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**Understanding the Lived Experience of Dementia in Individuals with Down  
Syndrome**

**By**

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**A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of  
Clinical Psychology**

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## **Dedication**

For my parents who taught me to always be curious.

## **Declaration**

The thesis was carried out under the supervision of Dr Sunny Kalsy and Dr Amanda Gatherer. Dr Sunny Kalsy also provided access to participants. Dr Stephen Joseph and Dr David Giles provided advice on analysis techniques carried out in chapters two and three. I carried out all the interviews and apart from these collaborations the thesis is my own work. Authorship of any papers from this work will be shared with Dr Sunny Kalsy and Dr Amanda Gatherer. The thesis has not been submitted for a degree to any other university. The literature review will be submitted to Qualitative Health Psychology, empirical research paper 1 will be submitted to the American Journal on Mental Retardation and empirical research paper 2 will be submitted to the Journal of Policy and Practice in Intellectual Disabilities.

All names and other means of identification have been removed to ensure participant anonymity.

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## Summary

Previously published studies have highlighted the increased risk of dementia in individuals with Down syndrome but little is known about the impact of the disease on their daily lives. The aim of this research was to explore the lived experience of dementia in people with Down syndrome. The literature review discussed the utilisation of qualitative interview methodology with individuals with expressive language deficits. It was concluded that, whilst such research remains relatively limited due to potential difficulties it presents, these challenges can and should be overcome in order to better understand the perspectives of those with limited communication skills. The first empirical research study conducted semi-structured interviews with 6 adults with Down syndrome and dementia. Accounts were analysed using Interpretative Phenomenological Analysis to gain a level of understanding concerning the impact of dementia upon respondents' lives and sense of self. Five main themes emerged: (1) Self-image, (2) The Relational Self, (3) Making Sense of Decline, (4) Coping Strategies and (5) Emotional Experience. Whilst the process of adjusting to dementia appeared comparable to the general population, the content of this was influenced by multiple levels of context specific to having a concurrent intellectual disability. The second empirical research study investigated the objective and subjective impact of dementia upon residential caregivers of individuals with Down syndrome, using questionnaire measures. Responses given by caregivers of individuals with Down syndrome and dementia ( $n = 9$ ) were compared with responses from those caring for recipients with Down syndrome and no additional cognitive decline ( $n = 11$ ). Findings suggested that, whilst there was little difference in the level of caregiving tasks or the perceived difficulties of caregiving, caregivers of individuals with Down syndrome and dementia reported increased levels of emotional

exhaustion. For both empirical studies, methodological issues and clinical implications were discussed. A reflective paper considered the process of conducting this research, including the development of the research question, the researcher's own position, issues of ethics, data collection, transcription, analysis and writing-up. The paper concluded by considering the impact of the research, both in wider context and on personal clinical practice, the impact of others on the research process and personal reflections.

## **Chapter 1**

# **Conducting Qualitative Interview Research with People with Expressive Language Difficulties – A Literature Review**

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## Abstract

Despite the increasing application of qualitative interviewing and analysis approaches, individuals with expressive language difficulties are still frequently excluded from such research. This article seeks to clarify the role for and importance of conducting qualitative interviews with respondents with impaired expressive language. Current research is reviewed with reference to studies conducted with individuals with intellectual disabilities, dementia or those who have experienced stroke or traumatic brain injury, and deficits are identified within existing research. The challenges and difficulties are considered that contribute to the limited inclusion of individuals with impaired expressive communication in qualitative interviews and the way forward is discussed with suggestions of possible means of overcoming these obstacles. It is argued that a willingness to adapt methodology appropriately and to modify expectations are important factors in ensuring that researchers hear the voice of respondents with expressive language deficits.

Qualitative interviewing and analysis techniques have increasingly been utilised within published research in recent years in order to obtain a more detailed and flexible understanding of individuals' beliefs, perceptions and accounts relating to particular issues. Studies applying such methodology now cover a vast range of issues, with the majority conducting semi-structured interviews in order to gain an in-depth account of the topic from participants (Patton 2002; Taylor and Bogdan 1998). Methods of analysis vary between differing qualitative approaches, ranging from a realist perspective seeking to uncover a factual account, to a relativist approach which rejects the assumptions of an underlying, independent reality (Barker, Pistrang and Elliott 2002).

A general consensus suggests that traditional criteria of validity and reliability utilised within quantitative research are unsuitable for the evaluation of qualitative studies (Smith 2003). Instead issues such as sensitivity to context, commitment, rigour, transparency and coherence have been identified as pertinent in assessing such research (Yardley 2000). In relation to the abilities or characteristics required of respondents participating within qualitative interviews, little has been written, which could suggest that there is no definite exclusive criteria. Yet within published research there is an identifiable and consistent pattern of recruiting only those individuals with the likely ability to articulate their views using a reflective, clear and articulate style (Paterson and Scott-Findlay 2002). In contrast, individuals with cognitive impairment whose ability to express themselves verbally is compromised have been included in qualitative interview research much less frequently. Such populations may include individuals with intellectual disabilities, dementia, those who have experienced traumatic brain injury (TBI) or strokes or have any neurological impairment resulting

in dysphasia. The extent to which qualitative interview research has been conducted within each of these groups is variable, however overall such research remains significantly limited compared with the general population.

This article offers a review of the literature with regards to the inclusion of individuals with expressive language difficulties in qualitative interview research. It seeks to establish the potential role for and importance of conducting qualitative interviews with individuals with impaired expressive language. The current situation is then described, drawing upon evidence relating to the above listed populations, whilst identifying the deficits within existing research. The article considers the possible challenges and problematic issues that may have led to the limited inclusion of individuals with expressive language difficulties in qualitative interviews. Finally, the way forward is discussed in terms of possible means of overcoming these obstacles.

Appropriate articles for this review were identified using the following databases; PsychINFO, Medline, Science Direct, Cochrane Library, AMED and IBSS. Articles were identified using the following search terms; qualitative research/interviews and language difficulties/language deficits/dementia/learning disabilities/intellectual disabilities/mental retardation/stroke/traumatic brain injury/aphasia/dysphasia. Only articles published between 1980 – present time were included. Search results revealed 97 relevant articles. The reference sections of these were then used to identify further pertinent articles. Articles were excluded if they could not be obtained in English language.

## Importance and Benefits

The benefits innate to qualitative interview research include its flexibility, the opportunity it provides to access meanings, perspectives and interpretations and embrace individual differences and its sensitivity to diverse forms of expression (Willig 2001). It would seem futile to apply these advantages only to those populations who are most verbally articulate and therefore deemed “easiest” to work with. In many respects the arguments for including individuals with expressive language problems in qualitative interview studies mirror those that could be applied to all other groups without such difficulties. However, there are also a number of additional and specific reasons why it would seem important to ensure that qualitative interview research is conducted with those who have communication problems. These are discussed below:

### *Understanding the Perspective of the Individual*

One means of overcoming the difficulties in attempting to interview individuals with expressive language problems has been to seek the views of carers or proxy respondents instead. Such representations provide more information about the experiences and subjectivity of the carers or proxies themselves than the individual (Kitwood 1993; Cohen 1994), and the only way to truly attempt to capture their perspective is to ask the individual to express it directly. It would seem particularly valuable to attempt to elicit the experiences and perspectives of individuals with expressive language difficulties, given the strong possibility that they may have problems making their voices heard in everyday life. It is difficult to respond adequately to the needs of a person when the understanding of their experience remains limited. This is particularly pertinent for individuals whose language

difficulties are linked to an ongoing process, such as dementia or TBI, requiring ongoing support and care. In the case of a progressive condition such as dementia, those encountering it have no realistic influence over their situation or the ultimate decline ahead, which is likely to result in feelings of awkwardness, futility and perplexity (Svanstrom and Dahlberg 2004). For this very reason it would seem all the more imperative for such individuals to have a voice to express these feelings and for their experience to be understood more clearly.

Cohen (1991) argues that whilst understanding of the cognitive challenges of dementia may have developed, this tells us little about how individuals adapt to living with a progressive degenerative brain disorder. The same could be argued for stroke and TBI survivors. Qualitative interview methodology aims to utilise listening techniques directed at enabling participants to express themselves freely and openly on their own terms (Swain, Heyman and Gillman 1998). The approaches also take into account psychological factors and are equipped to elicit emotional and intellectual dimensions (Howorth and Saper 2003). They should therefore be an ideal means of seeking the perspective of the individual and the fact that they may have some difficulty verbalising these perspectives or do so in more simplistic terms should not be regarded as an insurmountable barrier. Indeed, the limited amount of research conducted within this field thus far (see below for review), suggests that it is possible to elicit perspectives and experiences verbally from individuals with expressive language difficulties and that even in situations where this is accompanied by progressive cognitive impairment (e.g. dementia), a voice can still be found.

## *Improving Service Provision and Care*

The failure to seek an understanding of individuals' experiences beyond the results of medical, cognitive and functional assessments brings with it the risk of delivering inadequate care provision and support (Cohen 1991). Providing opportunity for a person to express and attempting to understand their thoughts, beliefs, feelings or desires can be an effective means of informing service provision, thus improving welfare and leading services to be more responsive, flexible and suited to individual needs (Cohen 1991; Keady, Nolan and Gilliard 1995). This is particularly pertinent given the recent emphasis on user involvement within mental health services (Cheston, Bender and Byatt 2000; Pilgrim and Waldron 1998).

In the limited amount of research that has been published, success has been reported in using qualitative interview techniques to elicit the perspectives of users with expressive language impairment (e.g. Carnaby 1997; Cheston, et al 2000; Mozley et al 1999; Stalker Gilliard and Downs 1999). Holst and Hollberg (2003) suggested that reactions and adjustment to dementia varies between individuals and therefore a case-specific approach is required in order to achieve the best care provision. The same can be argued for adjustment to life after a stroke or TBI. Faircloth et al (2004) conducted a qualitative study with stroke survivors and emphasized the importance of taking into account differences in individual's biographical construction of the lived self, which are largely ignored within published research. They suggested that treating all survivors as a homogenous group leads to the exclusion of significant aspects of survival experience and can result in poorly designed interventions and low outcomes. Such research has indicated that qualitative interviews are a good method of exploring and devising the best approach to understanding and engaging with information

concerning individual differences. This information could then be applied to consider how service provision can be modified to account for these.

### *Challenging Disempowerment*

By the very nature of their difficulties, those with expressive language deficits have a limited voice and are therefore vulnerable to being disempowered and marginalized within society. Swain et al (1998) have argued that the difficulties presented by conducting qualitative interview research with people with intellectual disabilities should be viewed as a challenge that needs to be addressed in order to avoid the essentially political act of research further perpetuating disempowerment and oppression. The same can be argued for the need to include other groups of individuals, whose limited expressive language has thus far led to limited research being conducted. Historically, the suggestion that such individuals are not lucid or articulate enough to express their own views and perspectives has also been previously linked with almost every disempowered group in society, including those with mental health difficulties, children and women (Proctor 2001).

By overlooking an individual's personal response and perspective on the basis of an assumed inability to communicate, the individual becomes marginalized and made invisible by the labels of their condition or situation (Gillies 2000). Failing to seek a means of overcoming the challenges presented by including those with expressive language difficulties in qualitative interview research is simply another means of conspiring with this stance. Equally, as will be discussed later, individuals with expressive language difficulties are likely to become vulnerable to secondary handicap as a result of negative social or environmental responses (Proctor 2001).

This has been defined as defensive exaggerations that increase the apparent severity of a primary disability (Sinason 1992). Whilst this poses additional complications for the interview process, failing to attempt such research for this reason can be seen as simply compounding the causes of secondary handicap. Sinason (1992) has described “mild secondary handicap,” when individuals compliantly exacerbate their original difficulties to please the outside world, and argued that this has a wider political application. Only by validating individuals can negative attitudes be challenged. Kitwood (1990; 1997) has outlined the concept of a “malignant social psychology” to which people with dementia are frequently subjected and which results in consequences such as disempowerment, labelling, infantilisation, stigmatisation, invalidation, ignoring and objectification. Individuals with intellectual disabilities or other forms of neurological impairment may be equally vulnerable to this. As a solution, a “helpful and empowering social psychology” was recommended (Kitwood and Bredin 1992a; 1992b). It has been proposed that the first stage in achieving this is listening to the views of individuals themselves (Killick 1997; Proctor 2001). The objectification of individuals with intellectual disabilities has also been described by Gillman, Swain and Heyman (1997), who highlighted “the tyranny of professional discourses” as a factor. Moreover, Oliver (1992) suggested that disability research should be seeking to learn from feminist research paradigms in facilitating processes of emancipation, empowerment and combating oppression. This process is easier to consider for the area of intellectual disabilities, where self-advocacy and user involvement has increased over recent years, than for individuals with degenerative difficulties such as dementia. However it is argued that the process of empowerment can and should begin simply by providing individuals with a voice and the right to

express their own perspectives (Morris 1992; Shakespeare 1996). This can be facilitated through the process of qualitative interviews.

Such research also needs to be designed to take into account cultural and ethnic diversity. It has been argued that procedural norms, related to the view of science as an institutionally structured social process, have resulted in persistent cultural insensitivity within research (Rogler 1999). This is likely to result in the subjugation of those with minority status within society or culture. As a result of its flexibility, qualitative interview research should be sensitive to all forms of diversity and this should equally apply to research undertaken with individuals with expressive language difficulties.

### **Current Research**

A metasynthesis of 293 qualitative studies within the area of chronic illness found that few of these involved respondents who were not considered to be well educated and communicative (Thorne and Paterson 2000). The authors argued that this tendency to focus only on individuals who were articulate and reflective, provided little insight into the experiences and perspectives of those with more limited communication styles. Whilst a deficit clearly exists in qualitative interview research with regard to people with impaired expressive language, a review of recent literature indicates a growing number of such published studies. However such research tends to be based within a particularly narrow context of western society and therefore does not take into account factors such as cultural diversity. The current situation regarding the qualitative interview research involving several populations who frequently experience communication difficulties is outlined below:

## *Intellectual disabilities*

The communication difficulties commonly observed within people with intellectual disabilities have been frequently documented in published research. These include limited understanding of more complex grammatical phrases or abstract concepts and difficulties verbalising responses that are content specific to the situation (Abeduto and Hagerman 1997; McLean, Brady and McLean 1996; Bedrosian 1993; Brinton and Frujiki 1993; 1994). Inevitably this results in expressive language that is compromised in its content and richness, although clearly the extent of this varies with level of individual cognitive impairment.

In terms of individuals with expressive language difficulties, people with intellectual disabilities have perhaps most frequently been included in qualitative interview studies in recent years and face-to-face interviewing is the technique most commonly used to elicit their perspectives (Myers et al 1998). Such research has covered a range of topic areas, including experiences of personal relationships (Lofgren 2004; Pottie and Sumarah 2004), employment and education (Cinamon and Gifsh 2004; Li 2004 Hamil 2003; Hagner and Davies 2002; Morningstar Turnbull and Turnbull 1996), social integration (Mactavish, Mahon and Lutfiyya 2000), parenting (Kroese. Hussein, Clifford and Ahmed 2002), beliefs regarding experienced difficulties (Harker-Longton and Fish 2002; Ruef and Turnbull 2002), service evaluation (Macdonald, Sinason and Hollins 2003; Koch, Marks and Tooke 2001; Carnaby 1997; Hagner, Helm and Butterworth 1996; Mcvilly 1996; Mishna 1996), family life (Poston et al 2003), leisure (Rogers, Hawkins and Eklund 1998) and self identity (Meadan and Halle 2004; Scior 2003; Higgins, Raskind, Goldberg and Herman 2002; Thompson 2002; Davies and Jenkins 1997). A number of papers have emerged

explicitly discussing the methodological issues that arise when seeking to conduct qualitative interviews with people with intellectual disabilities and proposing strategies that could be applied to overcome difficulties (Finlay and Lyons 2001; Booth and Booth 1996; Biklen and Moseley 1989).

Established methods of qualitative analysis have also been applied successfully within a number of the existing studies, including narrative techniques (e.g. Booth and Booth 1996), interpretative phenomenological analysis (e.g. Macdonald, Sinason and Hollins 2004), phenomenographic methodology (e.g. Harker-Longton and Fish 2002), constant comparative methodology (e.g. Li 2004; Rogers et al 1998), content analysis (e.g. Li 2004), life history research (e.g. Goodley 1996) and discourse analysis (e.g. Scior 2003). This could be seen as challenging conventional wisdom suggesting that accounts provided by individuals with intellectual disabilities are not sophisticated enough to be subjected to formal analysis techniques.

Despite these promising recent developments, it is clear that the quantity and range of qualitative interview studies conducted with people with intellectual disabilities still remains limited compared to those carried out within the general population. Equally, it should be noted that a number of these existing studies focus on people categorised as having mild intellectual disabilities (e.g. Cinamon and Gifsh 2004; Morningstar et al 1996; Li 2004), thus suggesting that the views of those at the more severe range of the spectrum are still being neglected.

## *Dementia*

A growing body of research has been produced concerning illness narratives and the subjective experiences of individuals with chronic diseases or ailments (e.g. Kleinman 1988; Good 1994; Garro and Mattingly 1994). However, comparably few studies have explored the experiences, emotions and beliefs of individuals suffering from dementia. As a result of this, whilst the aetiology of dementia had become well established, until recently, little was known about how people experiencing dementia lived with the illness on a daily basis or the meanings it held for them (Phinney and Chelsa 1993). The progressive and global cognitive and functional decline resulting from dementia has led to assumptions that individuals experiencing this are not coherent or lucid enough to express their own views or perspectives (Proctor 2001). Thus there has been a tendency to rely upon the proxy opinions of carers (e.g. Bamford 1998; Gilleard, Gilleard, Gledhill and Whittick 1984; Levin, Sinclair and Gorbach 1989). However, these representations are likely to provide more information about the experiences and subjectivity of the carers themselves than that of the individual with dementia (Kitwood 1993; Cohen 1994).

In recent years a growing attempt has been made to develop a greater understanding of this area. Several recently published studies have applied qualitative interviews to explore the perspectives of people with dementia. The focus of this research has included the daily experience of living with dementia (Gillies 2000; Menne, Kinney and Morhardt 2002; Nygard and Borrell 1998; Phinney and Chelsa 2003; Quayhagen and Quayhagen 1996; Robinson, Ekman and Wahlund 1998; Svanstrom and Dahlberg 2004), insight and awareness into symptoms of dementia (Clare 2002a; 2002b; 2003; Howorth and Saper 2003; Phinney 2002), coping strategies (Clare 2002a; Pearce,

Clare and Pistrang 2002), the impact of dementia on sense of self (Beard 2004; Harris and Sterin 1999; Holst and Hallberg 2003), spiritual beliefs of individuals with dementia (Katsuno 2003), the experiences of younger people living through the dementia process (Beattie, Daker-White, Gilliard and Means 2004), the perspectives of women with dementia (Proctor 2001) and perceptions of service provision (Aggarwal et al 2003). Within some of these studies, information obtained through interviewing was also supplemented with additional data collection means, such as participant observation (e.g. Nygard and Borell 1998) or additional interviews with carers (e.g. Quayhagen and Quayhagen 1996, Svanstrom and Dahlberg 2004). This suggests that interview accounts provided by individuals with dementia alone were deemed as potentially insufficient. Nevertheless, a range of qualitative analysis methods have been successfully applied to interview transcripts elicited from individuals with dementia, including interpretative phenomenological analysis (e.g. Clare 2002a; 2003; Pearce et al 2002), comparative contextual analysis (e.g. Beattie et al 2004), thematic coding (Aggarwal et al 2003; Gillies 2000) and grounded theory (e.g. Beard 2004).

It should be noted that the majority of the studies reviewed here focused only on individuals with early to mid stage dementia, presumably because of the likelihood that their communication and comprehension skills would be less impaired. Equally, despite the fact that research has established that the occurrence of dementia is significantly greater in individuals with Down syndrome than in the general population (Zigman, Schupf and Haveman 1997), no previous published attempt has been made to utilise qualitative interview techniques with this group.

## *Stroke*

Neurological damage retained during a stroke may result in language impairment (Ross and Wertz 2001). Research has indicated that both the severity of impairment sustained and the extent to which individuals recover from this, differs significantly between stroke types (Ross and Wertz 2001). A limited but growing number of studies have utilised qualitative interview techniques in an attempt to capture the experience and perceptions of individuals who have survived a stroke (e.g. Bays 2001; Clarke 2003; Cox, Dooley, Liston and Miller 1998; Dowswell, Dowswell, Lawler, Green and Young 2002; Faircloth, Rittman, Boylstein, Young and Van Puymbroeck 2004; Haeggsrtoem et al 1994; Kvigne and Kirkevold 2003; Lilley, Lincoln and Francis 2003; MacLean, Pound, Wolfe and Rudd 2000; Murray and Harrison 2004; Pound, Bury, Gompertz and Ebrahim 1994; Pound, Bury, Gompertz and Ebrahim 1995). The extent to which the participants within these studies experienced expressive language difficulties was not explicitly outlined, implying a tendency to recruit participants for whom this was not an issue. Many of the interviews took place several months, or even years after discharge from hospital when participants had frequently resumed a number of routines present prior to their stroke. Faircloth et al (2004) reported that 70% of participants they interviewed were currently still in paid employment outside of their home. Equally, in a study relating to perceptions of the value of physiotherapy, Pound et al (1994) reported that those who agreed to participate within the study were less likely to be disabled by the effects of their stroke than those who declined. This suggests that sampling bias may also originate from a reluctance to participate in individuals who have acquired language impairments.

## ***Traumatic Brain Injury***

A range of language deficits, including expressive language difficulties have been described as a consequence of traumatic brain injury (TBI) (e.g. Rey et al 2001; Miceli 2000). A study exploring the long-term cognitive-communicative impairments of people following a severe cerebral insult concluded that they frequently experienced significant communication difficulties. When combined with additional factors such as fatigue and memory deficits this regularly led to unsatisfactory interpersonal communication experiences (O’Flaherty and Douglas 1997).

A relatively small number of published studies have undertaken qualitative interviews with individuals who have sustained a TBI in an attempt to explore their views and experiences (e.g. Conneely 2003; Darragh, Sample and Krieger 2001; Nochi 1998a, 1998b, 2000; O’Flaherty and Douglas 1997; Paterson and Scott-Findlay 2002). It is unclear from many of these the extent to which expressive language was a difficulty for the respondents recruited. Nochi (2000) acknowledged that their participants were not representative overall of the TBI population and were selected for their level of self-awareness, insight and interest in verbally reflecting on their experiences. A study reviewing the challenges of interviewing TBI survivors, and calling for further inclusion of participants with communication impairments, also nevertheless reported that respondents were still screened for cognitive and speech impairments before being recruited to the research (Paterson and Scott-Findlay 2002).

