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

Using identity interruption theory to explain increased levels of psychological distress in deaf people with hearing identities.

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Submission date: 4th August 2003

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And finally, thank you to the friends and family who have supported me – the people who have calmed and advised, the WAY Foundation who have looked after many of my emotional needs, my colleagues on the course who have kept in touch and maintained my sanity, and to Ben and Mick, who allowed me the time and space I needed. Thank you!
Declaration

The thesis was carried out under the supervision of Dr. Sue O'Rourke and Dr. Mark Forshaw, who helped with designing the study, and developing and translating the measure described in Chapter Two, and in collaboration with Miss Emma Coleman, who helped with the translation process described in Chapter Two. The literature review was supervised by Dr Delia Cushway. Apart from these collaborations, the thesis is my own work. Authorship of any papers from this work will be shared with the above. The thesis has not been submitted for a degree to any other university.

The literature review is being prepared for submission to the British Journal of Clinical Psychology (Marriott and Cushway), the main paper is being prepared for submission to the British Journal of Social Psychology (Marriott, O'Rourke, Forshaw and Coleman), and the brief paper is being prepared for submission to the British Journal of Clinical Psychology (Marriott, E.C., O'Rourke, S, and Forshaw, M.J.) (see Appendix 16 for guidelines for contributors).


Marriott, E.C., O'Rourke, S., Forshaw, M.J. and Coleman, E. *Creating a scale to measure interruption to the social identity of Deaf people.* Unpublished paper.
Summary

The literature review looks at how hearing parents adapt to a deaf child in the family, and considers how this literature supports a disability-stress model of maternal adaptation. Partial support is found for the model, and a revised version is suggested.

The aim of the empirical papers is to examine the relationships between psychological distress, social identity, and identity interruption in culturally and non-culturally deaf adults. Research suggests that interruption to social identity leads to increased psychological distress, and that deaf people who adopt a hearing identity have increased levels of psychological distress. This research aims to consider identity interruption as an explanation for higher levels of psychological distress in deaf people with a hearing identity. The first paper describes the development of an Identity Interruption Scale for Deaf people. Four types of identity interruption are identified, and five questions developed for each of the four types. The 20-item scale was pilotted with 44 deaf adults in the Midlands. Cronbach's alpha was conducted, and principal components analysis yielded five factors based on the four identity interruption types – broken loop, over-controlled identity, episodic identity, interference from other identities (work), and interference from other identities (family). On the basis of this analysis, a 16-item scale was finalised.

In the second study, 130 deaf and hard-of-hearing adults completed the Identity Interruption Scale for Deaf People, alongside measures of Deaf identity (Deaf Attitude and Identity Questionnaire) and of psychological
distress (General Health Questionnaire–28). It was found that a stronger Deaf identity correlated positively with lower levels of psychological distress and decreased identity interruption. Higher identity interruption correlated positively with increased psychological distress. These findings are discussed, and clinical implications put forward.
Chapter One: The applicability of a disability-stress model to the adaptation of hearing parents to a deaf child.
1.1 Abstract

**Purpose:** To consider research into the adaptation of hearing parents to a hearing-impaired or deaf child in the family, and to look at how this research may fit a disability-stress model of parental adaptation proposed by Wallander and Marullo (1997). **Methods:** Seventeen empirical studies of hearing parents' adaptation to a child with a hearing loss were analysed. The studies were analysed alongside a model of disability-stress coping (Wallander and Marullo, 1997). This model indicates risk and resilience factors for the adaptation of parents to a child with a disability. The extent of support for this model was looked for in the studies reviewed. Factors affecting the adaptation of hearing parents that are not considered within the model are also highlighted. **Results:** Partial support for model is reported. A revised model is proposed. Further research is needed to confirm the model's usefulness when considering hearing parents' adaptation to a deaf child.
1.2 Introduction

This paper aims to examine literature on the adaptation of hearing parents to a deaf or hearing-impaired child, focusing primarily on children of pre-school age. Papers were identified by literature searches for the years 1980-2003. Searches were conducted on Internet versions of Ingenta, Bath Information and Data Services (BIDS), ProQuest, Psychinfo and Medline databases. Key words and phrases looked for included: deaf child and family, adaptation and hearing parents, disability and parents, and parent stress and disability. Only papers in English were used. Other exclusion criteria included areas where additional variables such as hospitalisation and cognitive impairment would be present (for example, post-operative cochlear implants, dual diagnosis of a learning disability, and medical research).

