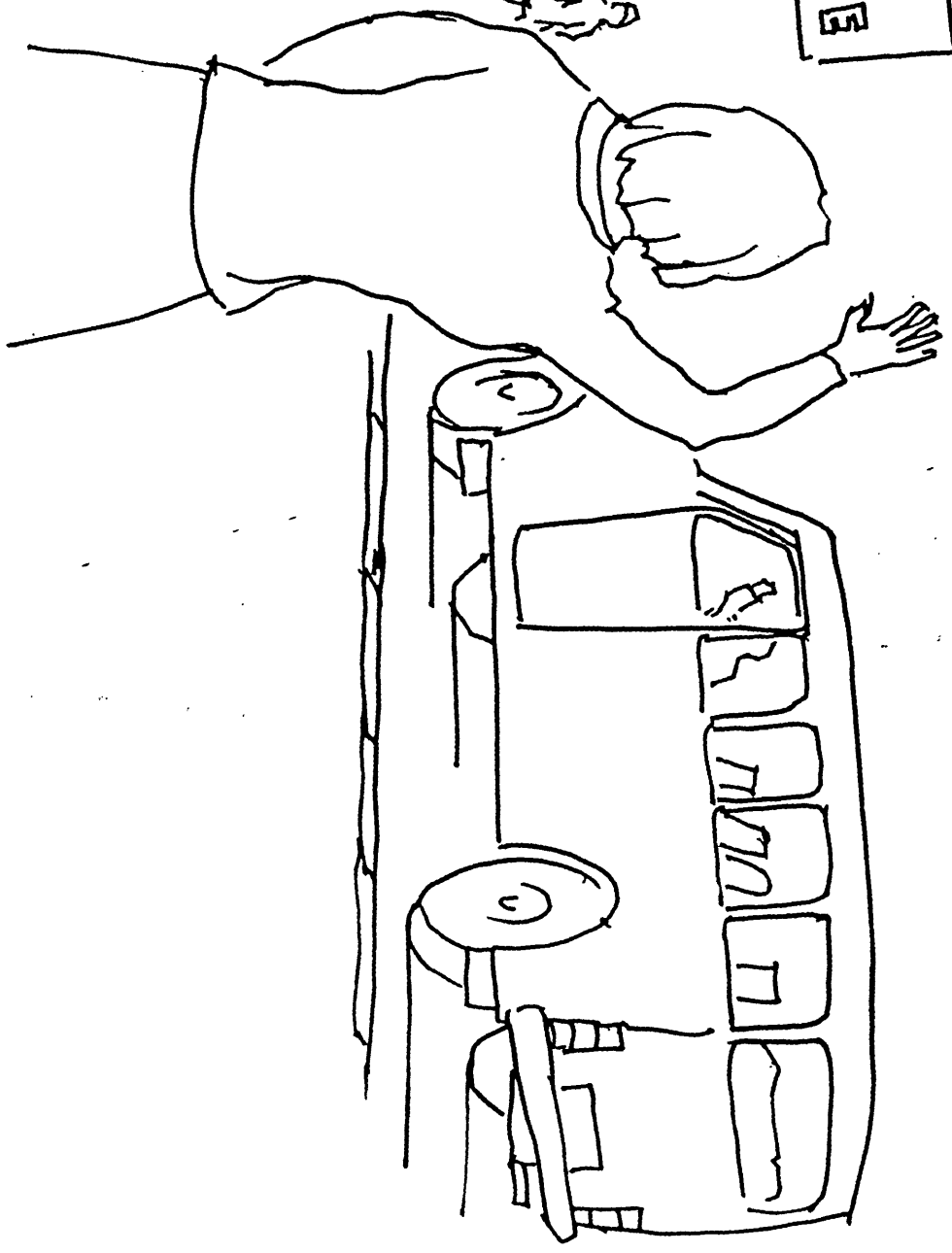
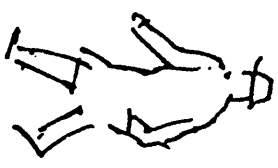
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