## **Difficulties and Challenges**

Limited language ability has frequently been cited as an impediment to eliciting valid responses when conducting qualitative interviews (Perry and Felce 2002) and this is

likely to explain the paucity of such research carried out with these populations.

Potential difficulties and challenges that may occur are outlined within this section.

### *Credibility of Interview Responses*

In the case of the populations being considered within this review, expressive language difficulties are also accompanied by varying degrees of cognitive deficit.

This presents the somewhat complex dilemma of determining the extent to which an individual's response is being limited by their inability to fully express themselves verbally, and how much it simply reflects a lack of comprehension or insight. The greater extent to which the latter applies may mean that responses are viewed as being less credible or meaningful.

Factors outlined that may effect the credibility of qualitative accounts given by individuals with expressive language and cognitive impairment include poor or inconsistent memory for events (Hubbard, Downs and Tester 2003; Paterson and Scott-Findlay 2002), lack of insight or awareness (Keady 1996; Paterson and Scott-Findlay 2002), confabulated or meaningless responses (Cohen and Eisdorfer 1986), poor temporal orientation (Biklen and Moseley 1988; Flynn 1986), difficulty in responding to abstract or socially reflexive questions or those relating to unfamiliar situations (Booth and Booth 1996; Finley and Lyons 2001; Szivos-Bach 1991) and a tendency towards acquiescence when more direct questions are used (Heal and Sigelman 1995; Sigelman et al 1980; 1981a; 1981b).

### ***Richness of Data***

Impaired language ability is frequently regarded as a key impediment to eliciting valid responses via interview (Perry and Felce 2002) and in part this relates to concerns that less articulate participants will be unable to produce adequate responses at a level rich enough for qualitative analysis. In terms of individuals with intellectual disabilities, it has been reported that open-ended questions frequently result in limited responses, with many individuals either unable to answer or providing little information (Biklen and Moseley 1988; Sigelman et al 1981a, 1981b; 1982). Equally, dementia is often characterized by vague and empty speech, dwindling vocabulary and disordered speech patterns (Bourgeois 1991; Whitehouse et al 1997). These characteristics would compromise the ability to respond with fluency to open questioning. Finally, a qualitative study with survivors of TBI reported that as the interviews progressed, responses became increasingly succinct and concrete and less focused (Paterson and Scott-Findlay 2002).

### ***Researcher Interpretation***

Goodley (1996) argued that the risk of researchers imposing their own perceptions and interpretations onto the accounts of respondents was increased when participants were less verbally articulate and responses more difficult to comprehend. The researcher's position within the dominant political and social framework may also lead to biases in interpretation. It has been argued that research is often dominated by a biomedical model that is heavily tainted by ageist cultural and social values (King 1997). This potentially compromises the aims of conducting qualitative interviews if

the final analysis reflects the researcher's concerns and views more than it does the participants'.

### *Secondary Handicap*

Expressive language difficulties, particularly when accompanied by other cognitive and functional deficits, may also be associated with the additional presence of presentations associated with secondary handicap. This has been described as additional limitations primarily related to society's negative attitudes towards such individuals (Proctor 2001; Sinason 1992). In terms of dementia, it has been argued that decline results not only from degenerative neurological processes, but also from the reactions of others to this impairment and the quality of a person's environment (Sabat and Harre 1992; Kitwood and Bredin 1992a; 1992b). This may equally be argued for individuals with intellectual disabilities or survivors of neurological damage from stroke or TBI. Clearly such responses are likely to be transferred into the interactions taking place within qualitative interviews and may further limit or impair the participant's responses. Power imbalance within the research relationship has also been highlighted as a common issue and may further exacerbate the factors associated with secondary handicap, such as the desire to present oneself in the way others appear to expect. Proctor (2001) interviewed women with dementia and described their frequent concern that their responses would be incorrect, despite the researcher's emphasis on the fact that there were no correct answers and they were simply seeking the individual's experiences. Participants may also view the interviewer as a health professional with potential influence over their care or service provision.

## *Consent*

Informed consent is a fundamental basis for ethical research and this becomes more pertinent when the participants involved have expressive language difficulties that may impair their ability to fully express their concerns or reservations, particularly when this is also accompanied by cognitive impairment. Competence to provide full and informed consent has been described as a dilemma for interview research conducted with individuals with dementia (Reid, Ryan and Enderby 2001) and people with intellectual disabilities (Swain et al 1998). In terms of individuals with dementia, Cheston et al (2000) argued that the factors that made it important to seek the views of these individuals (e.g. the nature of their impairment) also made them vulnerable to abuse regarding consent. This is equally applicable to other individuals with expressive language difficulties and increases with the degree of cognitive impairment.

### **The Way Forward: Overcoming the Challenges**

The act of conducting qualitative interviews with individuals with expressive language difficulties indicates recognition of the fact that they have both important views and perspectives worth eliciting and the ability to articulate these in a way that can be comprehended (Cheston et al 2000). For individuals whose limited expressive language skills frequently result in them not being heard as people in their own right, the significance of this cannot be underestimated and failing to take this stance suggests depersonalisation. Whilst expressive language impairment may make communication more difficult within qualitative interviews, it does not make it impossible. It can be argued that it is the response of those who do not listen carefully enough that transforms this difficulty into a handicap (Cheston et al 2000).

This emphasizes the importance of identifying remaining communication assets and enabling individuals to express themselves as fully as possible. Equally, it could be that rather than accepting only a temporally coherent narrative, researchers need to consider alternative ways of articulation when attempting to capture the experience of individuals with communication difficulties. Cohen (1995), in arguing the need for more research into subjective experience of dementia, has suggested that seeking to hear a person's "voice" rather than obtain their narrative is a more suitable approach. This does not necessarily presume temporal coherence but still suggests dialogue and is premised on the acts of communication and listening. Indeed, it has been suggested that the lack of knowledge on subjective experience of dementia in the general population may be partly attributed to researchers' inability to listen rather than the inability to communicate in those affected (Cohen 1995). This criticism may easily be applied to the gaps in our understanding related to others with expressive language problems. Booth and Booth (1996) suggest that too frequently the difficulties in interviewing those who are less articulate are viewed in the context of their deficits not in that of the limitations of the methodology being used. Therefore the way forward should focus not on further legitimising the exclusion of individuals with expressive language deficits from qualitative interview research, but in finding effective means to overcome the challenges posed by their inclusion. The challenges and difficulties identified previously will now be revisited in terms of strategies that could be applied to overcome them.

### *Credibility of Interview Responses*

In considering the credibility of accounts given by individuals with dementia, Stalker Gilliard and Downs (1999) argued that researchers needed to question whose reality

they were working within. Views expressed by individuals at any given time arguably represent some aspect of their reality and perspective. It may be more useful for qualitative research to focus upon the value of this and look for reasons behind the telling of particular stories when communicating with those with expressive language difficulties. This avoids attempts to reconstruct the truth and the devaluation of accounts on the basis that they may not fit with external perceptions. Qualitative techniques such as discourse analysis do not seek to establish an objective reality from individual's responses but focus instead on the meaning they give to events and the way in which accounts are constructed (Scior 2003). This may be a useful means of conducting qualitative interview research with those whose cognitive, as well as expressive language problems, lead to doubts concerning the reliability of objective details within their communication. By their very nature qualitative research techniques are less concerned with traditional positivist criteria regarding reliability and more focused upon reinterpreting findings from a different position or exploring similar issues in different contexts than expecting or desiring consistent accounts (Banister, Burman, Parker, Taylor and Tindall 1994).

It is also possible that poorly expressed or ambiguous questions within interviews may lead to confusion or confabulation. It is argued that research findings regarding high incidence of acquiescence in people with intellectual disabilities may, in part, be attributable to the illogical or contradictory nature of some of the questions used leading to uncertainty and confusion (Simons, Booth and Booth 1989). Rapley and Antaki (1996) argued that many of the conversational strategies expressed by individuals with intellectual disabilities were also present within repertoires of people in the general population and that researchers needed to adopt a more respectful

approach. Consistency could also be sought by interviewing on more than one occasion (Cheston et al 2000), although variations may equally reflect changes in perception over time.

### *Richness of Data*

The argument that data elicited from individuals with expressive language deficits may be inappropriate for formal qualitative analysis is disputed by studies previously published applying such techniques. Interviewers need to be aware of the extent to which their own communication styles and interview schedules may affect the quality of participant's responses. The phrasing of questions may be particularly important and despite suggestions that open-ended questions may be problematic, Finlay and Lyons (2001) reported that many individuals with intellectual disabilities were able to respond appropriately to this question style as long as complex concepts were avoided and sentence structure was clear.

Prout and Strohmer (1994) emphasize the importance of considering the expressive-receptive language dichotomy within individual abilities and suggest that more directive interview styles may be appropriate for those with limited expressive skills. Whilst this is not the traditional means of conducting semi-structured interviews, flexibility is required in order to ensure maximum inclusion for those whose language abilities are less fluent. It is suggested that more direct questions may trigger "script knowledge" (general memory for events) within individuals that they are likely to be able to verbalise more easily (Docherty and Sadelowski 1998). Meeting with respondents prior to the interview has also been suggested as a good way of establishing rapport, gauging an individual's expressive skills and adjusting question

style accordingly (Barnes 1992; Stalker et al 1999; Worth and Tierney 1993). The use of photographs as a prompt and aid to comprehension is a further possibility (e.g. Carnaby 1997).

Where qualitative interview techniques do appear likely to yield very limited data because of an individual's language or cognitive limitations, they could be supplemented with additional qualitative techniques to enhance understanding.

Hubbard, Downs and Tester (2003) combined interviews and observations within an ethnographic framework in a study with people with dementia. They suggested that this allowed them to include the views of individuals who were unable to respond to formal interview techniques. By conducting a series of very brief conversational interviews in the observational setting data was collected which yielded identifiable themes and interpretations.

### ***Researcher Interpretation***

The possibility of the researcher imposing their own views and perspectives onto the accounts of respondents is an innate risk within qualitative techniques and whilst it may be increased when participants have expressive language difficulties, it can still be addressed with the same strategies utilised at any other time. Reflexivity and ensuring the researcher owns their own positions and perspectives are vital aspects of this (e.g. Proctor 2001). The possibility of discussing findings with participants following analysis and incorporating their comments into the final account has also been suggested (Barnes 1992). This may become complicated however, when the participant is experiencing memory deficits likely to impair their recollection of the initial interview. Finally, many qualitative techniques (e.g. interpretative

phenomenological analysis) take into account the fact that access to the perception of others is affected by the researchers own conceptions and analysis is viewed accordingly (Smith and Osborn 2003).

### *Secondary Handicap*

An awareness of the possibility that issues relating to secondary handicap may be displayed during the interview process is of great importance but, far from providing a reason not to conduct qualitative interviews with individuals susceptible to presenting with this, it only further underlines the importance of doing so. The stigmatisation, disempowerment and marginalisation which forms the basis for the development of secondary handicap can only be challenged by providing people with a voice to express the perspectives that are truly theirs. The issue of secondary handicap also emphasises the need to focus upon developing rapport and appropriate interactional style. It has been argued that those working within research often have limited skills in conversing with individuals who may be less articulate or intelligent than themselves (Biklen and Moseley 1988) and that a means of facilitating rapport needs to be developed which ensures that people do not feel patronised or inadequate (Booth and Booth 1996). Such strategies are likely to diffuse the risk of secondary handicap being presented within the interview process.

### *Consent*

A number of strategies have been suggested for ensuring that the rights of individuals with expressive language difficulties are maintained with regards to consent to participate within qualitative interviews. Regarding consent as a continuous process as opposed to a discrete *a priori* event would seem advisable. This may include

periodically re-checking an individual's willingness to remain involved (Usher and Arthur 1998), particularly if initial consent is obtained on a separate occasion to the interview itself, or if a series of interviews are conducted. Equally, researchers should be particularly vigilant to non-verbal signals indicating discomfort or distress.

The fact that expressive language deficits are frequently accompanied by additional cognitive difficulties means that the issue of ability to provide informed consent is a complex one which has been reviewed at length within published research (e.g. Swain et al 1998). No definitive consensus has been reached and where doubt exists regarding ability to give informed consent strategies such as "substituted judgement" (Burton 1997) have been suggested. Recent literature appears to have focused increasingly on seeking to collaborate with individuals with cognitive impairments in seeking consent (Reid et al 2001) and it is argued that respect must be given to those areas of functioning where individuals retain competency and inability to consent should not simply be assumed (Kane 1998). Clearly the issue of consent is relevant whenever people with expressive language difficulties or cognitive impairment are to be involved in participating in any form of research and it would be absurd to suggest that this simply should prevent their inclusion. Therefore qualitative interview studies can seek to be informed by the current thinking elsewhere in overcoming this difficulty.

## **Conclusion**

Social constructionists argue that the existence of an individual's sense of self depends on the social cooperation of others and that social recognition, or the lack thereof, has a profound impact on the ways in which behaviour is viewed and an individual is treated (Sabat and Harre 1992). This highlights the importance of

including individuals with expressive language difficulties in qualitative interview research, both as a means of gaining greater insight into their perspectives and needs and as a form of validation and empowerment. Clearly this process presents a number of challenges to research but, as has been highlighted within this article, these are not insurmountable and can be overcome. The key to success appears to lie in a willingness to adapt methodology appropriately and to modify expectations in order to hear the voice of respondents with expressive language deficits. This can be achieved through the implementation of a number of strategies discussed within this article. And, whilst the growing body of published qualitative interview studies involving individuals with communication difficulties is encouraging and provides support for the utility of this approach, more research is needed within this area to begin truly addressing the deficit.

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## **Chapter 2**

### **Empirical Paper 1: The Subjective Experience of Individuals with Down Syndrome Living with Dementia**

Word count: 6020 (excluding raw data, references, tables and figures)

## **Abstract**

An increasing number of studies have begun to explore the subjective experience of individuals with dementia. However, despite the increased prevalence of dementia in individuals with Down syndrome, no such published research has been undertaken within this population. The aim of this study was to explore the perspectives and subjective experiences of 6 individuals with Down syndrome and dementia. Semi-structured interview accounts were analysed using Interpretative Phenomenological Analysis, in order to gain a level of understanding concerning the impact of dementia upon respondents' lives and sense of self. Five main themes emerged: (1) Self-image, (2) The Relational Self, (3) Making Sense of Decline, (4) Coping Strategies and (5) Emotional Experience. Whilst the process of adjusting to dementia appeared comparable to the general population, the content of this was influenced by multiple levels of context specific to having a concomitant intellectual disability.

## Introduction

Dementia is an “umbrella” term used to describe various brain disorders characterised by the acquired loss of intellectual ability that is usually progressive and eventually severe, occurs over a period of time and affects multiple areas of cognitive functioning (Alzheimer’s Disease Society 2005; Williams 1995). Common deficits found in individuals with dementia include memory difficulties, poor concentration, apraxia, aphasia, disorientation to time and place, difficulties with self-care, domestic tasks and problem solving and changes in mood and behaviour (Alzheimer’s Disease Society 2005). The Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV, American Psychiatric Committee on Nomenclature and Statistics 1994) states that the impact of these deficits must be clearly identifiable in an individual’s social and occupational functioning for a diagnosis to be made. However, eventually cognitive abilities usually become so impaired in an individual with dementia that they become fully dependent on the care of others (Holden and Stokes 2002).

Over 100 different forms of dementia are currently known to exist, with the most common form being Alzheimer’s disease, accounting for at least 50% of cases, although definite diagnosis can only be achieved after death (Holden and Stokes 2002). The disease is irreversible and usually progressive over a number of years culminating in severe impairment to memory, orientation and communication (Holden and Stokes 2002; Dalton and Janicki 1998). No specific cause of Alzheimer’s disease has been established, although possible identified risk factors have included a family history of the disease, head trauma, cardiovascular disease, stroke, diabetes, the presence of apoleprotein E-4 and previous major depressive episodes (Zigman et al 1997). Equally the marked prevalence of neurofibrillary tangles and amyloid plaques

in widespread areas of the brain in people afflicted by the disease has been subject to intense research (Dalton and Janicki 1998). Both neurofibrillary tangles and amyloid plaques are also apparent in the brain tissues of older adults without any apparent dementia, but in much smaller numbers. It is at present unclear whether their increased prevalence in individuals with Alzheimer's disease is a possible cause or simply a consequence of some, as yet unidentifiable, process within the disease (Dalton and Janicki 1998).

### ***Dementia in People with Down Syndrome***

Research has established that the occurrence of dementia, and specifically Alzheimer's disease, is significantly greater in individuals with Down syndrome than in the general population (Zigman et al 1997). Approximately 15-20% of people with an intellectual disability have Down syndrome. It has been suggested that virtually all adults with Down syndrome over 40 years-old develop the neuropathological hallmarks of Alzheimer's disease (e.g. high prevalence of neurofibrillary tangles and amyloid plaques) (Dalton and Wisniewski 1990), but that only a proportion of these go on to develop the accompanying clinical findings of the dementia (Brugge et al 1994). Prevalence estimates of dementia in a population of people with Down syndrome can be found in *Table 1* (Alzheimer's Disease Society 2005).

***Table 1: Prevalence of Dementia in People with Down Syndrome***

Age Group	Percentage of people affected by dementia
30 – 39 years	2%
40 – 49 years	9.4%
50 – 59 years	36.1%
60 – 69 years	54.5%

Reasons for the significant increased risk of dementia in people with Down syndrome are as yet unclear, as are the impacts of possible risk factors identified within the general population (Zigman et al 1997). Aging is known to be a significant risk factor and the increasing life expectancy for people with Down syndrome over the past 100 years has also resulted in increasing prevalence of dementia (Holland 1998).

However, this does not account for the increased vulnerability of people with Down syndrome to dementia compared with the general population. Research has focused upon the presence of trisomy 21 (having three chromosomes 21, rather than two) in people with Down syndrome due to the fact that three of the genes implicated in the development of Alzheimer's disease are found on chromosome 21, but no conclusive evidence has been reported (Holland 1998).

Overall, research in the area of dementia specifically relating to people with intellectual disabilities has been somewhat limited until recently, particularly when taking into account the level of risk presented. The progression of the disease in people with Down syndrome appears comparable to the well-documented profile of cognitive deterioration found within the general population (Lai and Williams 1989; Burt et al 1995; Devenny et al 1996; Oliver, Crayton, Holland, Hall and Bradbury 1998). However research relating to behavioural and psychiatric symptomatology in dementia has suggested that individuals with Down syndrome may present with higher incidence of symptoms such as low mood, restlessness or over-activity, disturbed sleep, uncooperativeness and aggression (Cooper and Prasher 1998). In recommending strategies for supporting individuals with intellectual disabilities and dementia, the Alzheimer's Disease Society (2005) emphasize the need for enabling people with as much control as possible and seeking to understand their feelings and

possible causes of displays of negative emotions or behaviour. Clearly, in order to achieve this as fully as possible it is important to seek to listen to, understand and take into account the perspectives and experiences of people with intellectual disabilities living with dementia.

### *The Subjective Experience and Impact of Dementia in Individuals with Down Syndrome*

Comparably few studies had explored the experiences, emotions and beliefs of individuals suffering from dementia and as a result of this, whilst the aetiology of dementia had become well established, little was known about how people experiencing dementia lived with the illness on a daily basis or the meanings it held for them (Phinney and Chelsa 1993). It has been argued that it is difficult to assess and respond to the needs of people with dementia when understanding of their experience remains limited (Keady, Nolan and Gilliard 1995). Therefore in an attempt to develop a greater understanding of this area, several recent published studies have addressed the understanding, experiences, emotions and beliefs of people with dementia within the general population (e.g. Keady et al 1995; Gillies 2000; Pearce, Clare and Pistrang 2002; Clare 2002a; 2002b; Phinney and Chelsa 2003; Clare 2003).

This research has challenged the conventional notion that people with dementia are unable to understand or articulate what is happening to them on either a practical or emotional level (Gillies 2000). Phinney and Chelsa (2003) carried out 3 in-depth interviews with 9 people diagnosed with mild-moderate dementia and following Interpretative Phenomenological Analysis (IPA), reported the presence of three superordinate themes experienced in and through the lived body of individuals

experiencing dementia: 1) “Being slow,” 2) “being lost” and 3) “being a blank” Other themes identified across research relating to the subjective experiencing of dementia in the general population include attempting to balance the desire to maintain a prior sense of self with the need to reappraise and construct a new sense of self (Pearce, Clare and Pistrang 2002; Clare 2003), a sense of loss and attempts to manage this (Ostwald, Duggleby and Hepburn 2002) self-protective versus integrative responding (Clare 2002), a sense of frustration, fear or confusion about what was happening (Keady et al 1995), the tendency to compare self with former abilities and with others, the sense of dementia being experienced as a “memory problem” and the humiliating consequences of this (Gillies 2002).

Despite these interesting findings related to the experiences of individuals with dementia in the general population, this area of research has been all but neglected in relation to people with intellectual disabilities and dementia. Published knowledge is at present available solely through anecdotal accounts given by carers, which also tend to focus mainly on the progression of symptoms rather than beliefs, understanding or subjective experiences of the sufferer (e.g. Hammond and Benedetti 1998; Davis 1998; Fray 2000). Equally it has been argued that representations given by carers tend to provide more information about the experiences and subjectivity of the carers themselves than the individual with dementia (Kitwood 1993; Cohen 1994).

Understanding the experience of dementia in people with Down syndrome is complicated by a number of factors, including the deficits associated with concomitant disabilities, difficulties in making an early diagnosis and potentially limited existing communication abilities (Burt, Loveland and Lewis 1992). Research

suggests that pragmatic language skills may break down earliest in people with intellectual disabilities and dementia, given that these may never have been well-developed prior to the onset of the disease. Confusion and frustration may then encourage withdrawal from conversation even though communication is actually still possible (McCallion 1998). This emphasizes the importance of identifying remaining communication assets and enabling individuals to express themselves as fully as possible. Equally, it could be that rather than accepting only a temporally coherent narrative, researchers need to consider alternative ways of articulation when attempting to capture the experience of individuals with Down syndrome and dementia. Cohen (1995), in arguing the need for more research into subjective experience of dementia in the general population, has suggested that seeking to hear a person's "voice" rather than obtain their narrative is a more suitable approach. This does not necessarily presume temporal coherence but still suggests dialogue and is premised on the acts of communication and listening. Social constructionist accounts have argued that personal identity and sense of self remain intact beyond the disintegration of many cognitive and motor functions and that expression of this is dependent upon the cooperation of others within social situations (Sabat and Harre 1992). Indeed, it has been suggested that the lack of knowledge on subjective experience of dementia in the general population may be partly attributed to researchers' inability to listen rather than the inability to communicate in those affected (Cohen 1995). This criticism may easily be applied to the gaps in our understanding related to the experience of individuals with intellectual disabilities and dementia.