A disability-stress coping model of maternal adaptation, proposed by Wallander and Marullo (1997), will be used in order to organise the literature. This model will offer a means of clarifying the relationships between the many factors that may influence the adaptation of hearing parents to the deaf child within the family.

It is estimated that thirteen in every 10,000 children are pre-lingually deaf (Royal National Institute for Deaf People (RNID), 2002). Ninety per cent of deaf or hearing-impaired babies are born to parents with no recorded hearing deficits (Childs, 2000; Hindley, 1997; Muth, Emerson, & Williams, 1998), and 80% of these hearing parents never learn to communicate effectively with their child (Sign, 2001).
1.2.1 Models of deafness: The medical model views deafness as both an audiological condition and a physical disability. An alternative model of deafness views deafness not as a sensory impairment, but rather as a cultural group with its own language, that is, Sign Language. These two models are generally distinguished within the literature through the use of 'deaf' (medical condition) and 'Deaf' (cultural group).

1.2.2 Defining chronic physical disorders: A chronic physical disorder can be defined as one that interferes with daily functioning for more than three months in a year, or causes hospitalisation lasting more than one month in a year, or is thought at the time of diagnosis to do either (Pless & Pinkerton, 1975). It has been suggested that different physical disorders have many shared commonalities, for example nature of onset and course, visibility and social stigma (Wallander & Varni, 1998). In light of these criteria, childhood deafness could be viewed as a chronic physical disorder.

1.2.3 The disabled child within the family: When a child has a disability, the parents may feel that their adaptive capacities are overloaded (Pelchatt, Bisson, Ricard, Perreault & Bouchard, 1999). They may experience shock, numbness, disbelief, and feel isolated and fearful for the future of the child (Kerr & McIntosh, 1999).

How parents adapt to parenting a child with a disability is dependent on individual differences, both of the child, and of the parents themselves (Wallander & Varni, 1998). Early intervention (that is, within the first six
months of the child’s life) with parents of children with disabilities has been considered to promote parental adaptation. It is thought to minimise the threat of the parenting experience, and reduce emotional stress, anxiety, and depression (Pelchatt et al, 1999). However, deafness may not be diagnosed for years, with one study finding the average age of diagnosis to be 20.2 months (Kitrell and Arjmand, 1997). Parent-to-parent support, and emotional support from grandparents have both been shown to provide a stress-buffering influence on the experience of parenting a disabled child (Kerr & McIntosh, 1999; Trute, 2003).

1.3 Theoretical Framework.

Models have been proposed for both child and maternal adjustment to paediatric chronic physical disorders (Wallander & Marrullo, 1997; Wallander & Varni, 1998), which are suggested to be applicable to all chronic disabilities (Wallander & Varni, 1998). These models integrate risk factors for, and resilience factors against poor adaptation to a child’s physical disability by mothers and by the child. The model has been used when considering the adaptation of children to insulin dependent diabetes mellitus (Amer, 1999; Amer, 1999a).

In this model, risk factors fall into three categories: the child’s condition (for example, diagnosis, severity of condition, visibility, and cognitive functioning), functional care strain (for example, mobility, communication, and other activities of daily living), and psychosocial stress (such as major life events, problems of daily living, and disability-related problems). Resistance factors
are described as personal factors (for example, temperament and competence), social-ecological factors (such as the family environment and social support), and stress processing (cognitive appraisals and coping strategies).

The successful application of the disability stress model (Wallander & Varni, 1997) to child adaptation to diabetes mellitus suggested that this model might also be applicable to the adaptation of hearing parents to a deaf child.