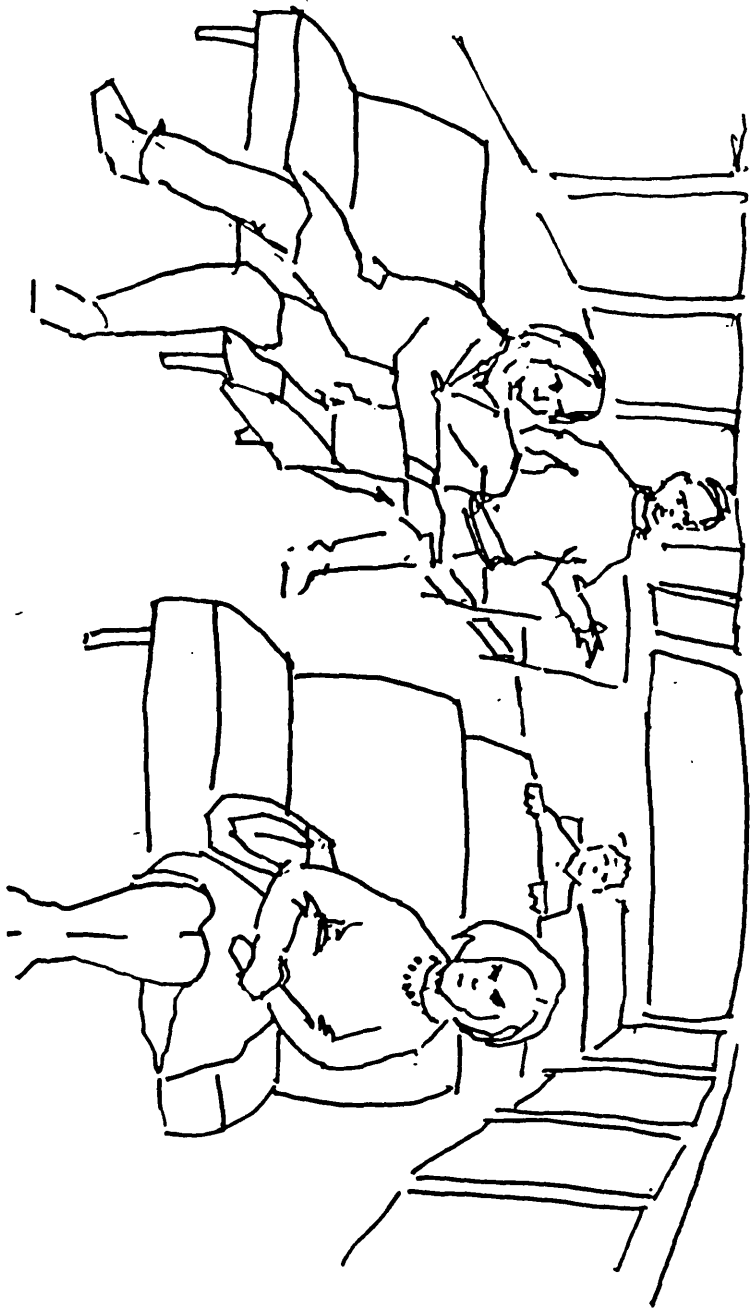
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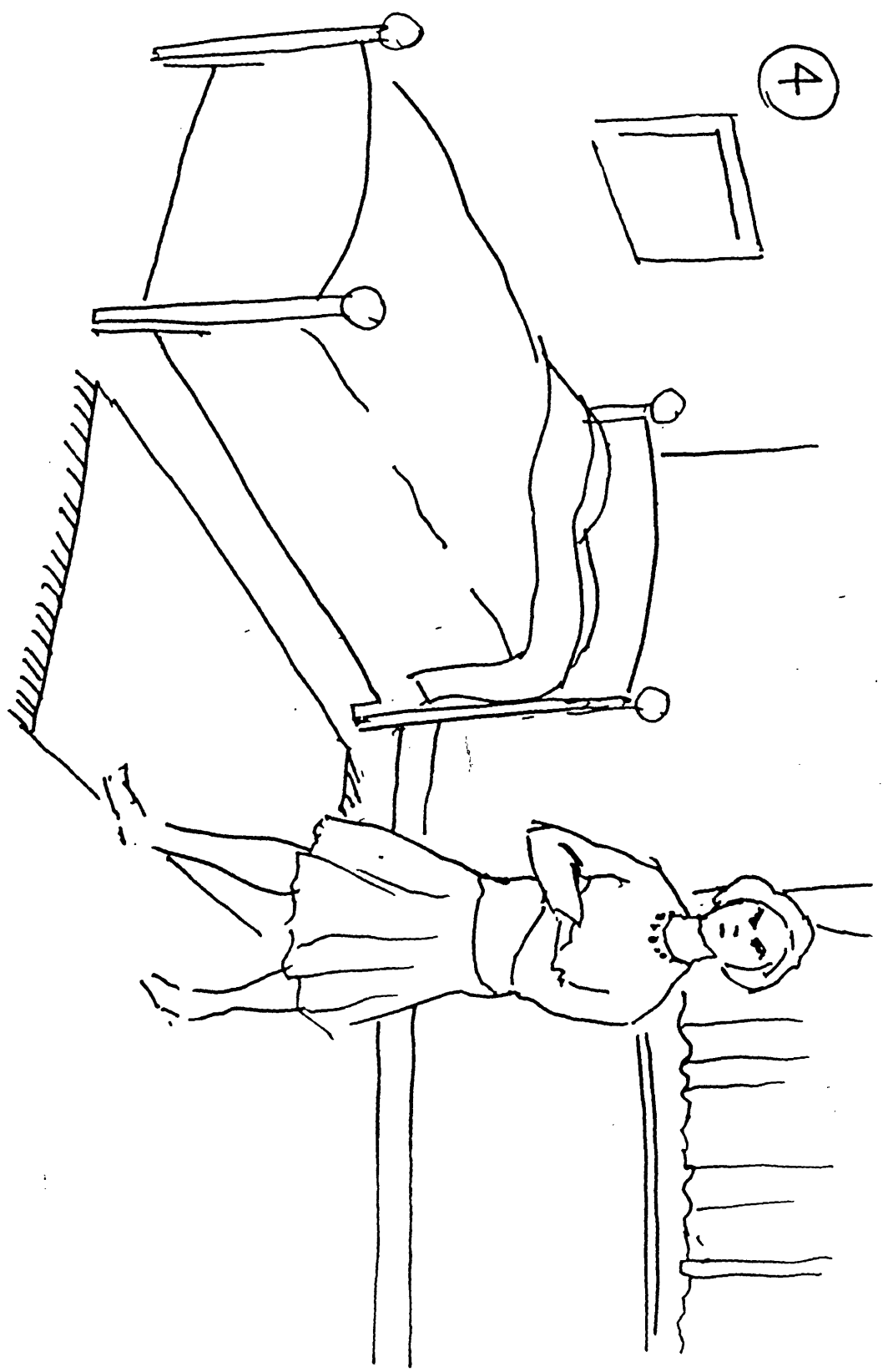