The fact that research carried out with individuals with dementia in the general population has been successful in eliciting subjective experiences and beliefs across a range of impairment (e.g. Keady et al 1995; Gillies 2000; Pearce et al 2002; Clare 2002; Phinney and Chelsa 2003; Clare 2003), suggests that this is also feasible for people with Down syndrome and dementia. Given the sometimes vastly differing life histories, prior skills and levels of functioning of people with intellectual disabilities compared with individuals from the general population, it seems unlikely that their beliefs and experiences of living with dementia can be fully understood simply by generalising from work carried out within a non-learning disability population. In people with Down syndrome, levels of awareness, understanding and means of making sense of and adjusting to their experiences may differ greatly from individuals in the general population. People with Down syndrome may be less likely to be informed or aware of a diagnosis of dementia. This does not prevent them from experiencing the disease or holding beliefs about what is happening to them. Equally, research has been successfully carried out within the mainstream population with people who were unaware that they had been diagnosed with dementia but were still able to provide reflections on their current life experiences (e.g. Gillies 2000).

### *Aims*

The aim of this research was to explore the perspectives and subjective experiences of individuals with Down syndrome living with dementia. Accounts were analysed using Interpretative Phenomenological Analysis (see below for definition and description), in order to gain a level of understanding concerning the impact of dementia upon respondents' lives and sense of self.

## Method

### *Participants*

The study presented here formed part of a wider investigation of dementia in older adults with Down syndrome and ethical approval was obtained as such (see Appendix 1). Individuals were invited to participate in this study if they had Down syndrome and could be identified as meeting the criteria for a clinical diagnosis of Alzheimer's disease as outlined by Holland (1998). This included the presence of gradual decline and cognitive impairment in the absence of significant health or sensory difficulties. Acquired cognitive decline in all participants was established through repeated periodic administration of a battery of direct neuropsychological tests and carer assessments, as proposed by Oliver et al (1998). All participants had undergone full medical check-ups to exclude any alternative health conditions that may have contributed to the presenting cognitive decline.

Participants were required to speak English and to be within the stage of disease process wherein they were still able to communicate verbally. Since it was likely that generation-related themes would be detected within the research interviews, all individuals recruited were over the age of 40 years. No restrictions were placed upon sampling in terms of gender or ethnicity. Written consent was sought for individuals to participate in a series of studies as part of an investigation of dementia in older adults with Down syndrome. Additional surrogate assent was also sought from caregivers where it was deemed that participants were unable to provide fully-informed consent. Prior to participation in this specific study, additional verbal consent was sought from each participant. This was also re-confirmed at the time of the interview itself and following its completion. A sample of nine possible

participants were recruited. Of these, one subsequently declined to participate in the interview process, one was deemed to have insufficient verbal communication skills and one could not be interviewed for ethical reasons due to deterioration in physical health. Six participants therefore completed the study. Their demographics and characteristics can be found in *Table 2*.

Participants’ mean age was 54 years (standard deviation 4.29). All were of white European origin and born in the UK. All resided in group residential home settings for individuals with intellectual disabilities, supervised 24-hours by paid caregivers. None of the participants were aware that they had been given a diagnosis of dementia.

***Table 2: Participant Demographics***

Participant	Pseudonym	Gender	Age
1	Mary	Female	58
2	Mark	Male	55
3	Billy	Male	54
4	Alice	Female	49
5	Peter	Male	49
6	Charlie	Male	59

***Procedure***

Qualitative data were collected in interviews with each participant. Prior to the main interview, initial meetings were held with four of the participants in order to facilitate the development of rapport and discuss the forthcoming research process (Barnes 1992). Due to time constraints and practical difficulties this was unfortunately not possible to arrange with the remaining two participants. The main study procedure

comprised of a semi-structured individual interview, which was audiotaped and transcribed verbatim. Interview lengths varied in duration from 20 to 45 minutes. An interview schedule was designed as a flexible guide for the interviewer and aimed to develop an understanding of individuals' own understanding, feelings and perception of their current life situation and state and how this related to thoughts concerning both the past and the future (see Appendix 3). The interviewer was also free to explore other interesting areas that arose and follow respondents' interests or concerns (Smith 1995). The purpose of this was to attempt to develop a "snapshot" of the experience of an individual with Down syndrome encountering the process of progressive cognitive decline related to dementia. Terms such as "Alzheimer's disease" and "dementia" were not used within the interviews, as participants were unaware of their diagnosis.

### *Analysis*

Data analysis for this study utilized Interpretative Phenomenological Analysis (IPA). IPA is a systematic and practical approach to analysing phenomenological data developed by Smith et al (1996a; 1999) and is particularly relevant for exploring phenomena such as individual's subjective perceptions of health and illness (Smith et al 1999). The overall aim of IPA is to explore in detail how participants make sense of their personal and social worlds and the meaning that particular experiences, events and states hold for them (Smith and Osborn 2003). It involves the development of a systematic, rigorous and comprehensive account of themes located within the data (Smith 1996a). The characteristics of IPA have been summarised as being: 1) Idiographic; commencing with a detailed examination of one case study and only extending to cross-case analysis when this has been fully achieved, 2) Inductive;

employing techniques flexible enough to allow emergence of unanticipated topics or themes, and 3) Interrogative; seeking to contribute to understanding through interrogating and illuminating existing research and discussing findings in the context of current literature (Smith 2004).

Interview transcripts were analysed following IPA guidelines proposed by Smith and Osborn (2003) and detailed in *Table 3*. Examples of the analysis process can also be found in Appendices 4 – 6.

### ***Validity***

An independent audit (Smith 1996b) was conducted for two of the case analyses by members of an IPA consultation group, consisting of other researchers utilising an IPA approach. This audit was not designed to produce a score of inter-rater reliability, but to verify that the analysis presented was systematic and logical and could be supported by the data it was derived from. Where this was not the case, appropriate changes were made, whilst additional codes were also detected and developed as a result of discussion within this consultation group. Each stage of the analysis was also reviewed by the second and third authors in order to assess the emerging analytic account. Further checks on validity were provided through discussion with other qualitative researchers. Reported results are illustrated with examples of raw data to allow readers to evaluate the interpretations made by the author (VL).

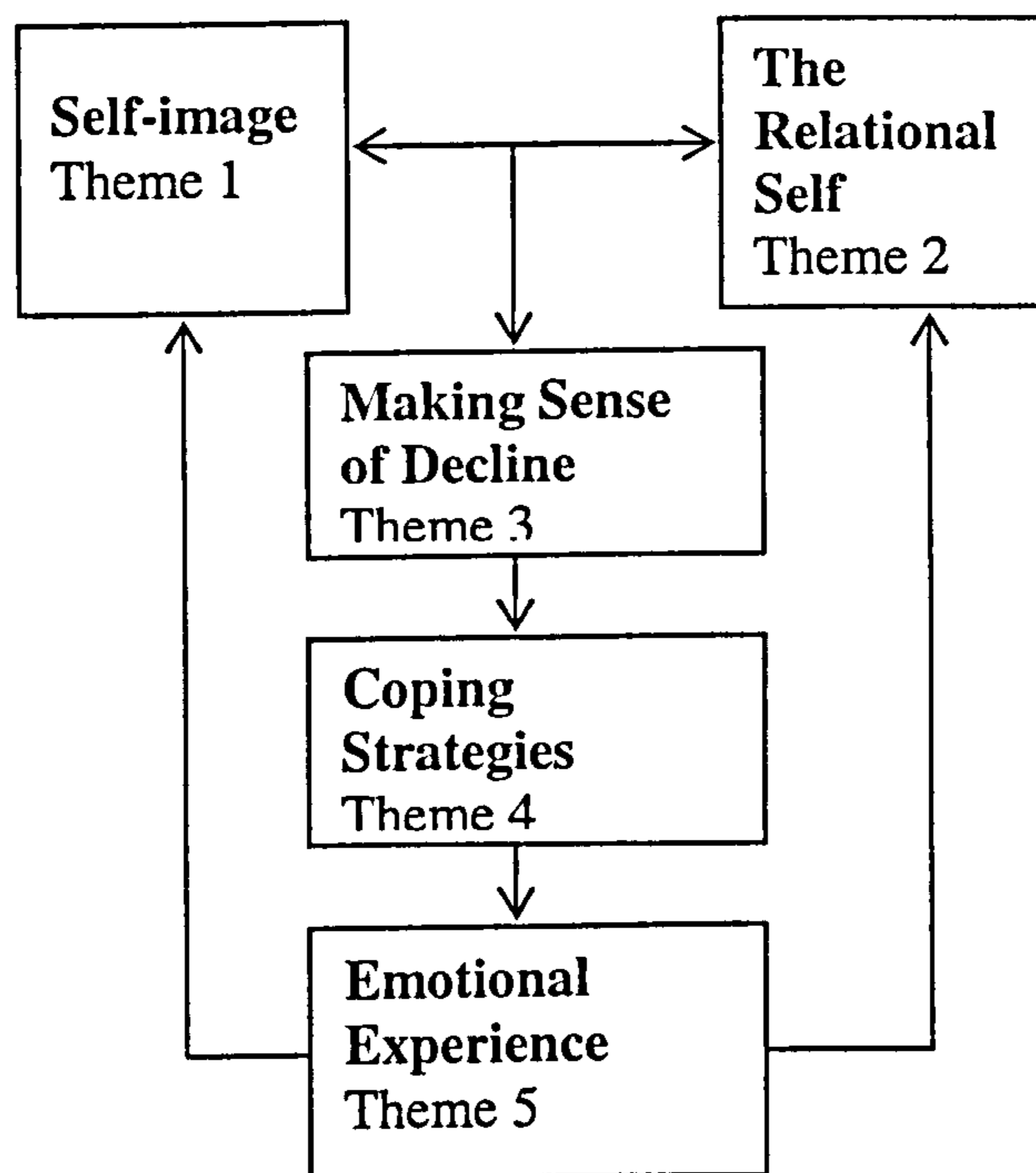
**Table3: Interpretative Phenomenological Analysis Process**

<b>Stage 1</b>	Reading the first transcript several times and noting anything of significance or interest e.g. summarizing or paraphrasing, associations, preliminary interpretations, contradictions, similarities or differences, use of language and any sense of the person that is being portrayed.
<b>Stage 2</b>	Producing a list of emerging theme titles, with initial notes being transformed into concise phrases to capture the essential quality of the data content. Care is taken to ensure that theme expressions remained grounded in what has been specifically said by the participant
<b>Stage 3</b>	Listing all emergent themes and seeking to make sense of them by finding connections between them. This leads to a more theoretical ordering with some themes clustering together and others emerging as superordinate concepts. Emerging sets of themes are verified against the original transcript to ensure connections generated fit with the data. This results in a complete hierarchically organised summary list of themes.
<b>Stage 4</b>	Clusters of themes given labels to represent superordinate themes.  Examples of where each theme is located in the original text are provided.
<b>Stage 5</b>	Stages 1 - 4 repeated for each remaining interview transcript.
<b>Stage 6</b>	Lists of themes for all participants read together and consolidated, allowing for the development of a final list of themes clusters and superordinate themes to be produced with are representative of all cases.
<b>Stage 7</b>	Final master list used as a basis for developing a narrative account of participant's experiences. Individual's names and other identifying features were altered for the purposes of confidentiality.

## Findings

Despite being unaware of any diagnosis of dementia, all participants presented with some level of explicit and implicit acknowledgement of decline. Five main themes emerged from the analysis and linked together as shown in *Fig. 1*.

**Figure 1: Relationship Between Emergent Themes**



The themes appeared to represent a process depicted in *Fig. 2*. The first two themes, *Self-image* (Theme 1) and *The relational self* (Theme 2), appeared to interact and were an integral part of the multiple levels of context relevant to the experience of being labelled with Down syndrome and the social and interactional positions this resulted in. This can be linked to systemic literature, proposing a hierarchy of fluid levels of context (e.g. content of a statement, the specific speech utterance, the specific social encounter/episode, definitions of the interpersonal relationship, life stories the individual has about themselves, family narratives, social laws, regulations and prescriptions and cultural patterns), in which the meaning of any level can be understood in the context of the higher levels feeding in (Burnham and Harris 1996).

Whilst the higher levels exert a contextual force downwards, the lower levels also exert an implicative force upwards and the relationship between levels can be viewed as circular and reflexive over time (Boscolo and Bertrando 1994; Burnham and Harris 1996).

These first two themes appeared to exert an impact upon the remaining themes. These were *Making sense of decline* (Theme 3), which in turn influenced the selection of *Coping strategies* (Theme 4), encapsulated in the fourth theme. This could be seen as impacting upon the fifth emerging theme, *Emotional experience* (Theme 5). This process appears to reflect a wider existing cognitive model of coping as a mediator of emotion, as proposed by theorists such as Folkman and Lazarus (1988). Within *Fig. 2* therefore, these themes are represented as *Coping processes*, which then feedback into *Self-image* and *The relational self*.

This process is not conceptualised as representing a discreet sequence of phases, although it is assumed that a degree of change or decline must be registered on some level for the cycle to commence. Instead the themes appear to represent an ongoing reiterative process, taking place within the individuals' lived experience of having Down syndrome and dementia, with multiple levels of context influencing *Self-image* and *The relational self*, which then impact upon *Coping processes* which in turn influence context and *Self-image* and *The relational self*. Thus the cycle is maintained throughout the disease process. The themes are described in greater detail below, with some areas being expressed explicitly whilst others were implicit within individuals' responses:

### *Self-image (Theme 1)*

All respondents perceived their own individual roles and jobs as key defining factors in their self-image. Domestic roles in particular were emphasized by all and female respondents made more frequent mention of embracing tasks which could be regarded as traditionally stereotypical to the roles of women and there was a clear sense of valuing ascribed to these positions:

Mary: Oh I like that, it's lovely. I set the table up, clean the table, mop the floor, sweeping the floor. (*pause*) Oh I like it, it's lovely. (1; 43-45)

It has been suggested that females with intellectual disabilities frequently position themselves within traditional gender stereotypes in order to meet a need to view themselves as women (Burns 1993; Scior 2003). By contrast, male participants appeared to define themselves by their role in carrying out a combination of domestic and more practical tasks, suggesting that they were also, but to a lesser extent, attempting to negotiate roles associated with the stereotype of their gender:

Mark: I tidy the (*pause*) these (*pause*) work surfaces. (*inaudible*) Laundry, working in the, in the woodwork shop, sewing and garden work and office skills. (2; 73-75)

If gender stereotyped roles are viewed as a means of embracing gender identity, by default this aspect of self-image is likely to become increasingly threatened as the course of dementia progresses and impedes the ability to successfully maintain such

roles. Having well-defined roles and designated chores also often seemed to be regarded as a sign of independence and usefulness, and therefore of status:

Interviewer: What sort of things do you do when you're at home?

Alice: Do some er (*pause*) me chores. Me washing, dry it, iron it (*pause*).

Settle meself down. I have a bath and wash me hair. Make me own lunch to come here (*daycentre*). I do everything all on me own....Sometimes I do all the washing for them (*other residents in group home*). (4; 78-83)

Mary: I don't need much help. I can make my own bed and wash up and clear up and everything. (1; 146-148)

This is mirrored in a study of people with intellectual disabilities by Rapley, Kiernan and Antaki (1998), in which interviewees took care to construct versions of themselves doing typical activities that presented them as competent and claiming membership in conventional social categories. However for some participants in this research, with the onset of dementia their self-image had become characterised by lack of or loss of roles, despite articulated wishes to be seen as useful:

Peter: Don't have jobs. Always trying to help something though. (5; 75)

Peter's emphasis of "always trying to help" appeared indicative of a constant cycle of seeking out defining roles and failing to find or be ascribed them. Throughout the interview Peter frequently reiterated his own name in response to questions, suggesting that in the absence of other external means of developing his self concept

and image he had come to rely upon this basic knowledge of his own identity as a means of defining himself. Where clear formal roles could not be located, some also attempted to construct their own by identifying everyday basic tasks or leisure activities as “jobs.” This appeared to be a means of seeking out status and self-worth in a life situation that offered limited opportunities for these:

Interviewer: What are your jobs?

Billy: Erm (*pause*) erm (*pause*) I like turning the lights on and off. (3; 94-95)

Mark: I go to do some shopping. I do my office work at the centre (*day centre*). (2; 33-34)

For Billy, a sense of role and purpose was obtained through the failure safe activity of switching lights on and off, whilst Mark appeared to locate status in a preferred leisure task of copying from books, which he formalised by defining it as “office work.” Self-image was also defined by some respondents through referring back to past roles they had carried out prior to the onset of dementia. It is likely that these offered a greater sense of fulfilment and status than current roles. This can be seen in Alice’s detailed account of her own previous role as her mother’s carer during a lengthy illness, given in response to a question about her current jobs:

Alice: I used to look after her. I used to give her (*pause*) it was midnight when she was poorly. She was lying in the living room and her head was going backwards and forwards. She said erm “I couldn’t hardly breathe.” I used to look after her. It was midnight, I went downstairs, put the kettle on, made her

a cup of tea and some biscuits. I gave her her tablets to calm her nerves down then I rushed and undressed her meself. (4; 135-141)

Research has suggested that individuals with dementia may recall emotionally laden material more successfully than neutral memories (Fleming et al 2003). This is likely to be the case for Alice's memories concerning her mother's illness and therefore it may be that she is certain of presenting a clear account and that this is also a factor in its selection. Equally, it has been proposed that people with dementia may focus upon incidents from the past in an attempt to seek some form of resolution to unresolved conflicts (Feil 1993).

Dissatisfaction was evident in some participant's accounts, where a disparity appeared to exist between their self-image as independent and competent and the opportunities their life circumstances presented to fulfil or confirm this. Charlie's desire for mainstream adult status in the form of independent living and a cohabiting relationship and his frustration at the lack of opportunity his home circumstances provided for this, is an example:

Charlie: No not happy here (*in residential group home*). I'd like to live in a proper home with Sally (*another resident*). Me and Sally live together on our own in a house. (6; 14-16)

### *The relational self (Theme 2)*

The importance of maintaining consistent attachments was highlighted within all participants' responses and residential care staff took a significant role within this.

Staff were often referred to both as friends and family:

Interviewer: Who are your friends?

Charlie: Louise and Jane (*residential home carers*), they're my friends.

Interviewer: Who else?

Charlie. Erm (*pause*) There's no one else. What do you mean? (6; 103-110)

Charlie's response indicated that staff were viewed as central to his social network, whilst Mark repeatedly referred to the managers of his group residential home as his "guardian parents," indicating his sense of them as family and of himself as childlike and dependent within the relationship. Such a "guardianship discourse" has been previously detected in interviews with individuals with intellectual disabilities (Scior 2003) and it is argued that this reflects society's interest in keeping individuals with intellectual disabilities in a state of "suspended childhood" (Burns 1992; Brown 1994).

The sense of self as being passive within relationships and of these offering a source of protection was evident amongst the majority of accounts:

Mary: Me family take me out at weekends. (1; 101)

Mark: I do love Emily (*residential home manager*). She's the best guardian mother in the world...She helps keep me out of trouble...I let her sort things out, not me. (2; 100-102, 107)

Passivity is implicit in Mary's description of being taken out by her family, rather than actively engaging within these events. This contrasts with more active descriptions given by Alice, who also continued to identify strongly with her own previous role as her mother's carer, compared with Mary who had lived in a residential care setting for much of her adult life. Mark's passive role in his relationship with the home manager is more explicitly expressed in his acknowledgement that deferring to her and allowing her to make choices on his behalf helped him to avoid "trouble." Passivity was also a key feature when many respondents related incidents of conflict within their daily lives, with a tendency to view themselves as innocent victims of others' unjust hostility or criticism:

Mary: I'm alright, it's lovely (*referring to her role working voluntarily in a coffee shop*). 'Cept one person's been picking on me, saying I'm doing it wrong.

Interviewer: Why do you think the person is saying you're doing it wrong?

Mary: I don't know, 'cause I'm not. (1; 47-54)

Alice: So we er had a bit of a (pause) up-and-downer today.

Interviewer: Yeah? Do those kind of up-and-downers happen often?