The disability-stress model shows how the risk and resilience factors all feed into maternal adaptation to a child’s disability. The child’s condition, functional care strain, parental personal factors, and social-ecological factors all impact on psychosocial stresses, and stress processing of personal and social-ecological factors is also indicated. Adaptation has three facets — mental, physical, and social.
Figure 1.1: Disability-Stress Coping model of adaptation in mothers with children who have a chronic physical impairment (adapted from Wallander and Marullo, 1997). Single lined boxes indicate risk factors, and double lines indicate resilience factors.
1.4 Overview of research on the adaptation of hearing parents to a deaf child

Research that considers the adaptation of hearing parents to a deaf child has been carried out within the fields of psychology, Deaf studies, paediatrics, audiological medicine, and social work. Although the disability stress model looks at maternal adaptation, much of the research into adaptation to a hearing-impaired child has considered 'parents'. In many of these, respondents have often been mothers. Research has suggested that there are few differences between maternal and paternal stress scores (Brand & Coetzer, 1994). Mothers are more likely to perceive their children as distractible, and to report more negative spousal relationships (Brand & Coetzer, 1994; Meadow-Orlans, 1995). Because of these minimal findings of difference, this chapter will consider overall parental adaptation. When research has considered only mothers, maternal adaptation will be referred to.

Although parental adaptation to having a child with a disability has been explored (for example, Pelchatt et al, 1999; Wallander & Varni, 1998; Amer, 1999a; Trute, 2003), when conducting literature searches for the purpose of this review, only a small number of articles (16) were found which examined the adaptation of hearing parents of deaf children (see Table 1.1). As can be seen from Table 1.1, study sizes have ranged from a qualitative single-case study (Allegretti, 2002), to much larger quantitative research (Paradise et al, 1999). One of the studies reviewed considered the issue of cochlear implants (Allegretti, 2002), and was included due to its reference to pre-implant adaptation.
<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Country</th>
<th>Sample size</th>
<th>Type of study</th>
<th>Age of sample</th>
<th>Measures</th>
<th>Support for model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brand and Coetzer (1994)</td>
<td>South Africa</td>
<td>30 married couples</td>
<td>Descriptive: test of difference</td>
<td>11 months – 11 years</td>
<td>Biographical questionnaire; QRS-SF; interviews</td>
<td>Parental involvement in education programs (socio-ecological resistance factor) significantly related to lower levels of stress</td>
</tr>
<tr>
<td>Densham (1995)</td>
<td>UK</td>
<td>Unspecified</td>
<td>Qualitative</td>
<td>5 months to 30 months</td>
<td>Sample surveys; Focused, in-depth, semi-structured interviews</td>
<td>Diagnosis process is lengthy and can create stress for parents (risk factor not included in model)</td>
</tr>
<tr>
<td>Meadow-Orlans (1995)</td>
<td>USA</td>
<td>20 hearing parents of deaf children; 20 hearing parents of hearing children</td>
<td>2 ½ year data collection</td>
<td>Measures at 9, 12, and 18 months</td>
<td>PSI; SLE</td>
<td>Work and financial situation (socio-ecological resistance factor) predict increased life stresses.</td>
</tr>
<tr>
<td>Kittrell and Arjmand (1997)</td>
<td>USA</td>
<td>291 children with sensorineural hearing-impairment</td>
<td>Retrospective analysis</td>
<td>4 – 20 years</td>
<td>Parental questionnaires; Data from school records</td>
<td>Diagnostic process too lengthy, resulting in increased parental stress (risk factor not included in model).</td>
</tr>
</tbody>
</table>