2)
DAY
CENTRE



3





4

Appendix 9:

Coding system for categorising participant responses

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Coding system for categorising participant responses

RESPONSE TYPE	EXAMPLE RAW DATA	CODE
'Cheering up'	'They told me to cheer up'	CHUP
'Calming down'	'I'd tell her to calm down'	CALM
Offering to make/making a cup of tea, coffee or alcohol; having a cigarette	'I'd make her a cup of tea'	DRIN
Self-management and activities that do not involve others	'I went for a walk'	SELF
Offered practical assistance	'She sent them away – she said she'd seen them and told them to go away'	PRAC
Give advice (behavioural)	'I'd tell her to 'phone a friend and ask them to come over'	ADBE
Give advice (cognitive)	'I'd say "don't worry about it"'	ADCO
Provide opportunity to ventilate/discuss feelings	'They sat down and talked with me quietly, and asked me "what are you angry about?"'	VENT
Presence ('being there')	'To be with people, to make them feel better'	PRES
Involve in social activities	'Thy took me to a disco'	SOCA
Distraction, ignoring it	'I'd tell him not to take any notice'	DIST
Getting someone else to help or do something for you	I'd want her to feel better – tell her that she needs help from staff, or a keyworker'	DOIT
Physical reassurance	'I'd give her a cuddle'	PHYS
No response offered	-	NONE
Don't know	'I don't know'	DK