Alice: Yeah. I don't ever have arguments with her. It's her. (4; 62-67)

Mary's complaint that others had been unfairly criticising her ability to successfully complete tasks was also present in accounts given by several respondents. It appeared to represent the relationship difficulties that arose when dementia-related decline became noticeable to others but were not being explicitly acknowledged by the individuals themselves within that context. The concept of others attempting to force awareness of decline has also been noted within literature in the general population (e.g. Phinney 2002). However, even when respondents were aware of their own mistakes or difficulties, the negative response of others was still an issue:

Alice: I forgot this morning to go up to drama. You know Kate? She was winding me up about it. (4; 182-184)

Apprehension concerning negative responses from others was often implicit within the interviews themselves, with individuals frequently feeling the need to apologise for being unable to recall specific facts or directly appealing for validation and approval from the interviewer. It has been argued that people with cognitive deficits seek to guard their fragile self-esteem by seeking evidence that others think well of them (Edgerton 1967). Individuals who already have pre-dementia cognitive difficulties as a result of their Down syndrome are likely to have been strongly socialised in this technique. An awareness of "othering" can also be seen in Alice's description of a recent theatre trip which indicates her sense of being separate from mainstream society:

Alice: Went to the theatre with Andy (*staff member*). In the community. (4; 91)

All participants indicated the need to increasingly rely upon the assistance of others in some aspects of their daily lives and this may have been a means of compensating for their own declining skills, as noted in people with dementia in the general population (e.g. Clare 2002a; Pearce et al 2002). Staff caregivers were usually the most likely targets for this. At times a tension could be detected between individuals' need to seek assistance from others and their desire to maintain their own image as independent and competent:

Charlie: I don't need any other help. Louise (staff caregiver) has to do my bed for me sometimes. But I help as well. (6; 146-147)

### *Making sense of decline (Theme 3)*

For all respondents, awareness of some level of decline was acknowledged, either explicitly or implicitly. Forgetting names was a commonly reported difficulty, but whilst some individuals connected this with the presence of more global memory decline, others denied any difficulties:

Billy: They tell me and I keep forget, yeah. Yeah, errm they told me Julie, I forgot the name, Julie. I can't think, yeah. (3; 144-154)

Mary: And another one. Oh I've forgotten all the names, sorry. I keep forgetting these things. (1; 156-158)

For both Billy and Mary, forgetting specific names appeared to be linked to wider memory difficulties and, in Billy's case, the perception that his cognitive skills were

somehow impaired despite his best efforts. This contrasted with Alice. Despite repeatedly reporting difficulties in recalling the names of acquaintances throughout the interview, when she was directly questioned about whether she had problems remembering names she denied any awareness:

Alice: No, it's quite easy. (4; 194)

A sense of getting lost easily, confusion about daily routine and reported spatial perception difficulties were present within all participants' accounts, except for Alice and Charlie, all of which indicated awareness of cognitive changes linked to the onset of Alzheimer's disease. An awareness of physical slowing and decline was also expressed explicitly by all respondents and many appeared to have noted that this had restricted their levels of activity. This has also been highlighted by interviewees with dementia within the general population (Phinney and Chelsa 2003). Research suggests that insight into decline varies across domains in individuals with dementia (Vasterling, Seltzer, Foss and Vanderbrook 1995; Green, Goldstein, Strockman and Green 1993). It may be that physical deterioration was more easily recognised than cognitive changes for these respondents with Down syndrome:

Mark: I don't go out much at all now. I like listening to music in my private room. I get tired at night. I get tired every afternoon. (2; 60-61)

Interviewer: What do you do (*at evening club*)?

Mary: Sit down and talk. I can't really dance no more else I'm out of breath.

Interviewer: Did you used to like dancing?

Mary: Oh yes, yes. But now it's too much for me. Dunno why. Tired. But I like it. (1; 93-100)

Both Mark and Mary indicated that their activity levels had been reduced and they made sense of this by viewing it as a result of feelings of tiredness and physical slowing. For Mary there was a feeling that the demands of an enjoyable activity had become too great.

Despite the fact that all respondents provided an indication of some degree of decline or change, their overall attitude to it remained passive and accepting and only Mark expressed concerns that it may be linked to some kind of medical or health disorder, by expressing a wish to consult with a doctor. Arguably, in the absence of any indication to the contrary (e.g. all respondents were unaware of their diagnosis of Alzheimer's disease), it was logical that individuals would seek an explanation in normality (Gillies 2000). Aging and a perception of growing old were common themes within several individuals' responses and it may be that they implicitly linked decline and changes with this process:

Peter: I'm I'm I'm Peter. Bit old. (5; 137)

Interestingly, both Alice and Charlie, who had previously denied any awareness of cognitive decline also presented with a reluctance to accept the process of growing older:

Interviewer: You're 59 (*years-old*)?

Charlie: Am I? Yes.

Interviewer: Do you think 59 is old or young?

Charlie: Hmmm? I'm not old, I'm still young.

Interviewer: What happens when a person is old?

Charlie: I don't know. I'm not worried at the moment. (6; 172-177)

Alice: I think I am getting old actually.

Interviewer: And what does that feel like?

Alice: It feels a bit strange. Because I'm not, I'm not really an old person. (4; 217-221)

Alice expressed feelings of cognitive dissonance relating to her perception of herself as aging and the belief that she as a person was not old. Within Charlie's account this was less explicit but he appeared to avoid the question relating to perception of his own age, focusing instead on his belief that he as an individual was not old, suggesting some similar level of contradictory feelings. A similar unwillingness is presented when he is asked to consider his views on what occurs during the aging process. This sense of not feeling old has also been reported in literature with older adults in the general population with dementia (e.g. Reid, Ryan and Enderby 2001). However, by contrast to these studies, because of the earlier onset of Alzheimer's disease and physical aging symptoms in people with Down syndrome, the respondents in this study were in an age range that wouldn't be considered old within the general population. Therefore cognitive dissonance and resistance could be regarded an understandable reaction.

### *Coping Strategies (Theme 4)*

None of the respondents were able to explicitly describe employing any coping strategies to manage or adjust to the changes and decline they had noted and this appeared to be in keeping with an overall passive and accepting attitude towards the difficulties. It has been suggested that people tend to employ coping strategies constant with their role socialization (Schilling, Schinke and Kirkham 1985), and as discussed previously, the majority of respondents characterised themselves in passive terms, in keeping with literature relating to individuals with intellectual disabilities. However, a number of coping responses and strategies were implicit within participants' descriptions of their difficulties and also their life situation and daily routines. This theme appeared to encapsulate not just coping strategies employed to deal with cognitive decline, but also the approaches respondents utilised to make sense of their own world and daily living experiences. Minimization of difficulties was a commonly used defence by all participants, with the exception of Billy:

Interviewer: Can you remember things ok?

Charlie: I can yes. But it's a bit bad. But I know this (*spells out own name with fingers*) (6; 123-126)

Whilst acknowledging a degree of memory impairment, Charlie immediately minimized this, both in his use of the phrase "a bit bad" and in attempting to demonstrate cognitive skills that had remained intact. Minimization of difficulties appeared to be a commonly used strategy by many respondents within all aspects of their lives:

Alice: At first when I moved here I didn't like it at first and I went to her (*sisters*) house and was being naughty. You know upstairs, in my home, upstairs in my bedroom? I was hiding things in the room. (4; 164-167)

Alice's account relates to her difficulties in adjusting to leaving her family home after the death of her mother and moving to a group residential home. For any individual, this sudden change in environment, combined with the impact of bereavement and the fact that she was required to leave behind family pets and many possessions, would be traumatic and distressing. Yet, Alice minimized this by describing her own negative response to it as "being naughty," indicating both infantilisation of herself and the belief that she should have simply accepted the situation without complaint. Such a reaction is likely to have been conditioned by the responses of others and examples of individuals with intellectual disabilities having their voices silenced by internalisation of the dominant societal voice, which denigrates their feelings and complaints as being unimportant, has been reported in previous literature (Proctor 2001). This approach would then be employed if the person had to deal with the difficulties associated with Alzheimer's disease.

Explicit denial of difficulties, even when these had already been disclosed within the interview also appeared act as a conscious or unconscious strategy employed by many participants. This presentation has also been described within literature relating to dementia in the mainstream population (Weinstein, Friedland and Wagner 1994).

Interviewer: How do you feel?

Peter: There's nothing the matter. My name is, my name is Peter. (5; 98-99)

Peter's answer contradicted prior and subsequent responses, which suggested a number of physical and cognitive difficulties. He also appeared to be gaining additional reassurance from the repetition of his own name and the sense of his own identity as someone who had no difficulties. This can be seen in the context of a dominant social myth that people with intellectual disabilities are always happy, an ideal that can translate itself into pressure on the person themselves to conform accordingly (Sinason 1992).

A common theme amongst all participants was a lack of insight into their own performance quality and the suggestion that liking things or simply doing them inevitably equated to success. The importance of maintaining routine and the concept of a life defined by a timetable was also very apparent amongst all individuals' responses and such familiarity is likely to act as a protective coping strategy against exacerbated confusion. However for some individuals there was a sense that maintaining activity levels was also crucial to their everyday coping styles. This may have occurred both as the result of learned experience and in response to suggestions from others:

Interviewer: And what's it like doing these things? (*Leisure activities*)

Alice: I like it. It's the best thing to keep busy. (4; 104-105)

This contrasted with responses elicited from other individuals, who reported an increased tendency to withdraw, a strategy also reported within the general population (Robinson, Ekman, Meleism, Winblad and Wahlund 1997). This may have been an attempt to avoid demands they no longer felt able to meet:

Mark: I'm alright, just want peace and quiet. Just want to go in my room. (2; 134-135)

In Mark's case, he had also developed an elaborate "fantasy family" who he described spending long periods of time with. Whilst this pre-dated the detection of dementia-related changes, it appeared to have increased in frequency with progression of this decline. It could be hypothesised that it provided him with a means of companionship that was not impacted upon by dementia-related decline.

Strategies employed to mask confusion or inability to respond, were implicit within all participants' responses, although it was unclear whether these were being employed consciously or unconsciously. These included not only confabulation and, but also recency responses, in which people appeared to respond only to the latter section of a question, thus if this was not recognised they appeared to be giving an irrelevant or nonsensical response. This attempt to use language as a means of disguising difficulties has been reported in qualitative studies of dementia within the general population (e.g. Gillies 2000).

Many individuals had a misperception of their own age, which in itself is likely to act as an unconscious coping strategy:

Mark: I like playing, like a boy. (2; 16)

Mark's infantilisation of himself was likely to serve to reduce his expectations of himself regarding his own abilities, skills and levels of independence. It also fitted

with the dominant historical social construction of individuals with intellectual disabilities as “childlike” (Scior 2003). There was a clear indication that many of the activities that individuals were encouraged to engage in reinforced this misperception, as can be seen in Mary’s descriptions of the evening club she attended, which sounded more like a youth club than a group for older adults:

Interviewer: Is that something you do in the evening?

Mary: Yes, but it’s noisy.

Interviewer: Why is it noisy?

Mary: The records.

Interviewer: They play lots of loud music?

Mary: Oh God yes. And we have a drink and sweets and anything. (1; 86-92)

Both Alice and Charlie, who were reluctant or unable to explicitly acknowledge their symptoms of decline, described coping strategies in everyday life that involved using replacement as a means of defending against the impact of loss. In speaking about the loss of a relationship with another resident of his home who was terminally ill in hospital, Charlie simultaneously acknowledged the coping method of replacement with another relationship:

Charlie: Sally is my best friend now. I miss Rose. (6; 112-113)

It is possible that individuals who routinely apply such a coping technique are also likely to do so as a means of defending against the losses associated with the onset of Alzheimer’s disease. Shontz (1975) described “fragmentation,” as a form of denial, in

which individuals split themselves off from experiencing an illness and argued that this resulted in instability. As will be described, both Alice and Charlie presented with generalised feelings of loss and frustration, despite their denial of and attempts to defend against dementia-related changes.

When all respondents were asked to consider ways in which life may be different or more preferable they were unable to do so. This is also likely to act as a means of coping in that it defends against dissatisfaction and, to an extent, prevents apprehension about the future.

### *Emotional Expression (Theme 5)*

The extent to which respondents were able to express their emotional reaction specifically linked to dementia-related changes was somewhat limited. However, a clear indication of distress was given by some individuals:

Mary: Oh it's horrible. It's my mind (*pause*) I forgot now. It's terrible. (1; 225-226)

Despite her struggle to describe her cognitive difficulties, Mary was still able to verbalise her emotional distress. "Terrible" was also a descriptor employed by Alice when speaking about aging and further discussion around these subjects led her to focus upon her mother's illness and subsequent death and her fears concerning her own aging:

Alice: I don't want to pass away, I don't want to die. I can't, I can't lose.

Interviewer: Do you worry about that a lot?

Alice: Yeah (*pause*), I don't want to pass away. I don't want to get old. I don't want to go to heaven. I can't, I can't lose it.

Interviewer: What can't you lose?

Alice: The way things are. (4; 237-245)

It is possible that Alice, on some level, connected the dementia-related changes and decline in herself with aging and thus with her mother's aging and death, leading to feelings of distress and fear. Fear has been described as a pervasive emotion in people experiencing dementia in the general population (Keady et al 1995). A sense of loss is also apparent in Alice's concerns about her current situation. A more generalised sense of and preoccupation with loss were present in the accounts of other respondents. Froggatt (1988) made a distinction between the "experiencing self" based on emotions and preconscious process and the "cognitive self" and it has been suggested that the latter may be more severely effected by the dementia process (Howorth and Saper 2003). Therefore the generalised emotions expressed by respondents may have reflected registering of dementia-related difficulties at an emotional level, even though these could not be expressed in formal cognitive appraisal. This also mirrors qualitative findings with people with dementia within the general population (e.g. Howorth and Saper 2003).

Some individuals also expressed feelings of frustration and being restricted:

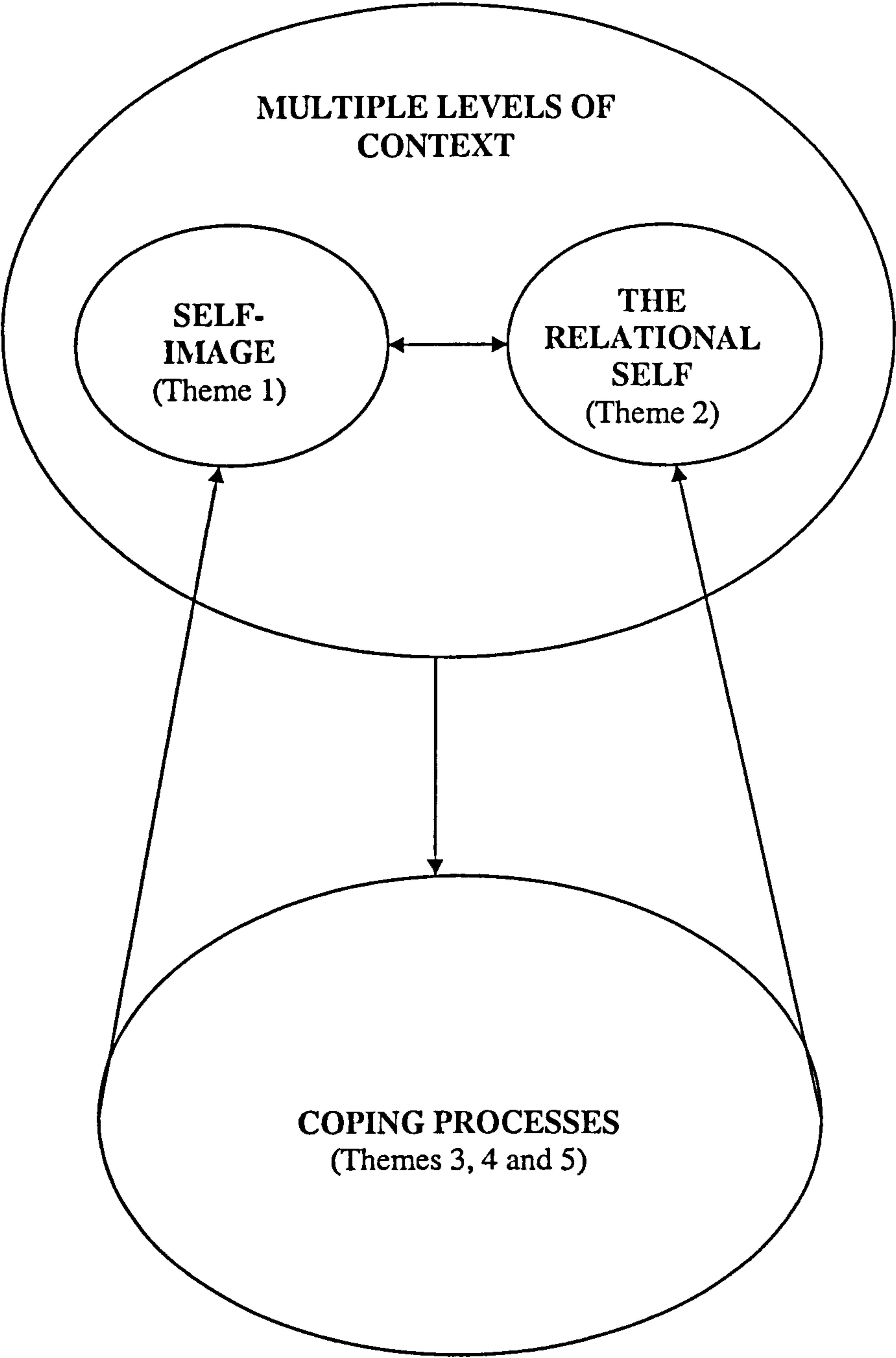
Charlie: Here? I don't like it. I can't go out, I can't do nothing what I want.

When I was first living here before, I always went out. (6; 30-32)

Billy: Need to (*pause*) need to. But can't. Linda (*staff member*) er, Linda told me, "you can't do that." (3; 84-85)

Charlie was able to articulate his frustration at being unable to do the things he wished to and a sense of nostalgia for the past. It was unclear what he attributed these increased restrictions to. Billy's sense of frustration is less coherently described but he appeared to have externalised its cause to staff, as opposed to his own limitations. Throughout the interview Billy repeatedly expressed having a constant desire to "go" or "get out," suggesting a pervasive sense of being trapped and in a situation that was not comfortable. This appeared to relate to his wider life situation rather than the interview context specifically, as Billy declined offers to terminate the interview process several times. Stokes and Goudie (1990) have argued that apparently disorientated thoughts and speech (e.g. the desire to wander) may be a function of current unmet needs, such as security and safety.

*Figure 2: An overview of the relationship between themes describing the experience of individuals' with Down syndrome living with dementia*



### *Clinical Implications*

The accounts presented within this research suggest the value of allowing individuals with Down syndrome and dementia to articulate their feelings and responses and be involved as active participants in shaping their present and future care. The fact that some level of explicit awareness of change was present in all respondents' accounts also raises the issue of how this should be addressed when a diagnosis of dementia has been made. At present very few individuals with Down syndrome are likely to be informed of this diagnosis (indeed, none of the respondents in this study had been provided with any information). The arguments concerning this dilemma are too complex to fully explore here but the insight and emotional impact elicited in this study could be used to suggest that more effort needs to be made to assist individuals with Down syndrome in developing an understanding and acceptance of their situation. This may improve their experience of the disease process.

The importance of maintaining a positive self-image appeared to be central for the respondents in this study. Therefore efforts would be well focused in ensuring that individuals with Down syndrome and dementia are able to maintain active and appropriate roles and are provided with assistance in developing realistic and appropriate strategies for dealing with the change in skills resulting from dementia.

### *Limitations*

It might be suggested that a sample size of six participants is somewhat small. However this has been cited as an appropriate number for studies utilising an IPA approach (Smith 2003). Whilst the information obtained and the conclusions reached reflect the responses of the respondents within this study, it is not claimed that these

can be generalised to all individuals with Down syndrome and dementia and this would not be appropriate to the methodological approach taken (Smith 2003). Instead it would be anticipated that these findings could be applied as a means of warranting further and more specific exploration through future research.

The participants recruited to this study shared many similarities in terms of their demographics and background. Given the apparently individual nature of the construction of understanding and coping processes, it is important to consider that these may differ significantly for people of different groups (e.g. gender, social class, ethnicity, culture). Therefore future research would also be useful to focus on these potential differences. Finally, by the nature of the methodology, only individuals who were able to provide some level of verbal response were included. Whilst this is an inevitable consequence of the methodology, it may be useful to consider including alternative approaches (e.g. participant observation, communication through sign language or pictures) in an attempt to engage with those whose verbal skills are too limited.

## ***Conclusion***

The findings from this research indicated that the self-image and relational selves of the respondents were located within the multiple contexts applicable to having Down syndrome and that these factors impacted upon coping processes employed in response to the onset of decline associated with Alzheimer's disease. These coping processes appeared to mirror generalised cognitive models proposed, in that appraisal appeared to determine coping strategies which in turn influenced emotion (Folkman and Lazarus 1988). However the content of the coping processes appeared to be

specific to individuals with Down syndrome and dementia and their own unique life contexts, supporting the view that it is inappropriate to simply generalise from literature obtained within the general population.

Coping processes had a feedback effect into the individual's self-image and relational self, creating a reiterative cycle throughout the disease process. Given that no previous published research has been conducted in the area of subjective experience of people with Down syndrome and dementia, it can only be speculated whether progressive stages in the dementia process lead to changes within this cycle and therefore further attention is required to this area.

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## **Chapter 3**

### **Empirical Paper 2: The Impact of Dementia Upon Residential Care for Individuals with Down Syndrome**

Word count: 2808 (excluding references, tables and figures)

## **Abstract**

### **Background**

Despite the increased prevalence of dementia in individuals with Down syndrome, relatively little is known about the impact of this upon care provision. Caregivers may be familiar with the demands of assisting a person with Down syndrome, but have little knowledge about the impact of dementia. This may lead to stress, which can have a detrimental effect on the caregiver and the quality of care for their recipient.

### **Specific Aims**

The aim of this exploratory study was to examine the objective and subjective impact of dementia upon residential caregivers of individuals with Down syndrome.

### **Method**

The study utilised the Caregiver Activities Scale – Intellectual Disabilities (CAS-ID), the Caregiver Difficulties Scale – Intellectual Disabilities (CDS-ID) and the Maslach Burnout Inventory (MBI). Responses given for these measures by caregivers of individuals with Down syndrome and dementia ( $n = 9$ ) were compared with responses from those caring for recipients with Down syndrome and no additional cognitive decline ( $n = 11$ ).

### **Findings**

No significant differences were found between caregivers of individuals with Down syndrome and dementia and caregivers of individuals with Down syndrome only, on measures of objective (CAS-ID) or subjective burden (CDS-ID). However the MBI revealed that caregivers of individuals with Down syndrome and dementia reported significantly increased levels of emotional exhaustion.

## **Discussion**

Findings suggested that, whilst even when there is little difference in the level of caregiving tasks or the perceived difficulties of caregiving, the onset of dementia in individuals with Down syndrome resulted in increased emotional exhaustion for caregivers. Additional factors not considered within this study, such as challenging behaviour, may also be pertinent to caregiver burden.

## Introduction

Despite the increasingly well-documented symptomatology relating to dementia in people with Down syndrome (Lai and Williams 1989; Burt et al 1995; Devenny et al 1996; Oliver, Crayton, Holland, Hall and Bradbury 1998), relatively little is known about their changing care needs, thus leading to little understanding of the resources required for service provision to respond effectively (McCarron, Gill, Lawlor and Begley 2002a). Literature within the general population has indicated that caregivers may spend an average of 11 hours out of every 24-hour period assisting a person with dementia in daily activities (Davis et al 1997). The fact that individuals with Down syndrome frequently experience more severe and precipitous cognitive decline (Prasher, Chung and Haque 1998) means that requirements upon caregiver resources may be even more immediate and intense (McCarron, Gill, Lawlor and Begley 2002b). The Caregiver Activity Survey (Davis et al 1997) was designed to measure time spent by caregivers assisting individuals with dementia in a range of daily activities in the general population. McCarron et al (2002a) modified this to develop the Caregiver Activity Survey – Intellectual Disability (CAS-ID) and piloted the measure in an Irish population of residential homes. Results indicated that staff caregiving time increased significantly when an individual with Down syndrome was diagnosed with dementia.