Table 1.1: Review of studies of the adaptation of hearing parents to a deaf child.
<table>
<thead>
<tr>
<th>Authors(s)</th>
<th>Country</th>
<th>Sample size</th>
<th>Type of study</th>
<th>Age of sample</th>
<th>Measures</th>
<th>Support for model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mapp and Hudson</td>
<td>USA</td>
<td>98 parents</td>
<td>Correlational study.</td>
<td>3 – 14 years</td>
<td>Ways of Coping Questionnaire; QRS -SF</td>
<td>Communication difficulties (functional care strain risk factor) predicts increased parental stress; Maternal education and income (social-ecological resistance factor) not related to higher parental stress.</td>
</tr>
<tr>
<td>Vostanis et al</td>
<td>UK</td>
<td>Parents of 84</td>
<td>Descriptive Mann-Whitney U</td>
<td>2 – 18 years</td>
<td>CBCL; PCL.</td>
<td>Unclear which factor being measured</td>
</tr>
<tr>
<td></td>
<td></td>
<td>children</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Paradise et al</td>
<td>USA</td>
<td>2278 children</td>
<td>Longitudinal. Descriptive,</td>
<td>2 months – 3 years</td>
<td>Life events inventory; PSI (short form); CBCL</td>
<td>Socioeconomically disadvantaged groups (social-ecological resilience factor) had higher parental stress; no relationship between life events and parental stress.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>correlational design</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Young (1999)</td>
<td>UK</td>
<td>12 carers; 6</td>
<td>Qualitative: semi-structured</td>
<td>20 months to 2 years 8 months</td>
<td>Qualitative interview study</td>
<td>Inconclusive findings regarding early intervention with parents (social-ecological resilience factor)</td>
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<tr>
<td></td>
<td></td>
<td>teachers of the</td>
<td>interviews</td>
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<td></td>
<td></td>
<td>deaf; 6 deaf</td>
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<tr>
<td></td>
<td></td>
<td>consultants; 9</td>
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<td>children</td>
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</tbody>
</table>

Table 1.1: Review of studies of the adaptation of hearing parents to a deaf child (continued).
<table>
<thead>
<tr>
<th>Authors(s)</th>
<th>Country</th>
<th>Sample size</th>
<th>Type of study</th>
<th>Age of sample</th>
<th>Measures</th>
<th>Support for model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hintermair (2000)</td>
<td>Germany</td>
<td>317 parents</td>
<td>Descriptive: tests of difference</td>
<td>Not specified</td>
<td>PSI; additional demographic information</td>
<td>Additional disabilities predict increase interactive stress for parents (child condition risk factor)</td>
</tr>
<tr>
<td>Hintermair (2000a)</td>
<td>Germany</td>
<td>317 parents</td>
<td>Descriptive: analysis of variance</td>
<td>1 – 12 years</td>
<td>PSI</td>
<td>Communication difficulties associated with stress and conflict in family (functional care strain risk factor)</td>
</tr>
<tr>
<td>Magnuson and Hergils (2000)</td>
<td>Sweden</td>
<td>10 parents of 8 children</td>
<td>Qualitative</td>
<td>3 years 5 month – 7 years</td>
<td>In-depth semi-structured interviews</td>
<td>Delayed diagnosis may cause difficulties for parents (risk factor not included in model); communication difficulties linked with increase stress (functional care strain risk factor)</td>
</tr>
<tr>
<td>Mikkelsen, Nielsen and Rasmussen (2001)</td>
<td>Denmark</td>
<td>607 parents</td>
<td>Descriptive; questionnaires</td>
<td>0 – 18 years</td>
<td>Questionnaires</td>
<td>Early intervention helps reduce parental stress (social-ecological resilience factor)</td>
</tr>
</tbody>
</table>

Table 1.1: Review of studies of the adaptation of hearing parents to a deaf child (continued).
<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Country</th>
<th>Sample size</th>
<th>Type of study</th>
<th>Age of sample</th>
<th>Measures</th>
<th>Support for model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allegretti (2002)</td>
<td>USA</td>
<td>1 family</td>
<td>Qualitative: Thematic analysis</td>
<td>2 years</td>
<td>Investigator-designed interviews administered on 3 occasions; behaviour checklist</td>
<td>Child characteristics predictor of parental stress and adaptation (child condition risk factor)</td>
</tr>
<tr>
<td>Lederberg and</td>
<td>USA</td>
<td>23 hearing</td>
<td>Longitudinal; descriptive, analysis of</td>
<td>22 months – 4</td>
<td>QRS–SF; PSI; Social support questionnaire</td>
<td>Communication difficulties associated with higher parental stress (functional care strain risk factor)</td>
</tr>
<tr>
<td>Golbach (2002)</td>
<td></td>
<td>parents of deaf children; 23 hearing parents of hearing children</td>
<td>variance</td>
<td>years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pipp-Siegel et al</td>
<td>Colorado</td>
<td>184 mothers</td>
<td>Descriptive; Correlations and regresional analysis</td>
<td>6 months to 5 years 7 months</td>
<td>PSI (short form); PDHS; FSS; MCDI – Expressive Language Scale</td>
<td>Additional disabilities (child condition risk factor), perceived daily hassles (psychosocial stress risk factor, social support and income (social-ecological resilience factor) all predictors of stress</td>
</tr>
<tr>
<td>(2002)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yoshinaga-Itano</td>
<td>USA</td>
<td>Several studies</td>
<td>Findings of several studies by author and colleagues</td>
<td>Birth onwards</td>
<td></td>
<td>Early intervention (social-ecological resilience factor) reduces functional care strain risk factor</td>
</tr>
<tr>
<td>(2002)</td>
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</table>