This can be considered in the context of findings indicating that, whilst caregivers are familiar with the demands associated with assisting an individual with intellectual disabilities, they may have little knowledge or understanding about the impact of dementia (Whitehouse, Chamberlain and Tunna 2000). This can result in a disparity between the demands placed upon the caregiver and the resources they have to fulfil them, a situation that increases the likelihood of stress and eventual burnout (Hobsfoll and Freedy 1993; Leiter 1993). Burnout has been defined as a pattern of emotional overload and exhaustion resulting from becoming

overly involved and overwhelmed by the emotional demands of working with those who are distressed (Maslach 1982). Burnout and stress are likely to have a negative impact on both the well being of the individual caregiver and the client they are working with (Hastings, Horne and Mitchell 2004; Rose, Jones and Fletcher 1998a; 1998b). It has also been suggested that some difficulties accompanying dementia (e.g. uncooperativeness, anger and depression) are not solely attributable to neuropathological changes in the afflicted person's brain, but can arise from problematic interactions with caregivers (Sabat 1994).

Before professionals are in a position to provide adequate support to caregivers in order to ensure both their wellbeing and the quality of care received by recipients, they must have a clear understanding of their needs and perceptions and the demands that are placed upon them. The aim of this study was to explore both the objective and subjective impact of dementia upon residential caregivers of individuals with Down syndrome. The study also aimed to pilot the use of the CAS-ID (McCarron et al 2002a) within a West Midlands service provision population as a valid assessment tool for exploring impact of dementia on care provision for individuals with Down syndrome.

## **Method**

### ***Participants***

Questionnaires were sent out to 28 professional caregivers working within group residential homes for adults with intellectual disabilities. The study presented here formed part of a wider investigation of dementia in older adults with Down syndrome. All targeted caregivers were keyworkers/main caregivers of an individual with Down syndrome or Down syndrome and acquired cognitive decline suggestive of dementia. The study focused solely upon residential care as individuals with Down syndrome who are experiencing dementia are more likely to be

living within residential accommodation as opposed to residing with family members. It was deemed inappropriate to attempt to make direct comparisons between paid and family caregivers as their situations differ so significantly.

Completed questionnaires were returned by 20 keyworkers/main caregivers, indicating a response rate of 71%. Of these care recipients, 9 (45%) were male and 11 (55%) were female. Ages ranged from 35 to 65 years old, with a mean age of 51.7 years (standard deviation (SD) = 7.8). 9 (45%) of these individuals presented with cognitive deterioration suggestive of a dementing process. This specifies that for such cognitive deterioration to be considered present, a series of repeated neuropsychological assessments should indicate acquired aphasia, apraxia, agnosia and learning and memory decline (Holland 1998; Oliver et al 1998). 11 (55%) presented with no additional cognitive decline.

### ***Design***

This study utilised a between-groups questionnaire design, comparing responses of main caregivers of individuals with Down syndrome and dementia with those provided by main caregivers of people with Down syndrome only.

### ***Procedure and Measures***

Staff caregivers were asked to complete the following measures with reference to their specific client with Down syndrome or Down syndrome and dementia:

*Caregiver Activity Survey – Intellectual Disability (CAS-ID)* (McCarron et al 2002a) - This is a quantitative measure of the amount of time paid caregivers spend in assisting people with learning disabilities in 8 primary daily living activities over a typical 24-hour period; (1)

dressings, (2) bathing, (3) looking after appearance, (4) toileting, (5) eating and drinking, (6) housekeeping, (7) nursing care related activities and (8) supervision and behavioural management. At present the measure has only been piloted in an Irish population where indications of reliability and validity were good (McCarron et al 2002a; 2002b).

*Caregiving Difficulty Scale – Intellectual Disability (CDS-ID)* (McCallion and McCarron 2005) – This is a modification of the Caregiver Hassles Scale (Kinney and Stephens 1989) and is a 38-item questionnaire designed to measure subjective burden of staff caregivers working with individuals with learning disabilities and dementia. It covers 3 subscales; (1) Day to Day Care, (2) Resources and Conflicts and (3) Family Concerns. Preliminary piloting of the measure in Ireland and USA suggests it provides a valid means of exploring subjective burden in staff caregivers (McCallion and McCarron 2005).

*Maslach Burnout Inventory (MBI) Human Services Survey* (Maslach and Jackson 1996) – This questionnaire asks staff to rate how frequently they experience 22 statements concerning their feelings about their job. These contribute to 3 subscale scores relating to burnout; (1) Depersonalisation, (2) Emotional Exhaustion and (3) Personal Accomplishment. The MBI is one of the most well-established measures of burnout with high levels of reliability and validity reported (Maslach, Jackson and Leiter 1996).

### ***Data Analysis***

Descriptive statistics (means and standard deviations) were used to explore the relationships between the dementia and non-decline group in terms of time spent caregiving (CAS-ID), perceived caregiver difficulties (CDS-ID) and self-rated burnout (MBI). T-tests were applied to test for significance of any differences found. Pearson's correlations were applied to explore the relationships between objective and subjective levels of reported burden overall.

Pearson’s correlation was also used to investigate the relationships between length of time engaged with psychology services and objective and subjective reports of burden.

Results

*Impact of dementia on time spent caregiving*

Mean number of minutes spent caregiving in each domain measured by the CAS-ID can be found in *Table 1*. T-tests revealed no significant differences between the dementia and non-decline groups in time spent caregiving in any specific domain (1) Dressing:  $t(18) = 0.55$ , non-significant (n.s.), 2) Bathing:  $t(18) = 0.28$ , n.s., 3) Looking after appearance:  $t(18) = 0.74$ , n.s., 4) Toileting:  $t(18) = 0.84$ , n.s., 5) Eating/drinking:  $t(18) = -0.54$ , n.s., 6) Housekeeping:  $t(18) = 0.49$ , n.s., 7) Nursing care:  $t(18) = 0.20$ , n.s., 8) Behaviour management:  $t(18) = 0.60$ , n.s., 9) Other:  $t(18) = 0.18$ . n.s.) or for overall time spent caregiving ( $t(18) = 4.11$ , n.s.).

*Table 1: Mean time (minutes) spent caregiving in typical 24-hour period*

	Dementia	Non-decline
Dressing	46.22 (SD 49.43)	35.45 (SD 37.78)
Bathing	45.56 (SD 36.79)	52.27 (SD 63.18)
Appearance	22.56 (SD 20.85)	34.36 (SD 43.74)
Toileting	15.22 (SD 26.47)	29.27 (SD 44.07)
Eating/drinking	51.44 (SD 82.79)	36.54 (SD 37.69)
Housekeeping	22.33 (SD 23.11)	30.00 (SD 41.41)
Nursing	19.11 (SD 24.62)	21.63 (SD 31.56)
Behaviour management	58.11 (SD 93.67)	98.63 (SD 182.51)
Other	53.44 (SD 81.36)	61.09 (SD 105.61)
Total	334.00 (SD 283.61)	399.27 (SD 401.11)

*Impact of dementia on caregiver’s perceived burden*

The CDS-ID measured perceived caregiver difficulties. The mean score for all caregivers was 18 (SD 13.26). The mean score for the dementia group was 16.22 (SD 11.57), whilst the mean score for the non-decline group was 19.45 (SD 14.89). A t-test revealed no significant difference ( $t(18) = 0.53$ , n.s.).

The MBI measured burnout in staff caregivers. Mean scores can be found in *Table 2*. These means indicated moderate levels of emotional exhaustion and depersonalisation amongst all caregivers but high levels of personal accomplishment (Maslach and Jackson 1996). Within the dementia group only, mean scores indicated a moderate level of emotional exhaustion, a low level of depersonalisation and a high degree of personal accomplishment. Within the non-decline group mean scores revealed low levels of emotional exhaustion and depersonalisation and high levels of personal accomplishment. T-tests revealed that the dementia group exhibited significantly greater scores associated with Emotional Exhaustion ( $t(18) = -2.83$ ,  $p<0.05$ ). No significant differences were found for Depersonalization ( $t(18) = -.053$ , n.s.) or Personal Accomplishment ( $t(18) = 1.01$ , n.s.) subscales.

*Table 2: Mean scores on MBI*

	Dementia	Non-decline
Emotional Exhaustion	24.22 (SD 11.98)	12.36 (SD 6.47)
Depersonalization	3.56 (SD 3.56)	2.82 (SD 2.93)
Personal Accomplishment	9.67 (SD 3.96)	12.73 (SD 8.30)

### *Relationship between objective and subjective caregiver burden*

A significant positive correlation was revealed between time spent caregiving (CAS-ID total score) and perceived difficulties in caregiving (CDS-ID score) ( $r = 0.76$ ,  $p < 0.001$ ). No other significant correlations were found.

### *Impact of Length of Time Engaged with Psychology Service*

Length of time engaged with clinical psychology services ranged from 0 – 49 months. The overall mean length of time was 17.5 months (SD 16.38). The mean time engaged with psychology services for individuals without cognitive decline was 21 months (SD 19.78), compared with 13.6 months (SD 11.44) for individuals with dementia. This difference was non-significant ( $t(18) = 0.99$ , n.s.). Significant positive correlations were revealed between length of time engaged with psychology services and both time spent on caregiving tasks (CAS-ID total score) ( $r = 0.49$ ,  $p < 0.05$ ) and perceived difficulties in caregiving (CDS-ID score) ( $r = 0.52$ ,  $p < 0.05$ ).

## **Discussion**

The findings of this study suggested that there was little difference in time spent on caregiving tasks for paid caregivers working with individual with Down syndrome and cognitive decline suggestive of dementia and those working with people with Down syndrome and no additional decline. Over a typical 24-hour period, those caring for individuals with Down syndrome and dementia reported spending an average of 5.56 hours on care and support, compared with 6.50 hours reported by those caring for individuals without cognitive decline. This contrasts with previous findings utilizing the CAS-ID, which suggested that caregiving demands were significantly greater for people with Down syndrome and dementia (McCarron et al 2002b). Within that study, it was reported that caregivers of people with Down syndrome

and dementia spent an average of 9 hours on caregiving tasks, as opposed to 2.53 for those without dementia. This presents a disparity with the caregivers surveyed within this study, where those working with individuals with Down syndrome and dementia appeared to be reporting lower task demands, whilst those working with people with Down syndrome were reporting greater lengths of time spent providing care.

Therefore it would appear that factors in addition to the presence of dementia-related decline could be equally important in determining the time demands placed upon caregivers. The study conducted by McCarron et al (2002b) surveyed caregivers of individuals in mid-late stage dementia. By contrast, all but one of the individuals with dementia in this study was classified as early-mid stage. This suggests the value of further research exploring the task demands placed upon caregivers within each stage of dementia and the findings of this study add further support to the utility of the CAS-ID as a useful measure of this.

A second aim of this study was to explore the subjective burden and impact of caregiving for individuals with Down syndrome and dementia versus those with Down syndrome only. No significant differences were revealed in perceived caregiver difficulties, as measured by the CDS-ID. The CDS-ID was designed predominantly to measure difficulties experienced in caring for individuals with Down syndrome and dementia. However, within this study many caregivers of people with Down syndrome and no decline nevertheless reported a number of these issues to be occurring. This suggests that it may have been useful to measure additional factors, such as challenging behaviour, as they may have proved more closely related to perceived caregiver difficulties than the label of dementia alone. It also supports the value of further investigation regarding aspects of difficulty that may be unique to those caring for people with Down syndrome and dementia, compared with those that are shared by caregivers

of people without dementia. The findings of this study suggest the value of further research to explore the validity of the CDS-ID, as it currently provides a unique means of exploring difficulties relevant to individuals' caregiving for those with within the Down syndrome population.

In terms of findings related to burnout in this study, as measured using the MBI, these suggested that caregivers of individuals with Down syndrome and dementia experienced significantly greater levels of emotional exhaustion. This may appear surprising given that differences in time spent caregiving or perceived difficulties could not be detected. However, no data was available to indicate the level of care previously required by individuals before they developed dementia, thus it may be that this had still increased markedly even though it had not reached the levels described by other studies (e.g. McCarron et al 2002b). Equally, if staff caregivers have little knowledge or understanding about the impact of dementia within their care recipient (Whitehouse et al 2000), it could be argued that this will increase the emotional stress of the caring role overall. The experience of observing care recipients deteriorate with a dementing condition is also likely to be distressing. Therefore, even if the actual physical management process had not become too arduous for the caregivers surveyed in this study, this could be a factor in their increased levels of emotional exhaustion.

The actual demands presented by spending a specific amount of time providing care or assistance to someone with dementia are likely to be much greater than those involved in spending the equivalent time period assisting someone without such decline. The onset of dementia may introduce a level of unpredictability into a care recipient's once familiar behaviour and previous studies have suggested a correlation between behavioural unpredictability and stress in caregivers (Bromley and Emerson 1996). This mirrors generic

findings regarding the link between occupational stress and uncertainty (Brodsky 1985). Thus the finding regarding enhanced emotional exhaustion in caregivers of those with dementia could be viewed in this context. Whatever its specific causes, emotional exhaustion is an indication of potential burnout (Maslach and Jackson 1996) and may be detrimental both to the carer themselves and their care recipients. Therefore further research exploring this and the possible causes for it is required in order to develop appropriate means of addressing it and providing support within service provision.

The relationship between perceived and objective caregiver demands was also considered. Findings indicated a positive correlation between time spent caregiving and levels of difficulty experienced within this, suggesting that overall increasing demands on time are also likely to involve increasing stresses. Given the association reported between challenging behaviour and caregiver well-being (Donaldson 2002), this is likely to have an impact upon quality of long term care. In addition, positive correlations were found between length of time a care recipient had been engaged with psychology services and both time spent on caregiving and reported difficulties experienced. This further supports the hypothesis of the influence of additional long-term issues and problems, independent of dementia status and not explicitly explored within this study, on caregiver burden. Equally, all care recipients with Down syndrome and dementia had received psychological input for at least 6 months. This is likely to have been influential in informing caregivers about appropriate management of everyday issues related to dementia, thus reducing some of the difficulties in this, which may have otherwise been perceived.

A number of limitations are present within this research. Due to population limitations and the fact that this only aimed to be an exploratory study, the number of participants is relatively

small. No information on staff characteristics, such as demographics, was collected as it was felt respondents may have perceived this as being a threat to their anonymity and therefore have been less willing to complete the questionnaires, particularly the MBI. It also needs to be taken into account that the concepts of burnout and the perception of work-based difficulties are complex constructs that are likely to be affected by additional factors not taken into account within this study. These include personal vulnerabilities, external factors and issues within the working environment. Whilst the staff surveyed were the main caregivers of an individual with Down syndrome or Down syndrome and dementia, the unexplored impact of working with other specific care recipients was also impossible to exclude.

### ***Conclusions and Clinical Implications***

This exploratory study highlights a number of areas requiring further and more detailed research. In general more research is required to explore the needs and perceptions of caregivers of people with dual diagnosis of Down syndrome and dementia as this area has been greatly neglected. This study supports the value of gaining a greater understanding of the impact dementia has upon quality of care for those with Down syndrome and upon the well-being of those providing it. The findings suggest that it would be of particular interest to further explore factors associated with emotional stress and impact, in order that service provision and working environments may better meet these needs. It would also be of use to assess objective and subjective demands placed upon caregivers longitudinally, as dementia progresses in care recipients and their needs change. Such research would help to clarify specific interventions appropriate to varying stages of the disease.

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## **Chapter 4**

### **Reflective Review of the Research Process**

Word count: 3010 (excluding references)

Throughout the entire research process I have used a reflective journal as a means of recording my developing views, questions and emerging ideas as the research has progressed. The following reflections are based both on the entries recorded in my journal and my own thoughts following the completion of my doctoral research project.

### **Developing a Research Question**

My interest in working with individuals with Down syndrome and dementia dates back to my post as an Assistant Psychologist. In this post, I worked within a psychology service for older adults with intellectual disabilities and became aware of the increased vulnerability of people with Down syndrome to developing Alzheimer's disease. During my first year of clinical psychology training I developed an interest in the subjective perspectives and experience of individuals with dementia but was struck by the fact that, whilst very little research had been undertaken in this area within the general population, no published studies existed at all relating to individuals with intellectual disabilities. I was concerned by this, given the increased vulnerability of people with Down syndrome to developing dementia, and in reflecting on my experience working with this population, I felt that it would be insufficient to simply generalise from findings within the general population because life experiences, perspectives and contexts were likely to vary so significantly.

From this point I began to develop my research question. I was particularly interested in the way that people with Down syndrome spend their lives experiencing the internal and external consequences of cognitive difficulties and how this would impact upon their ability to make sense of and cope with the deterioration associated

with the onset of dementia. From my own clinical experience I was aware that very few people with Down syndrome were informed when they were given a diagnosis of dementia and therefore wondered what constructions and appraisals they developed for themselves. Equally, I had also observed that the early stages of dementia in people with Down syndrome were frequently misinterpreted by those around them as challenging or difficult behaviour. I was interested in whether the individual themselves would have insight into their changing behaviour and abilities and the impact that interactions with others had. In developing my research question I hoped to be able to capture a “snapshot” insight into the lived experience of people with Down syndrome and dementia.

My interest in this area also led me into the development of the brief paper question, as I became aware research was also very limited considering the impact of dementia on the residential care that individuals with dementia received. I felt that the onset of dementia was likely to impact upon the caregivers as well as this individual themselves and that this in turn could affect their entire life context.

### **Researcher Position**

Having chosen a main research question that was best suited to the use of Interpretative Phenomenological Analysis (IPA), I began to develop an understanding of the importance of acknowledging my own position as the researcher within the area I was exploring. Goodley (1996) emphasised the need for reflection in qualitative research, both in relation to the role of the researcher when participants’ accounts are collected and the researcher’s role in the interpretation and presentation of these. This

led me to reflect upon my own position and the potential impact I may have upon the research process.

With regard to the interview process, a number of factors appeared pertinent and I became aware of the similarities and differences between myself and the participants that could be potentially influential. I am female and therefore shared gender status with two respondents. In terms of age, cognitive impairment and life situation however there were many differences. Perhaps the most significant issue I was aware of was the status of health professional versus service user. As a clinical psychologist in training, I conducted this research as part of a requirement for my doctorate training in clinical psychology. Whilst this was made clear to my research participants, I was also undertaking a specialist placement within the same service meaning that some were aware of me in my capacity as a professional within the service they received. This may have impacted upon the power dynamic of the interviewer-respondent relationship. In particular I was aware of the desire of some of my participants to give the “correct” response, despite the fact that I had emphasized my interest in their own views and opinions. Some participants apologised repeatedly when they were unable to recall a particular item of information. This may have reflected a natural tendency to do so within their everyday lives, but could also have been a result of their perception of me as health professional leading to enhanced anxiety concerning the validity of their responses.

A number of issues concerning my position in interpreting and presenting participants’ accounts within this research should also be considered. This study was greatly informed by my own experience working with individuals with Down

syndrome and dementia and by literature gathered from studies of dementia in people within the general population and qualitative accounts given by individuals with intellectual disabilities but no additional cognitive decline. In conducting this research I hoped to gain some greater understanding of the relationship and link between all of these.

A further impetus for this study arose from my own interest in literature around the personal identity and social positions held by individuals with intellectual disabilities and the potential impacts that additional cognitive deficits derived from dementia may hold. I was also particularly attracted to the concept of research as a means of facilitating the voice of individuals who have been traditionally silenced due to their intellectual and communicative difficulties. However I was also aware of the need to hold in mind the argument that, whilst research can be justified as a means of facilitating the concerns of individuals labelled disabled, there is also a need to be honest about the benefits researchers received from conducting such research (Zarb 1992). For me as a researcher, the primary benefit lay in my wish to successfully complete my doctoral qualification. Therefore I had to be aware of the balance I was holding between wanting to present the voice of participants who had not previously been heard within published research and wanting to ensure that my research met the necessary standards required to pass the course. In considering this potential dilemma I found it useful to refer to previous literature where this had also been addressed as a relevant issues (e.g. Proctor 2001; Scior 2003).

## **Ethics**

Due to the potential vulnerability of my research population, ethical considerations were highly significant. I was particularly concerned with issues of informed consent and that respondents should not feel coerced into participating. As my respondents were already involved in ongoing research relating to Down syndrome and dementia, consent had already been obtained. However I also sought additional consent both prior to commencing my interviews and during the entire process. I was also guided by literature relating to conducting research with individuals with cognitive deficits, which recommended being vigilant to additional cues, such as body language. Whilst this research did not explicitly address the concept of dementia, as all participants were unaware of their diagnosis, the topics discussed still held potential for distress. Therefore I attempted to be sensitive to this possibility throughout the process of interviewing.

## **Data Collection**

This research presented my first opportunity to use semi-structured interviewing as a means of data collection. I found the process of developing an interview schedule particularly challenging, in ensuring that questions were phrased in an appropriate way for individuals to comprehend and respond to and the advice and suggestions of supervisors skilled in this area of clinical practice was invaluable. I was also particularly keen that the interviews should present individuals with the opportunity to voice their own concerns and that the interviews should therefore be open enough for them to redirect the conversation if they wished. I felt that this would be a means of avoiding being constrained by my own agenda as a researcher.

Challenges within the interview process included managing my own anxieties when communication difficulties arose. Respondents having difficulty understanding my questions and my issues relating to their indistinct speech responses were particularly common. However, as the interviews progressed I began to note that initial communication barriers were often eliminated as rapport increased and the respondents and myself adjusted to each other's articulation and comprehension styles and abilities. I also found that pre-interview meetings were particularly useful in developing this but was unfortunately unable to conduct these with all participants due to time constraints.

Prior to conducting the interviews I had been aware of the possibility that issues which were potentially distressing to participants may be raised. I was attracted by Hubbard et al's (2003) recommendation that, though the primary role of research is evidence gathering, it is important to be sensitive to respondents' emotional states and provide support if necessary. It was argued that otherwise researchers risk inadvertently contributing to heightened feelings of loss, fear and distress (Hubbard et al 2003). As a result I attempted to remain sensitive to participant's responses throughout and provide frequent reassurance and empathy. All interviews were also conducted within a private room in the individual's home or day centre, to ensure familiar surroundings, both during and afterwards. However I found that this process was still not always easy to manage. Two respondents within the study spoke in detail about recent bereavements and on these occasions I found it challenging to maintain a balance between providing support and gathering information within the interview. The fact that I was also on placement within the psychology service where I conducted the interviews was very helpful, as it ensured I knew the procedures for

offering additional support if required and also had opportunities to discuss my own feeling and responses with my supervisor.

For my brief paper research, questionnaires were utilised and this process also presented its own challenges. In conducting interviews I had become used to having an active impact on the collection of my data. Therefore awaiting the return of postal questionnaires felt somewhat passive and anxiety provoking.

### **Transcription and Analysis**

The process of transcribing the interviews provided its own unique frustrations and challenges. Sound quality was often impaired when playing back the taped interview and I seemed to spend a lot of time rewinding and re-listening to particular segments of each interview where I was unable to discern what a respondent had said. This inevitably also seemed to occur just as they seemed to be expressing something of particular interest! I am also not a natural touch-typist and therefore the process of listening and typing felt somewhat arduous. There were however, positive aspects. I found the transcription stage to be invaluable to familiarising myself with my data and developing preliminary thoughts and observations which were later utilised within the analysis process. I also found that the process of transcribing impacted upon my own views of speech and the use of language, by increasing my awareness of both my client's use of language within the therapeutic context and my own speech patterns and habits and the potential impacts of these.

In terms of analysis, IPA was a new methodological approach to me. Therefore a lot of time was spent reading around this area and familiarising myself with studies

which had also employed the technique. An additional source of challenge for me was the paucity of published research utilising qualitative interviews with individuals with cognitive impairment and communication deficits. At times I felt anxious that my interviews would be insufficiently long or rich enough to use IPA. This anxiety was reduced as I actually progressed with interviewing and commencing analysis and began to realise that, whilst respondents discourse was at times fragmented, disorganised or brief, they nevertheless had interesting and discernable stories and opinions to relate. Analysis also confirmed that identifiable themes were emerging and at this time I began to relax and enjoy the research process somewhat more. I also remained very vigilant to ensuring that my interpretations remained grounded in the interview data, aware of the warning that through analysis the voices of people with intellectual disabilities can be filtered and given meaning in the researcher's own terms (Swain et al 1998). Whilst a degree of this is an expected and accepted consequence of using IPA, I was keen to avoid entirely appropriating and silencing the respondents' perspectives, particularly given their expressive language limitations.

The opportunity to analyse questionnaires using quantitative techniques provided me with an interesting contrast to the qualitative methods I was applying to my main research interviews. It also increased my awareness of the unique advantages and disadvantages presented by qualitative and quantitative approaches and prompted me to clarify my own position more clearly with regard to this. In particular it has increased my interest in utilising qualitative methods to gain a greater understanding of lived experience. I have also developed a greater interest in the use of such approaches with individuals who have traditionally been excluded from this research, such as those with expressive language deficits.

## **Writing-up**

Despite anticipated and realised stress regarding impending deadlines, the write-up process was particularly rewarding for me. Having spent many months attempting to familiarise myself both with the relevant literature and my own data, I found that writing-up my research enabled me to develop my understanding about the links between all of these and finally gain a clear focus of the position of my own findings. The distinct chapters of my research also interrelated and writing-up each provided valuable insights into the others. For example, my literature review, examining the use of qualitative interviews with individuals with expressive language difficulties, provided useful insights into my own experience of interviewing people with Down syndrome and dementia for my main research paper, and vice versa.

## **Impact of Others**

Advice, suggestions and support from others played a vital role in the entire research process. I found regular meetings with clinical and academic supervisors to be invaluable in assisting in the development of ideas and focus and, at times, in containing my own anxieties. Their own practice as clinical psychologists also formed an important influence in shaping this research. I also participated in an IPA consultation group along with other researchers utilising this approach. This proved to be a useful means of developing my own understanding of and ability to use the technique in providing me with the opportunity to discuss and validate my own analysis and doing the same for others. It was also reassuring to find that others made similar interpretations to those I had, confirming that they were grounded within the data.

## **Impact of the Research**

One of my primary focuses in undertaking this research was the appeal of using research to give voice to a population who had not been heard within published studies. The process of the research has led me to reflect upon the impact it can actually have. I was interested to consider arguments for the use of qualitative research in an emancipatory and empowering way for marginalized populations (Barnes 1992). However I am also aware that this can only occur when individuals are able to empower themselves (Proctor 2001), and society currently presents limited viable means (e.g. self-organised action groups) for individuals with Down syndrome and dementia. Zarb (1992) distinguished between participatory and emancipatory research, and in reflecting on this research it is hoped that it was at least participatory and provided the opportunity for individuals to express their subjective realities. Equally, through dissemination in appropriate journals it is hoped that this research could be used both to enhance understanding in this area and as a means of prompting further studies.

## **Impact of Research on Clinical Practice**

Conducting this research has impacted upon my clinical practice in a number of ways. From a practical perspective, my ability to balance research and clinical commitments has developed through the experience of conducting this research predominantly whilst on placement at the same time. However I have also been aware of changes and developments in my conceptualisation within clinical practice as a consequence of this research. My specialist placement conducted alongside this research provided an opportunity for my research to be informed by my clinical work and vice versa. I feel that my research has enhanced and informed my understanding of the perspectives

and experiences of the clients I have been working with and their caregivers. Equally, many of the links I have been able to make within the research process have been informed by my clinical experiences.

I have become particularly aware of the fact that individuals with Down syndrome are very rarely informed when they are given a diagnosis of Alzheimer's disease. Whilst there are increasingly recommendations concerning the need to inform older adults within the general population when they are diagnosed with dementia, this does not seem to be the case for adults with Down syndrome. I feel that I had previously accepted this with very little question. Having spent time hearing the perspectives and subjective experiences of people with Down syndrome living through dementia, I have now begun to consider whether coping processes may be enhanced by being provided with some form of explanation. Clearly this issue is accompanied by complex ethical and practical considerations but I feel that my research has led to me to begin considering how this might be best managed.

### **Personal Reflections on the Research Process**

When I commenced this research I had gained previous experience in completing a PhD. However that research was purely quantitative and also utilised non-clinical populations, conducting studies in laboratory conditions. Therefore I feel that my personal development and research skills have been further enhanced through the process of carrying out this research. It has provided me with the opportunity to develop skills, understanding and interest in the use of qualitative methodology. I have also found that my interest and enthusiasm has been maintained throughout because of the dual experience of conducting research and carrying out clinical

practice with the same client group. I have become more aware of the pressures of conducting research with a limited population size, particularly when time constraints are narrow. Overall, my research experience has been extremely positive and the initial interest that prompted the development of this area of questioning has only been increased and enhanced by the process of doing so. As I near completion I am left predominantly with more questions that I would like to explore within this area as a result of the conclusions I have drawn from my research.

## References

Barnes, C. (1992) Qualitative research: Valuable or irrelevant? *Disability, Handicap and Society*, 7, 115-124.

Goodley, D. (1996) Tales of hidden lives: A critical examination of life history research with people with learning difficulties. *Disability and Society*, 11, 333-348.

Hubbard, G., Downs, M.G. and Tester, S. (2003) Including older people with dementia in research: Challenges and strategies. *Aging and Mental Health*, 7, 351-362.

Proctor, G. (2001) Listening to older women with dementia: relationships, voices and power. *Disability and Society*, 16, 361-376.

Scior, K. (2003) Using discourse analysis to study the experiences of women with learning disabilities. *Disability and Society*, 18, 779-795.

Swain, J., Heyman, B. and Gillman, M. (1998) Public research, private concerns: Ethical issues in the use of open-ended interviews with people who have learning difficulties. *Disability and Society*, 13, 21-36.

Zarb, G. (1992) On the road to Damascus: First steps towards changing relations of disability research production. *Disability, Handicap and Society*, 7, 125-138.

## Appendices

**Appendix 1: Ethical approval**

## STUDENT SUBMISSION TO SCHOOL RESEARCH ETHICS COMMITTEE

1. Student's name: VICTORIA LLOYD  
(BLOCK CAPITALS)

2. Course: CLINICAL PSYCHOLOGY  
DOCTORATE COURSE

3. Title of project: DEVELOPING A PROTOCOL FOR PSYCHOSOCIAL INTERVENTIONS FOR PEOPLE WITH DOWN'S SYNDROME WHO DEVELOP DEMENTIA: A STUDY OF THE PERSPECTIVES, IMPACT AND LIVED EXPERIENCES OF LIVING WITH DEMENTIA IN INDIVIDUALS WITH DOWN'S SYNDROME

4. Summary of the project in jargon-free language and in not more than 120 words:

Sample: STUDY 1: 4-6 people with Down's Syndrome and Alzheimer's disease  
STUDY 2: 15 paid caregivers of people with Down's Syndrome and Alzheimer's disease and 15 paid caregivers of people with Down's Syndrome only

Research site:

Psychology Services for Older Adults with Learning Disabilities  
South Birmingham Primary Care NHS Trust (REC Trust ethical approval obtained)

Design (eg experimental): STUDY 1: qualitative case study approach

STUDY 2: Quantitative between Subjects comparison

Methods of data collection:

STUDY 1: Participants will be interviewed 4 times over a period of 8 months

Interviews will be semi-structured and take the form of a conversation around issues such as perception of current life situation and whether the person has noticed any changes or difficulties of late. Interviews will be audiotaped, transcribed and analysed.

STUDY 2: Participants will be given copies of the Caregiver Activity Survey - Intellectual Disabilities (CAS-10) and a questionnaire of caregiver burden based on the Carer Burden Scale or another suitable measure. Responses given by caregivers of people with Down's Syndrome and dementia will be compared to those given by caregivers of people with Down's Syndrome only

Access arrangements (if applicable): Participants will be recruited via the Adults with Down's Syndrome research project based at the University of Birmingham and South Birmingham PCT

- |  |   |  |
|--|---|--|
| 5. Will the project involve patients(clients) and/or patient(client) data?   | Yes <input checked="" type="checkbox"/> | No <input type="checkbox"/>            |
| 6. Will any invasive procedures be employed in the research?   | Yes <input type="checkbox"/>            | No <input checked="" type="checkbox"/> |
| 7. Is there a risk of physical discomfort to those taking part?  | Yes <input type="checkbox"/>            | No <input checked="" type="checkbox"/> |
| 8. Is there a risk of psychological distress to those taking part?   | Yes <input type="checkbox"/>            | No <input checked="" type="checkbox"/> |
| 9. Will specific individuals or institutions (other than the University) be identifiable through data published or otherwise made available? | Yes <input type="checkbox"/>            | No <input checked="" type="checkbox"/> |
| 10. Is it intended to seek informed consent from each participant (or from his or her parent or guardian)?                                   | Yes <input checked="" type="checkbox"/> | No <input type="checkbox"/>            |

Student's signature:

[Signature]

Supervisor's signature:

[Signature]

Date:

30/4/04

#### FOR COMMITTEE USE:

Immediate approval ☒

Referral to local Hospital Ethics Committee ☐

☒  
☐

Referral to full School Committee ☐

Decision pending receipt of further information (specify below) ☐

☐  
☐

Committee Member's signature:

[Signature]

Date:

12/5/04

**Warwickshire Local Research Ethics Committee**

Lewes House  
George Eliot Hospital  
College Street  
Nuneaton  
Warwickshire  
CV10 7DJ

Tel: 02476 865244  
Fax: 02476 865058  
pat.horwell@geh.nhs.uk

Our Ref : PH/PAH

Your Ref :

18<sup>th</sup> March 2004

Ms DM Adams,  
Part of the Ageing in Downs Syndrome Research Team,  
University of Birmingham,  
School of Psychology  
Edgbaston  
Birmingham B15 2TT

Dear Dawn,

**LREC REF : RE 447a The early signs of dementia in adults who have Downs Syndrome**

Further to the supply of the application of the above study we will treat the documentation you have submitted as for our information only and we are acknowledging this in writing. It will not require a further review by us.

We suggest that the next time there is a substantial amendment for this research you make an application to the MREC and if they decide that there are Local Investigators in Warwickshire then we will expect to receive a Part C for Site Specific Assessment together with a copy of the CV.

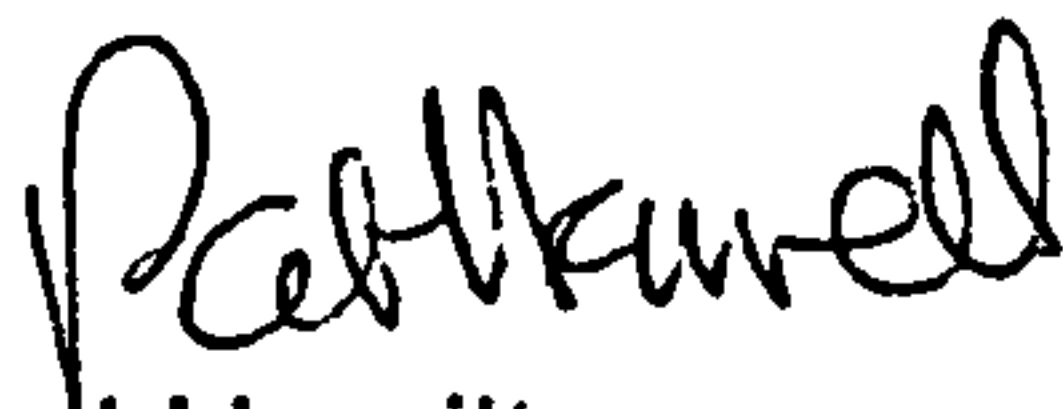
The Committee has had difficulty in following this research process and to advise you appropriately because it has coincided with a period of continuous change in the process.

In order to complete the audit trail I am copying this letter to the Warwickshire PCTs for their information and would be grateful if you would let me have a copy of the approval letter from the Birmingham 'Lead' LREC.

Please do not hesitate to contact me if you have any queries.

Your application has been given a unique reference number, please use it on all correspondence with the LREC.

Yours sincerely,



Paul Hamilton  
Chairman

Warwickshire Local Research Ethics Committee

c.c. NWPCT/SWPCT



# GOOD HOPE HOSPITAL

NHS TRUST

Good Hope Hospital  
Rectory Road  
Sutton Coldfield  
West Midlands  
B75 7RR  
Tel: (0121) 378 2211  
Fax: (0121) 311 1074  
Ext. 2676

XXXXXX  
direct fax:  
e-mail:

## NORTH BIRMINGHAM RESEARCH ETHICS COMMITTEE

Rec-29/6/00

Our ref: 521.00

26th June 2000

Dr. Sunny Kalsy  
Chartered Clinical Psychologist/Honorary  
Research Fellow  
Learning Disability Service  
66 Anchorage Road  
Sutton Coldfield B74 2PH

Dear Dr. Kalsy

**Re: Developing a Protocol for Psychosocial Interventions for People with Down's Syndrome who Develop Dementia.**

Thank you for attending the meeting of the North Birmingham Research Ethics Committee on 26th June 2000. Your input was very helpful.

The documents reviewed were:

- NBREC application form
- Revised Budgetary Details
- Questionnaire, ref. D.M.R.
- Interview Form, BASOLL: The behavioural assessment scale of later life.
- Patient Information letter
- Invitation to participate
- Patient Information Sheet
- Patient Information Sheet (2)
- Patient Consent Form
- Patient Consent Form (2)
- Guidelines for observing participants
- Letter from Dr. Kalsy to Revd. Ball dated 15th June 2000 enclosing Information Sheet (Intervention Stage) dated June 2000, Consent Form (Intervention Stage) (2), Guidelines to accompany information for Volunteers, Information for Volunteers incorporating Makaton symbols.

It has been decided by the North Birmingham Research Ethics Committee to approve the above study but the Committee would like to emphasise the following points:



1. For a patient/client to sign a consent form the evidence that the patient/client is competent to give a valid consent must be convincing.
2. If valid consent is not obtainable then the "assent" of the next of kin or carer must be obtained. The consent form needs to be amended so that it is clear that the carer is giving assent and they should sign to say that they know of no reason why the patient/client should not participate in the trial and that they feel the patient/client would be willing to do so.
3. If, at any time, the patient/client indicates a reluctance or refusal to co-operate with the research, either the assessment element or the interventional element, then this should be treated as the withdrawal of consent/assent and the patient/client should be withdrawn from the trial.

Although the NBREC has given approval of this study from an ethical point of view, it is still the responsibility of the investigator to obtain management approval, if this has not already been done, from the relevant Clinical Directors and/or Chief Executives of the Trusts (or Health Boards/DHAs) in which the work will be carried out.

The Committee requires notification of any amendments to your study. We would like a progress report annually until the conclusion of the study and a copy of the final report when it is available, please.

I hope all goes well with the research.

Yours sincerely

A handwritten signature in black ink, reading "Andrew T Ball", is written over a horizontal line.

**Reverend Andrew T Ball**  
Chairman  
North Birmingham Research Ethics Committee



# CITY HOSPITAL NHS TRUST

DUDLEY ROAD, BIRMINGHAM. B18 7QH

[www.cityhospital.org.UK](http://www.cityhospital.org.UK)

Ref: BS/SH.

Telephone: (0121) 554 3801

Fax: (0121) 507 5637

Direct Dial: (0121) 507 4396

Dr. S. Kalsy,  
Honorary Research Fellow,  
School of Psychology,  
University of Birmingham,  
Edgbaston,  
Birmingham, B15 2TT.

14th July, 2000

Dear Dr. Kalsy,

Re: LREC 00/04/81 - Developing a protocol for psychosocial interventions for people with Down's syndrome who develop dementia

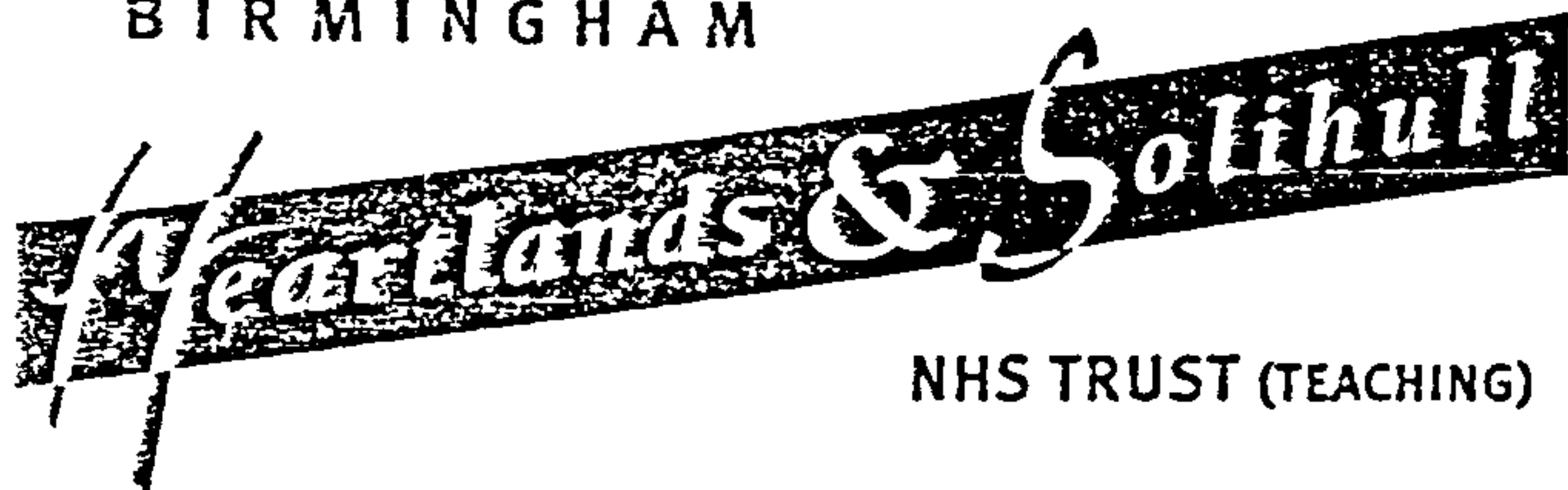
Thank you for submitting this proposed study and for supplying further information in the light of comments made by the LRECs in North and East Birmingham. I apologise for the delay in responding to your application.

The study has been reviewed by myself and another member of the Committee, and I am happy to give Chairman's approval for you to proceed with the project.

Yours sincerely,

B. SPECULAND,  
Chairman - Research Ethics Committee

BIRMINGHAM



BIRMINGHAM HEARTLANDS HOSPITAL  
BORDESLEY GREEN EAST  
BIRMINGHAM B9 5SS

TEL: 0121 - 766 6611  
FAX: 0121 - 685 5558

BIRMINGHAM HEARTLANDS HOSPITAL

EAST BIRMINGHAM LOCAL  
RESEARCH & ETHICS COMMITTEE  
UNDERGRADUATE CENTRE

Direct Line / Fax: 0121 685 5952

Administrator Ext 4945

SJR/LMH/0533

11 July 2000

Professor Chris Oliver  
School of Psychology  
University of Birmingham  
Edgbaston  
Birmingham  
B15 2TT

Dear Professor Oliver

Developing a protocol for Psychosocial Interventions for people with Down's  
Syndrome who develop dementia

Your project has been approved by the Ethics Committee, who have considered that this is quite acceptable as outlined in your submission. This approval is subject to the proviso that there is no significant deviation from the Protocol outlined and that any untoward reactions and complications are immediately reported to the Committee.

In order to comply with the Royal College of Physicians guidelines, I look forward to receiving a report on the outcome of this study.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Stephen J Rose', written over a horizontal line.

Stephen J Rose  
Chairman  
Research & Ethics Committee

NB This Committee abides by the guidance of the Department of Health. The committee endorses the Royal College of Physicians Report on 'Fraud & Misconduct in Medical Research Practice 1991'. This states that all original data (such as questionnaires, lab books, and hard copies of any computer data), are kept for a minimum of ten years in a retrievable form. If storage is going to be outside Birmingham Heartlands Hospital, the submission should state the site of storage. It is a condition of ethics approval that such storage occurs.



**GOOD HOPE  
HOSPITAL**  
NHS TRUST

Good Hope Hospital  
Rectory Road  
Sutton Coldfield  
West Midlands  
B75 7RR  
Tel: (0121) 378 2211  
Fax: (0121) 311 1074

~~direct line~~ Ext. 2676  
direct fax:  
e-mail:

## **NORTH BIRMINGHAM RESEARCH ETHICS COMMITTEE**

**Our ref: 521.00**

20th December 2000

Dr. Sunny Kalsy  
Chartered Clinical Psychologist/Honorary Research Fellow  
Birmingham Specialist Community Health NHS Trust  
Services for People with Learning Difficulties  
66 Anchorage road  
Sutton Coldfield B74 2PH

Dear Dr. Kalsy

**Re: Developing a Protocol for Psychosocial Interventions for People with Down's Syndrome who develop Dementia.**

Further to my letter to you of 6th December 2000, I am writing to inform you that the protocol amendments (amended Information Sheet (Assessment Stage) and the Invitation to Participate letter, both for the control group) were approved by the North Birmingham Research Ethics Committee at its meeting on 11th December 2000.

Yours sincerely

**Reverend Andrew T Ball**  
Chairman  
North Birmingham Research Ethics Committee



Winner of 2 NHS 'Beacon' Awards

Sir Bernard Zissman (Chairman) Jitf Chandra (Chief Executive)  
A Teaching Trust in partnership with Birmingham University medical school

REC 80/12/02

# EAST BIRMINGHAM LOCAL RESEARCH ETHICS COMMITTEE

Administrator  
Secretarial Assistant

Ext 42679  
Ext 43675

Email: [linda.hubbard@heartsol.wmids.nhs.uk](mailto:linda.hubbard@heartsol.wmids.nhs.uk)

SK/LMH/0533 (Please quote reference in all correspondence)  
13 December 2002

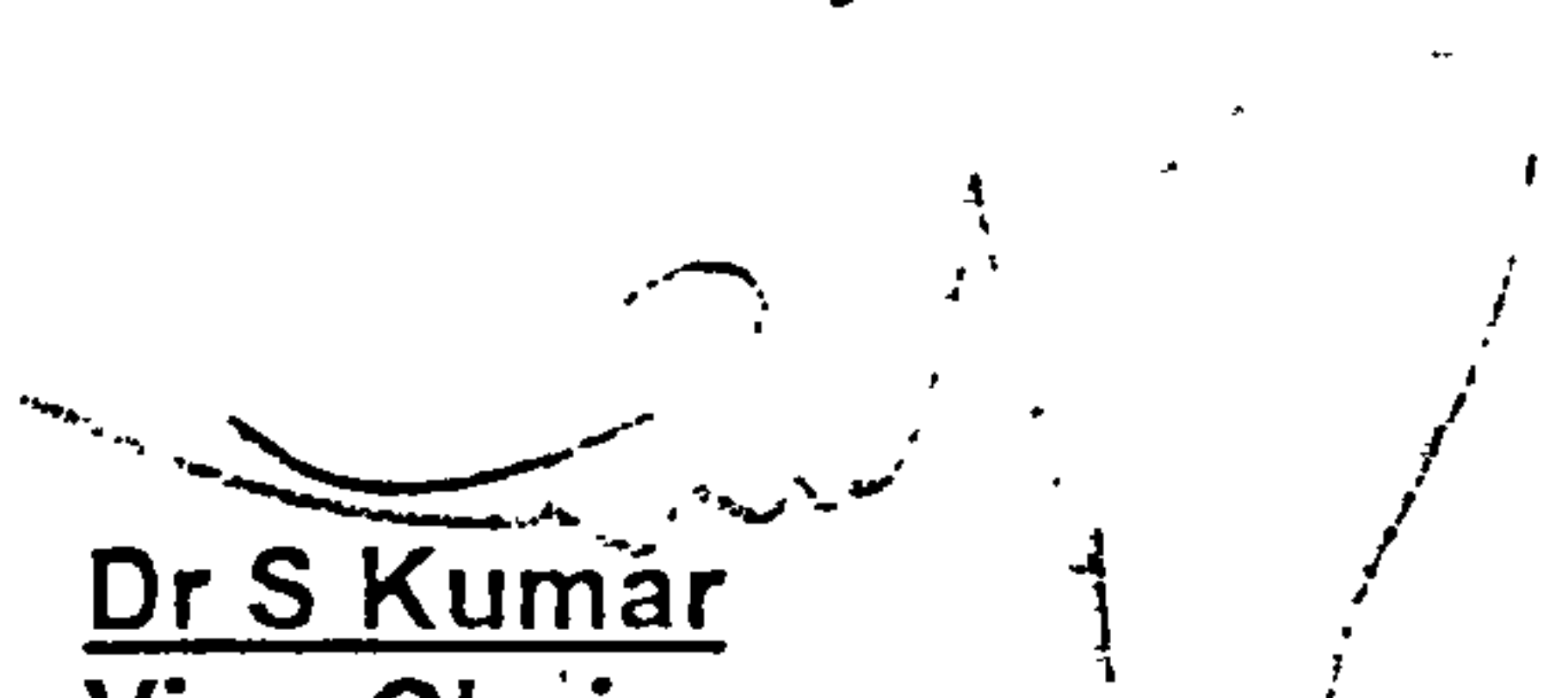
Dr Sunny Kalsy  
Clinical Psychologist/Project Manager  
South Birmingham Primary Care Trust  
66 Anchorage Road  
Sutton Coldfield  
West Midlands  
B74 2PH

Dear Dr Kalsy

## DEVELOPING A PROTOCOL FOR PSYCHOSOCIAL INTERVENTIONS FOR PEOPLE WITH DOWN'S SYNDROME WHO DEVELOP DEMENTIA

The East Birmingham LREC reviewed and approved your Protocol Amendment to increase the increased number of participants, and also the timescale in which this is to be done.

Yours sincerely

  
Dr S Kumar  
Vice-Chairman  
Research & Ethics Committee

# Birmingham Heartlands & Solihull



**EAST BIRMINGHAM LOCAL  
RESEARCH & ETHICS COMMITTEE  
UNDERGRADUATE CENTRE**

NHS Trust (Teaching)

**Birmingham Heartlands Hospital**  
Bordesley Green East  
Birmingham B9 5SS

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Administrator Ext 42679  
Secretarial Assistant Ext 43675

Tel: 0121 424 2000  
Fax: 0121 424 2200

email: [hubbardl@heartsol.wmids.nhs.uk](mailto:hubbardl@heartsol.wmids.nhs.uk)

**SJR/LMH/0533** (Please quote reference in all correspondence)  
01 December 2000

Dr Sunny Kalsy  
Chartered Clinical Psychologist/Honorary Research Fellow  
Services for People with Learning Disabilities  
66 Anchorage Road  
Sutton Coldfield  
B74 2PH

Dear Dr Kalsy

**DEVELOPING A PROTOCOL FOR PSYCHOSOCIAL INTERVENTIONS FOR  
PEOPLE WITH DOWN'S SYNDROME WHO DEVELOP DEMENTIA**

Thank you for your letter dated 21 November 2000, enclosing the following documents:

- Amended participant consent form
- Amended carer assent form
- Amended information sheet

The amendment to this study is approved.

Yours sincerely

**Dr Stephen Rose**  
**Chairman**  
**Research & Ethics Committee**



# CITY HOSPITAL NHS TRUST

DUDLEY ROAD, BIRMINGHAM. B18 7QH

[www.cityhospital.org.UK](http://www.cityhospital.org.UK)

Telephone: (0121) 554 3801

Fax: (0121) 507 5637

Direct Dial: (0121) 507 4396

Ref: BS/SH.

Professor C. Oliver,  
School of Psychology,  
University of Birmingham,  
Edgbaston,  
Birmingham, B15 2TT.

15th November, 2000

Dear Professor Oliver,

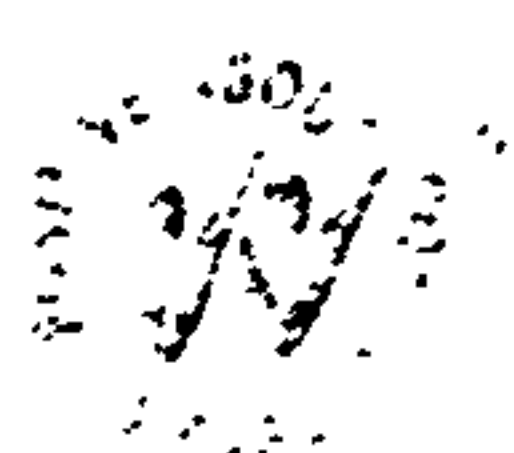
Re: LREC 00/04/81 - Developing a protocol for psychosocial interventions for people with Down's syndrome who develop dementia

Thank you for your letter of the 9th November, 2000 and for submitting a protocol amendment and extension for this study to involve a control group (adults with learning disability other than Down's syndrome).

I am happy to give Chairman's approval for this protocol amendment and extension.

Yours sincerely,

B. SPECULAND,  
Chairman - Research Ethics Committee



PAH

17th October 2000

Westgate House  
Market Street  
Warwick CV34 4DE

**WARWICKSHIRE RESEARCH ETHICS COMMITTEE**

Tel: 01926 493491  
Fax: 01926 495074

The following LREC trial protocol has been examined from an ethical viewpoint and the decision of the Committee is as follows:

		Documentation Reviewed <i>as itemised in ICH guidelines</i>	
1.	* Approved	Protocol	<input checked="" type="checkbox"/>
		Patient Information Form/ Consent Form	<input checked="" type="checkbox"/>
2.	Approved subject to amendments listed below	Indemnity (signed) CTX	<input checked="" type="checkbox"/> <input type="checkbox"/>
		Protocol Amendments	<input type="checkbox"/>
3.	Rejected for reasons listed below		
4.	Approved by Chairman's Action		

**Ethical Committee Minute Number 463/00 Dated 27.9.00**

**Protocol Title and Reference Number**

**RE 447 Developing a protocol or psychological intervention of people with Down's  
Syndrome who develop dementia**  
(Dr. S. Kalsy, Mr. A. Vassalos)

Signed.....

.....Committee Chairman:

Dated.....

18/10/00.

This approval is subject to the following standard conditions :

1. the study must begin within one year;
2. the researcher must seek the Committee's approval in advance of any proposed deviations from the original protocol;
3. any unusual or unexpected results which raise questions about the safety of the study must be reported to the Committee.
4. progress reports must be submitted to the Committee annually; and
5. a summary of the study's findings must be submitted to the Committee upon its completion.

## NORTH BIRMINGHAM RESEARCH ETHICS COMMITTEE

Chairman: Revd. Andrew T. Ball  
Administrator: Mrs. Margaret J. Rice  
Tel. Extension: 2676

E-mail: andrew.ball@goodhope.nhs.uk  
margaret.rice@goodhope.nhs.uk

Good Hope Hospital NHS Trust  
Rectory Road  
Sutton Coldfield  
West Midlands  
B75 7RR

Tel: 0121 378 2211  
Fax: 0121 311 1074  
www.goodhope.org.uk

**Our ref: 521.00**

20<sup>th</sup> March 2003

Dr. Sunny Kalsy  
Clinical Psychologist/Project Manager  
South Birmingham Primary Care Trust  
Psychology Services  
66 Anchorage Road  
Sutton Coldfield B74 2PH

Dear Dr. Kalsy

**Re: Research project "Development a Protocol for Psychosocial Interventions for People with Down's Syndrome who develop dementia."**

Thank you for your letter of 12<sup>th</sup> March 2003 regarding the Protocol Amendment for the above study. This Protocol-Amendment was considered by the North Birmingham Research Ethics Committee at its meeting on 17<sup>th</sup> March 2003 and granted approval on the understanding that you will follow the Protocol as agreed.

The documents approved were:

- Assessment phase documentation – Down's Syndrome Group: Letter to participant, amended February 2003; Invitation to take part, amended February 2003; Information Sheet, amended February 2003; Participant Consent Form, amended February 2003, Symbol Consent Form (with symbols), amended February 2003; Guidelines to accompany Information for Volunteers, undated; Information for Volunteers, (with symbols) undated; Surrogate Assent Form, amended February 2003.
- Intervention phase documentation – Down's Syndrome Group: Information Sheet, amended February 2003; Participant Consent Form, amended February 2003; Symbol Consent Form (with symbols), amended February 2003; Surrogate Assent Form, amended February 2003; Guidelines to accompany Information for Volunteers, undated.
- Control Group documentation – Letter to participant, amended February 2003; Information Sheet, amended February 2003; Invitation to take part in the study, amended February 2003; Participant Consent Form, amended February 2003; Symbol Consent Form (with symbols), amended February 2003;



Guidelines to accompany Information for Volunteers, undated; Information for Volunteers, undated; Surrogate Consent Form, amended February 2003.

Yours sincerely

A handwritten signature in black ink, reading "Andrew T Ball", with a horizontal line drawn underneath it.

Reverend Andrew T Ball  
Chairman

cc: Prof. Chris Oliver, The School of Psychology, University of Birmingham,  
Edgbaston, Birmingham B15 2TT

## **Appendix 2: Information Letters and Consent Forms**



Date as postmark

Dear Sir/Madam

**Research Study - Adults with Down's Syndrome Project**

We would like to invite you to take part in a study involving adults with Down's Syndrome. We hope to spend time with yourself and a carer who could be a member of staff or a relative or friend. The information we gather will help us identify how you and your carer may be best supported both now and in the future.

Any information gathered would be treated as strictly confidential and will be kept secure at all times. Furthermore, should you agree to take part in the study, your GP will be informed immediately. You do not have to take part in the study and you can withdraw at any time without giving a reason. This will not affect the health and social care that you may be receiving now or in the future.

If you would like to talk about the study before you decide whether or not to take part, please contact the project team on (0121) 255 4100 / 414 7206. An information sheet on the study and a consent form are also enclosed. Once you have decided whether or not to take part in the study, please complete the sheet over-leaf and a consent form (if appropriate) and return it to myself at the above address as soon as possible.

Thank you for taking the time to read this information.

Yours faithfully

A handwritten signature in black ink, appearing to be 'SK' or similar initials.

**Dr Sunny Kalsy**  
**Chartered Clinical Psychologist**

Enc.    Invitation to participate  
         Information sheet  
         Consent Form (x2)  
         Symbol information sheet  
         Symbol consent form

<b>INFORMATION SHEET (Assessment Stage)</b>
---

**University of Birmingham  
Adults with Down's Syndrome (An Assessment Project)**

***Background***

A research team at the University of Birmingham are carrying out a research project involving adults with Down's Syndrome, over the age of 30, living in the Birmingham area. In this project, we plan to study the behaviours shown by adults with Down's Syndrome who may develop dementia and evaluate psychological management strategies. We hope to get this information by spending time with you and a carer, who could be a member of staff or relative or friend. This information will help us find out how you and your carer can be best supported now and in the future.

***What will happen in the study?***

If you agree to take part in the study, a member of the research team will contact you to arrange a visit. You and your carer will then be interviewed. You will also be asked to complete a number of paper & pen puzzles. Your carer will be asked to fill in a questionnaire. Your carer will be present for all visits, or you may wish to have a visit by yourself. You will both be offered the opportunity of a feedback session. At this stage, the researcher may also ask if they can follow up with some further paper & pen puzzles and observations of you at your day/work placements. The researcher will also ask you if they may videotape you during these observations.

***Consent***

It is up to you whether or not you want to take part in this study. If you do decide to become involved then we need your consent. Once you (or your carer on your behalf) have agreed to take part in the study, then your GP will be informed immediately. If you decide not to take part, this will not affect your medical care.

***Withdrawal***

You or the person who granted consent, can ask that they stop taking part in the study at any time, without giving a reason. This can happen even after the interviews and the observations have taken place. Any information that we have collected about you will be destroyed. This will not restrict your access to other services and will not affect your right to treatment.

***Confidentiality***

Your confidentiality will be ensured. We will contact you through a member of health or local authority staff. When published, any information on you (and the other participants) will be presented without naming you in any way.

### *At the end of the study*

We will have a feedback session at the end of the study with you and your carer. We will talk about the results of the assessments here. We will then send a summary of the study findings to those people involved who want to see a copy. You or your carers can contact Professor Chris Oliver if you want any more information or advice.

### *Review*

The University of Birmingham, School of Psychology Research Ethics Committee has reviewed and approved this study. The North, East and West Birmingham Research Ethics Committees have also approved this study.

### *For further information please contact*

Prof. Chris Oliver, Project Director      (0121) 414 4909/7576  
or Dr Sunny Kalsy, Project Manager      (0121) 414 7206/(0121) 255 4100

Dr Sunny Kalsy  
School of Psychology  
University of Birmingham  
Edgbaston  
Birmingham  
B15 2TT

If you have any problems with the conduct of the study, you can telephone the secretary of the Ethics committee who has considered this application who will arrange for your worries to be investigated.

East –                      0121 424 0594  
West –                     0121 554 3801  
North –                    0121 378 2211

*Thank you very much for taking the time to read this information*

*If you would like to take part in this study then please complete the consent form and return to the above address.*

February 2003

# **GUIDELINES TO ACCOMPANY INFORMATION FOR VOLUNTEERS**

## **University of Birmingham**

- 1. The sheet "Information for Volunteers" incorporates Makaton symbols and has been designed in order to aid the understanding of potential volunteers.**
- 2. The information sheet covers what is considered to be the key points with regards to the research project. It has been kept brief in order to keep it simple.**
- 3. Its aim is to act as a supplement to a verbal explanation and has not been intended to be used on its own as the only source of information for potential volunteers.**
- 4. Carer's should go through the information sheet with the potential volunteer and explain in more detail the aims and purpose of the project and what will be expected of the person if they decide to participate.**

INVITATION TO TAKE PART IN THE STUDY

Name: .....

☐ Yes I would be interested in taking part in the study

Address .....  
.....

Please indicate your phone number if you would like someone to contact you for an appointment

Tel. Number .....

☐ No, I would not be interested in taking part in the study

Please return this form to:

Dr Sunny Kalsy  
School of Psychology  
University of Birmingham  
Edgbaston  
Birmingham  
B15 2TT

**PARTICIPANT CONSENT FORM (Assessment Stage)**

**University of Birmingham  
Adults with Down's Syndrome (An Assessment Project)**

If the participant is unable to give consent by reason of cognitive impairment, it is possible for surrogate assent to be given by an appropriate individual. If this is the case please complete the surrogate assent form.

**Please initial the boxes**

I confirm that I have read and understood the information sheet dated February 2003 for the above research study ☐

The above study has been explained to me and I have had the opportunity to ask questions ☐

I understand that participation in the study is voluntary and that I am free to end my involvement at any time, or request that the information collected in the study be destroyed, without giving any reason ☐

I understand that documents including video material, relating to me will not identify me by name and will be kept confidential ☐

I agree that my General Practitioner (GP) be told that I am taking part in the study ☐

I agree to take part in the above study ☐

**Please complete the information below**

Participant's name .....

Participant's signature ..... Date .....

Contact address and telephone number .....

..... Tel. ....

**FOR OFFICE USE ONLY**

Signature of researcher ..... Date .....

# SYMBOL CONSENT FORM

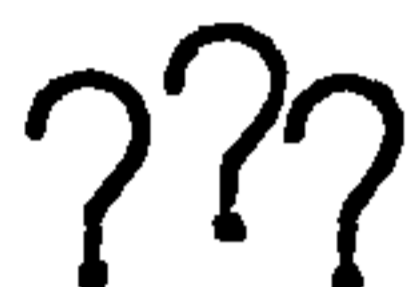
University of Birmingham

Please tick the boxes



read

I have read and understood the information sheet

☐

questions

I have been able to ask questions

☐

leave

I can leave the study when I want to

☐

papers



video

Any papers and video tapes of me will be kept private

☐

GP

I agree that my GP can be told

☐

agree

I agree to take part in the study

☐

Your name .....

Your signature .....

Date .....

Signature of researcher .....

Date .....

**SURROGATE ASSENT FORM (Assessment Stage)**

**University of Birmingham  
Adults with Down's Syndrome (An Assessment Project)**

**Please initial the boxes**

I confirm that I have read and understood the information sheet  
dated February 2003 for the above research study

☐

The above study has been explained to me and I have had the  
opportunity to ask questions

☐

I understand that participation in the study is voluntary and that I am free  
to end the person I care for's involvement at any time, or request that the  
information collected in the study be destroyed, without giving any reason

☐

I understand that documents including video material, relating to the person I care for  
will not identify them by name and will be kept confidential

☐

I agree that the person I care for's General Practitioner (GP) be told that they  
are taking part in the study

☐

I agree to the participation of the person I care for in the above study

☐

**Please complete the information below**

Participant's name .....

Participants signature .....

Contact address and telephone number .....

..... Tel. ....

Carer's name .....

Carer's signature ..... Date .....

Please state relationship with the participant .....

---

**FOR OFFICE USE ONLY**

Signature of researcher ..... Date .....

Dear

Please find enclosed some questionnaires relating to caregivers' experiences of supporting a person with Down syndrome. We would be grateful if your keyworker/main carer was able to complete and return in the stamped addressed envelope by 28<sup>th</sup> February 2005.

These questionnaires will help us to update our assessments and also gather information on what you do and how you feel. The information gathered will also help us to understand more about the experience of your carers and identify how you and your carers may be best supported both now and in the future. The information will also be used in a research study to be written up and submitted as a requirement of the Clinical Psychology Training Course at the Universities of Coventry and Warwick. The results may also be published in relevant journals. We will send a summary of the study findings to those people involved who want to see a copy. Any information that we gather will be treated as strictly confidential and will be kept secure at all times.

If you would like to discuss the questionnaires before completing then please do not hesitate to contact us on XXX XXXX. A member of the team will, nevertheless, be contacting you by telephone to ask if you require any further information or support in completing them.

Thank you for your ongoing support, We look forward to receiving your completed questionnaires

Yours sincerely

Vicki Lloyd  
Clinical Psychologist in Training

Dr Sunny Kalsy  
Consultant Clinical Psychologist

## **Appendix 3: Interview Schedule for Empirical Paper 1 (Chapter 2)**

### **Interview Schedule**

1. Current life situation – home, work, leisure activities, significant relationships
  - Do you like where you live? What's good/ bad? How do you feel when you're there?
  - What do you do during the day/ at night? Do you like it? What's good/bad? How do you feel when you're there?
  - How do you spend you time during the day/evening? What's it like doing these things?
  - What are your jobs? What things do you do for other people?
  - Who is important in your life? What things do you do together/do they help you with/do you help them with?
2. As people grow older they change. Sometimes they change in the way they feel. Sometimes they change in the things they can do.
  - How do you feel in yourself?
  - Can you remember things? Is this easy or hard for you? Do you forget things like people's names etc? What is it like when this happens?
  - What things did you like to do when you were at college/ at daycentre, etc? Can you still do these things? Do you still enjoy them? If not why not?
  - What kind of things are you good at?
  - What kind of things do you find difficult/need help with?
  - Do you think you're getting older? What's that like? If you met someone who was younger than you what things would you tell them about getting older?
3. If you had a magic wand and could make anything different in your life what would it be?
4. Do you think anything will be different/change in the future?

**Appendix 4: Example of Stage 1 IPA Analysis  
Participant 1, Lines 151 - 200**

<p><i>Forgetting names = transient and isolated incident</i></p> <p><i>Forgetting is recurrent &amp; global with names. Need to apologise.</i></p> <p><i>Self as passive recipient of staff care Vs emphasizing own usefulness/independence.</i></p> <p><i>Comparing self favourably with other clients re independence.</i></p> <p><i>Overgeneralization of positive comments.</i></p> <p><i>Dependent on staff for meals, drinks. Emphasizing not fully dependent – helps. Identifying self with clients &amp; separate from staff.</i></p> <p><i>Keen to emphasize own usefulness.</i></p> <p><i>Mind won't work. Minimizing memory difficulty as only today.</i></p>	<p>I: And who's important in your life here at home?</p> <p>J.L.: E (pause) I've forgot the name now (pause)</p> <p>A (staff member).</p> <p>I: A?</p> <p>J.L.: Yes. And another one. Oh I've forgotten all the names, sorry. I keep forgetting these things.</p> <p>I: That's ok. Why are they important to you?</p> <p>J.L.: They're kind to me. They give me nice food and make it nice. But I make my own bed and clean up. The staff do that for some others but I do my own.</p> <p>I: Uh huh.</p> <p>J.L.: Oh I like it, it's lovely.</p> <p>I: And do you ever need to ask them to help you with things?</p> <p>J.L.: Yes. When I need a drink or something to eat. They do our breakfast and dinner. But I help.</p> <p>I: So it sounds like they're very helpful to you but you help them too?</p> <p>J.L.: Oh yes.</p> <p>I: Tell me about college, what kind of things do you do there?</p> <p>J.L.: (pause) I can't think. I've forgot now. I'm no good today. [laughs]</p>
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<p><i>Rooted to present performance. Poor memory = self "no good"</i></p> <p><i>Identify self with nephew with intellectual disability? Contradicts earlier description of relationship. Highlighting own independence.</i></p> <p><i>Implicit reluctance to age? Not seeing self as old. Unsure of own age. Boyfriend = proof of being young? Misperception of own age will impact on expectations of self.</i></p> <p><i>Boyfriend not an exclusive relationship. Acquaintances = friends. Substituting specific info with generalisations.</i></p> <p><i>Minimising. Fatigue. Tiredness is acceptable and can be controlled/recovered from. Aware of physical slowing, wanting to sleep more.</i></p>	<p>good today. <i>[laughs]</i></p> <p>I: That's ok. Do you like college?</p> <p>J.L.: Oh yes. I see X there. He's my nephew. He goes as well himself. Catches the bus. Like me, I catch the minibus.</p> <p>I: That's good. Ok, you know that as people get older sometimes they can change, in the way they feel or the things that they can do?</p> <p>J.L.: Oh yes.</p> <p>I: Do you think that you're getting old?</p> <p>J.L.: <i>[laughs]</i> Oh no thank you. Not yet. I forgot now how old I am. On my last birthday I'm about 50. And I've got a boyfriend you know.</p> <p>I: Really?</p> <p>J.L.: Yes. There's two boys, Paul and John. They work in the meat shop. Oh I've known them two since....Oh a long time ago.</p> <p>I: And how have you been feeling in yourself?</p> <p>J.L.: Oh yeah, I'm ok. A little bit tired.</p> <p>I: Is that more tired than you used to feel?</p> <p>J.L.: Yes. Yes. I'm always wanting to go to sleep, on the settee or upstairs on the bed.</p>
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Appendix 5: Example of Stage 2 IPA Analysis  
Participant 1, Lines 151 - 200

I: And who's important in your life here at home?	
J.L.: E (pause) I've forgot the name now (pause) A (staff member).	<i>Forgetting names</i>
I: A?	
J.L.: Yes. And another one. Oh I've forgotten all the names, sorry. I keep forgetting these things.	<i>Awareness of global memory decline Needing to apologise</i>
I: That's ok. Why are they important to you?	
J.L.: They're kind to me. They give me nice food and make it nice. But I make my own bed and clean up. The staff do that for some others but I do my own.	<i>Self as passive in relationships Dependent on others Vs self as independent Having a domestic role.</i>
I: Uh huh.	
J.L.: Oh I like it, it's lovely.	
I: And do you ever need to ask them to help you with things?	
J.L.: Yes. When I need a drink or something to eat. They do our breakfast and dinner. But I help.	<i>Dependent on others Vs self as independent</i>
I: So it sounds like they're very helpful to you but you help them too?	
J.L.: Oh yes.	
I: Tell me about college, what kind of things do you do there?	
J.L.: (pause) I can't think. I've forgot now. I'm no good today. [laughs]	<i>Confusion about routine. Minimizing difficulties.</i>

<p>I: That's ok. Do you like college?</p> <p>J.L.: Oh yes. I see X there. He's my nephew. He goes as well himself. Catches the bus. Like me, I catch the minibus.</p> <p>I: That's good. Ok, you know that as people get older sometimes they can change, in the way they feel or the things that they can do?</p> <p>J.L.: Oh yes.</p> <p>I: Do you think that you're getting old?</p> <p>J.L.: [laughs] Oh no thank you. Not yet. I forgot now how old I am. On my last birthday I'm about 50. And I've got a boyfriend you know.</p> <p>I: Really?</p> <p>J.L.: Yes. There's two boys, Paul and John. They work in the meat shop. Oh I've known them two since....Oh a long time ago.</p> <p>I: And how have you been feeling in yourself?</p> <p>J.L.: Oh yeah, I'm ok. A little bit tired.</p> <p>I: Is that more tired than you used to feel?</p> <p>J.L.: Yes. Yes. I'm always wanting to go to sleep, on the settee or upstairs on the bed.</p>	<p><i>Importance of maintaining consistent attachments. Self as independent.</i></p> <p><i>Reluctance to age. Misperception of own age.</i></p> <p><i>Awareness of physical slowing/decline.</i></p>
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## Appendix 6: Master List of IPA Themes for all Participants

Theme	Number of participants articulating theme	Number of times theme appeared
<b>Theme 1: Self-image</b>		
Having a domestic role	6	14
Practical tasks	2	3
Valuing own roles	5	7
No sense of role	2	2
Constructing own roles	3	6
Focus on past roles	1	1
Wanting more status	1	1
<b>Theme 2: The relational self</b>		
Importance of maintaining consistent attachments	5	15
Staff as family	1	3
Staff as friends	6	4
Self passive in relationships	4	8
Self active in relationships	1	2
Victimization	4	8
Negative response from others	2	5
Needing to apologise	2	3
Seeking validation	2	2
Othering	1	1

Dependence on others Vs self as independent	4	7
<b>Theme 3: Making sense of decline</b>		
Forgetting names	4	10
Awareness of global memory decline	3	6
Being lost	4	4
Confusion about routine	4	4
Spatial perception difficulties	4	4
Awareness of physical slowing/decline	5	17
Getting old	4	6
Reluctance to age	3	7
<b>Theme 4: Coping strategies</b>		
Minimizing difficulties	5	15
Denial of difficulties	5	12
No sense of performance	5	5
Days defined by routine	5	11
Value of maintaining routine	5	10
Staying busy	3	5
Withdrawal	3	8
Fantasy	1	3
Confabulation	5	17
Recency responses	3	5

Misperception of own age	3	6
Replacement	2	5
No conception of things changing/being different	5	5
<b>Theme 5: Emotional expression</b>		
Distress	3	9
Fear	1	4
Loss	3	12
Frustration	2	2
Feeling restricted	3	9

## **Appendix 7: Caregiver Activity Survey – Intellectual Disability**



Trinity College Dublin

## Instructions for using the Caregiver Activity Survey-Intellectual Disability (CAS-ID)

**Please read carefully before completing.**

*The CAS-ID was developed to measure the amount of time formal caregivers spend assisting persons with the dual disability of Alzheimer's dementia and Down syndrome with their day-to-day activities of living.*

1. The CAS-ID contains 8 day-to-day activities of living:

- Dressing
- Bathing/showering
- Looking after ones appearance
- Toileting
- Eating and drinking
- Housekeeping
- Nursing Care Related Activities
- Supervision/Behavioural management

2. The caregiver/key worker is requested to record time spent caring on a 'typical day'. Unusual events for example time spent caregiving for clients with acute medical illness for example, epileptic seizure, hospital appointments, unusual behaviour changes etc, which don't generally tend happen on a typical day, please record as 'other'.

3. Over the next 24 hours (8am-8am) please record how much time you and others spend assisting the client in these day-to-day activities. Please record time spent immediately after the activity has taken place.

4. If an activity happens on more than one occasion during the 24hour period, for example dressing, eating/drinking, toileting etc, you add up the time spent on each occasion.

5. If a selected activity takes two staff members a total of 20 minutes to perform then you record time spent as 40 minutes (ie 20+20).

6. If however the second staff member was only required to assist for a period of 10 minutes then you record time spent as 30 minutes (ie 20+10).

7. If the client did not engage in a particular activity for example eating/drinking because of tube feeding, then record total time spent in this activity as 0 hours, and refer to No.7 Nursing Care Related Activities.



Trinity College Dublin

## The Caregiver Activity Survey-Intellectual Disability (CAS -ID)

Client ID: \_\_\_\_\_ Care Setting: \_\_\_\_\_

Date: \_\_\_\_\_ Key-Worker ID: \_\_\_\_\_

**Please read instruction leaflet carefully before completing**

### ***1. Dressing***

Over the next 24 hours please record how much time *you and others* spend assisting the client in these types of activities?

*Please consider the following as examples of activities associated with dressing:*

- Communicating with the client and orientating them to the activity
- reminding the client to dress
- choosing what to wear
- supervising and verbally prompting the client with dressing
- physically prompting the client to dress and undress
- keeping the client from undressing at the wrong time
- dressing the client

Total \_\_\_\_\_ hours \_\_\_\_\_ minutes

### ***2. Bathing/showering***

Over the next 24 hours please record how much time *you and others* spend assisting the client in these types of activities?

*Please consider the following as examples of activities associated with bathing/showering:*

- Communicating with the client and orientating them to the activity
- reminding the client to bath/shower
- organising items required for bathing/showering
- escorting the client to the bathroom
- supervising the client bathing/showering
- assisting the client transfer from chair to bath (hoist)
- bathing/showering the client

Total \_\_\_\_\_ hours \_\_\_\_\_ minutes

### ***3. Looking after ones appearance***

Over the next 24 hours please record how much time *you and others* spend assisting the client in these types of activities?

*Please consider the following as examples of activities associated looking after ones appearance:*

- Communicating with the client and orientating them to the activity
- reminding the client to brush teeth, brush hair, apply cosmetics, shave or care for nails
- supervising and/or helping the client to groom
- grooming and maintaining the clients appearance over the course of the day

Total \_\_\_\_\_ hours \_\_\_\_\_ minutes



Trinity College Dublin

#### **4.Toileting**

Over the next 24 hours please record how much time *you and others* spend assisting the client in these types of activities?

*Please consider the following as examples of activities associated with toileting:*

- Communicating with the client and orientating them to the activity
- reminding the client to go to toilet area
- escorting the client to toilet area
- assisting the client transfer from chair to toilet
- supervision and/or assistance of the client with some or all stages of toileting- positioning, clothing adjustment and hygiene
- attending to toilet hygiene if incontinent

Total \_\_\_\_\_ hours \_\_\_\_\_ minutes

#### **5.Eating and Drinking**

Over the next 24 hours please record how much time *you and others* spend assisting the client in these types of activities?

*Please consider the following as examples of activities associated with eating/drinking:*

- Communicating with the client and orientating them to the activity
- organising the client snackfood or drink
- escorting the client to the dining area
- supervision and/or verbally prompting the client to complete meal
- physically prompting the client
- feeding the client
- attending to personal hygiene after meal

Total \_\_\_\_\_ hours \_\_\_\_\_ minutes

#### **8.Housekeeping**

Over the next 24 hours please record how much time *you and others* spend assisting the client in these types of activities?

*Please consider the following as examples of activities associated with housekeeping:*

Communicating with the client and orientating them to the activity

- reminding the client to make bed and tidy room
- reminding the client to change dirty clothing and take them to laundry
- supervising housekeeping activities
- making bed, tidying room and organising laundry

Total \_\_\_\_\_ hours \_\_\_\_\_ minutes



Trinity College Dublin

### **7. Nursing Care Related Activities**

Over the next 24 hours please record how much time *you and others* spend assisting the client in these types of activities?

*Please consider the following as examples of nursing related activities:*

- Communicating with the client and orientating them to the activity
- administration of medications, injections, etc
- catheter care, insertion, irrigation etc
- colostomy care
- extensive skin treatments and the applications of creams etc
- inhalation therapy, nebulised ventolin and oxygen
- peg tube feeding and related care
- prevention of pressure sores
- suctioning
- barrier nursing
- palliative care

Total \_\_\_\_\_ hours \_\_\_\_\_ minutes

### **8. Behaviour Management and Supervision**

Over the next 24 hours please record how much time *you and others* spend supervising the client and managing behaviour problems?

*Please consider the following as examples of behavioural problems:*

- keeping the client who is wandering or pacing under constant supervision in order to ensure they do not get lost or injure themselves
- supervision of the client who is restless or agitated
- giving emotional support to the client who is fearful and anxious
- intervening with client who disturbs other residents by being noisy, physically or verbally aggressive

Total \_\_\_\_\_ hours \_\_\_\_\_ minutes

### **Other**

Over the next 24 hours please record how much time *you and others* spend assisting the client in any other related types of activities?

*Please record examples of activities:*

Total \_\_\_\_\_ hours \_\_\_\_\_ minutes

## **Appendix 8: Caregiving Difficulty Scale – Intellectual Disability**

***University at Albany and Trinity College Dublin***

This questionnaire is to be completed by staff working with at least one consumer who is experiencing symptoms of dementia.

**CAREGIVING DIFFICULTY SCALE**

Please check to what extent each item represented a difficulty for you during the past month.  
Please complete all items.

**FREQUENCY RATINGS:**

0= Behavior is not a difficulty  
Or behavior has never occurred  
1= Sometimes a difficulty  
2= Frequently a difficulty  
3= A great deal of difficulty

**Factor 1 Day to Day Care Issues (alpha .93)**

- |     |   |      |      |      |      |
|-----|---|------|------|------|------|
| 1.  | Assisting with care-recipient's toileting       | ___0 | ___1 | ___2 | ___3 |
| 2   | Transporting care-recipient                     | ___0 | ___1 | ___2 | ___3 |
| 3.  | Bathing care-recipient                          | ___0 | ___1 | ___2 | ___3 |
| 4.  | Care-recipient yelling swearing                 | ___0 | ___1 | ___2 | ___3 |
| 5.  | Care-recipient not cooperating                  | ___0 | ___1 | ___2 | ___3 |
| 6.  | Assisting care-recipient with exercises/therapy | ___0 | ___1 | ___2 | ___3 |
| 7.  | Doing care-recipient's laundry                  | ___0 | ___1 | ___2 | ___3 |
| 8.  | Care-recipient leaving tasks uncompleted        | ___0 | ___1 | ___2 | ___3 |
| 9.  | Care-recipient being confused, not making sense | ___0 | ___1 | ___2 | ___3 |
| 10. | Lifting or transferring care-recipient          | ___0 | ___1 | ___2 | ___3 |
| 11. | Care-recipient frowning/scowling                | ___0 | ___1 | ___2 | ___3 |

Please check to what extent each item represented a difficulty for you during the past month:

**FREQUENCY RATINGS:**

0= Behavior is not a difficulty  
Or behavior has never occurred  
1= Sometimes a difficulty  
2= Frequently a difficulty  
3= A great deal of difficulty

12.	Care-recipient living in past	___0	___1	___2	___3
13.	Helping care-recipient eat	___0	___1	___2	___3
14.	Picking up after care-recipient	___0	___1	___2	___3
15.	Being in care-recipient's presence	___0	___1	___2	___3
16.	Care-recipient talking about/seeing things that are not real	___0	___1	___2	___3
17.	Dressing care recipient	___0	___1	___2	___3
18.	Care-recipient not recognizing familiar people	___0	___1	___2	___3
19.	Giving medications to care-recipient	___0	___1	___2	___3
20.	Preparing meals for care-recipient	___0	___1	___2	___3
21.	Care-recipient wandering off	___0	___1	___2	___3
22.	Care-recipient's agitation	___0	___1	___2	___3
23.	Assisting care-recipient with health aids (e.g., dentures, hearing aid)	___0	___1	___2	___3
24.	Care-recipient requiring day supervision	___0	___1	___2	___3
25.	Leaving care-recipient with others	___0	___1	___2	___3
26.	Care-recipient hiding things	___0	___1	___2	___3
27.	Care-recipient requiring night supervision	___0	___1	___2	___3

Please check to what extent each item represented a difficulty for you during the past month:

- FREQUENCY RATINGS:
- 0= Behavior is not a difficulty  
Or behavior has never occurred  
1= Sometimes a difficulty  
2= Frequently a difficulty  
3= A great deal of difficulty

**Factor 2 Care Challenges (Alpha .98)**

28. Conflicts between care-recipient and housemates/peers

\_\_\_0\_\_\_1\_\_\_2\_\_\_3
29. Conflicts between care-recipient and staff

\_\_\_0\_\_\_1\_\_\_2\_\_\_3
30. Housemates/peers not showing understanding about Care-recipient

\_\_\_0\_\_\_1\_\_\_2\_\_\_3
31. Not having additional resources/staff to address dementia needs

\_\_\_0\_\_\_1\_\_\_2\_\_\_3
32. Design of the home

\_\_\_0\_\_\_1\_\_\_2\_\_\_3
33. Lack of adaptive equipment

\_\_\_0\_\_\_1\_\_\_2\_\_\_3
34. Attending to medical care needs as dementia progresses

\_\_\_0\_\_\_1\_\_\_2\_\_\_3
35. Not having enough knowledge and training in caring for persons with dementia

\_\_\_0\_\_\_1\_\_\_2\_\_\_3
36. Conflicts with other staff about appropriate care and level of dementia needs

\_\_\_0\_\_\_1\_\_\_2\_\_\_3

**Factor 3 Family Concerns (alpha .75)**

37. Family not showing understanding about care-recipient

\_\_\_0\_\_\_1\_\_\_2\_\_\_3
38. Not receiving caregiving help from family and guardian

\_\_\_0\_\_\_1\_\_\_2\_\_\_3

## **Appendix 9: Maslach Burnout Inventory**

**PAGE**

**NUMBERING**

**AS ORIGINAL**

# MBI Human Services Survey

HOW OFTEN:	0	1	2	3	4	5	6
	Never	A few times a year or less	Once a month or less	A few times a month	Once a week	A few times a week	Every day

**HOW OFTEN**  
0 - 6

Statements:

1. \_\_\_\_\_
- I feel emotionally drained from my work.
2. \_\_\_\_\_
- I feel used up at the end of the workday.
3. \_\_\_\_\_
- I feel fatigued when I get up in the morning and have to face another day on the job.
4. \_\_\_\_\_
- I can easily understand how my recipients feel about things.
5. \_\_\_\_\_
- I feel I treat some recipients as if they were impersonal objects.
6. \_\_\_\_\_
- Working with people all day is really a strain for me.
7. \_\_\_\_\_
- I deal very effectively with the problems of my recipients.
8. \_\_\_\_\_
- I feel burned out from my work.
9. \_\_\_\_\_
- I feel I'm positively influencing other people's lives through my work.
10. \_\_\_\_\_
- I've become more callous toward people since I took this job.
11. \_\_\_\_\_
- I worry that this job is hardening me emotionally.
12. \_\_\_\_\_
- I feel very energetic.
13. \_\_\_\_\_
- I feel frustrated by my job.
14. \_\_\_\_\_
- I feel I'm working too hard on my job.
15. \_\_\_\_\_
- I don't really care what happens to some recipients.
16. \_\_\_\_\_
- Working with people directly puts too much stress on me.
17. \_\_\_\_\_
- I can easily create a relaxed atmosphere with my recipients.
18. \_\_\_\_\_
- I feel exhilarated after working closely with my recipients.
19. \_\_\_\_\_
- I have accomplished many worthwhile things in this job.
20. \_\_\_\_\_
- I feel like I'm at the end of my rope.
21. \_\_\_\_\_
- In my work, I deal with emotional problems very calmly.
22. \_\_\_\_\_
- I feel recipients blame me for some of their problems.

## MBI Human Services Survey

The purpose of this survey is to discover how various persons in the human services or helping professions view their jobs and the people with whom they work closely. Because persons in a wide variety of occupations will answer this survey, it uses the term *recipients* to refer to the people for whom you provide your service, care, treatment, or instruction. When answering this survey please think of these people as recipients of the service you provide, even though you may use another term in your work.

On the following page there are 22 statements of job-related feelings. Please read each statement carefully and decide if you ever feel this way *about your job*. If you have *never* had this feeling, write a "0" (zero) before the statement. If you have had this feeling, indicate *how often* you feel it by writing the number (from 1 to 6) that best describes how frequently you feel that way. An example is shown below.

### Example:

---

HOW OFTEN:	0	1	2	3	4	5	6
	Never	A few times a year or less	Once a month or less	A few times a month	Once a week	A few times a week	Every day

---

### HOW OFTEN

0 - 6

Statement:

\_\_\_\_\_ I feel depressed at work.

If you *never* feel depressed at work, you would write the number "0" (zero) under the heading "HOW OFTEN." If you *rarely* feel depressed at work (a few times a year or less), you would write the number "1." If your feelings of depression are fairly frequent (a few times a week, but not daily) you would write a "5."



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Highlander statement of concern and call for action. (2000). Retrieved March 25, 2003, from <http://www.naripa.org/highlander.htm>

Lin, J.-D., Wu, J.-L., & Lee, P.-N. (2003). Healthcare needs of people with intellectual disability in institutions in Taiwan: outpatient care utilization and implications. *Journal of Intellectual Disability Research*, 47, 169-180.

U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research. (2000). Long range plan: 1999-2003. Washington, DC: Author.

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