CBCL: Child Behavior Checklist  
FSS: Family Support Scale  
MCDI: Minnesota Child Development Inventory  
PCL: Parents’ Checklist  
PSI: Parenting Stress Index  
PDHS: Parenting Daily Hassles Scale  
QRS-SF: Questionnaire on Resource and stress – short-form  
SLE – The scale to measure the stress of life events

Table 1.1: Review of studies of the adaptation of hearing parents to a deaf child (continued).
1.5 Risk Factors for Parental Adjustment

1.5.1 The Child Condition – additional disabilities: The ‘child condition’ has also been called disease parameters (Wallander & Varni, 1998) and indicates the individual characteristics of the disability. Included in this are additional disabilities, child characteristics (as measured by the Questionnaire on Resource and stress – short-form (QRS-SF)), and the adaptability, acceptability, and demandingness of the child (as measured by the PSI), and these have been found to be predictive factors for parental stress and adaptation to the child’s hearing loss (Allegretti, 2002; Hintermair, 2000; Hintermair, 2000a; Pipp-Siegel et al, 2002).

The presence of additional disabilities has been correlated with increased parental stress on the Dysfunctional Parent-Child Interaction subscale of the PSI (Pipp-Siegel et al, 2002). This research measured parental stress in a sample of 184 hearing mothers of deaf children. Of this sample 37.5% of the children had additional disabilities. However, the nature and severity of the disability was not stated.

A similar study took the type of disability into account, with this being roughly categorised by the symptoms described by the parents (Hintermair, 2000). From questionnaires returned by 317 parents, the most significant difficulty experienced was in the domain of interactive stress (particularly adaptability, acceptability, and demandingness of the child, as measured by the PSI).
Severity of hearing impairment has been shown to have a more complex relationship with parental stress, with higher levels of stress associated with lower (moderate) and higher (profound) degree of hearing impairment, but lower stress when the hearing impairment is between these two levels (severe). This will be discussed in more depth below.

1.5.2. Functional Care Strain - communication: Functional care strain can be considered to be the stress experienced as a result of the child's dependence on the parent in activities of daily living (Wallander & Varni, 1998). Lederberg and Golbach (2002) carried out a longitudinal study 46 hearing mothers (23 mothers of deaf children, 23 mothers of hearing children). Samples were matched as closely as possible on maternal age, marital status, years of education, child gender, and ethnicity, and all the children had a severe to profound hearing loss. The research attempted to explain the many different findings of previous research, by looking at the developmental aspect of parental stress, and controlling the children's age variable. They found that parents reported higher levels of stress when there were more severe communication difficulties between themselves and their deaf child.

Magnuson and Hergils (2000) conducted in-depth semi-structured interviews with the 10 parents of 8 children, and suggested that communication difficulties can lead to misunderstanding and conflict with the child. Conflict arose from both parent and child not understanding each other, with parents becoming angry when the child did not respond, and the child becoming angry when they were unable to understand what was happening around them. As
the model suggests, this would lead to daily hassles, but may also impact on the social-ecological resilience factor, at the level of family environment. This research considers parents' perceptions and subjective definitions of stress. Within the disability-stress model, this may be considered to fit more easily into the resilience 'stress-processing' factor. In order for this research to offer clear support for the model, this crossover would need to be clarified.

Finally, Mapp and Hudson (1997) completed questionnaires with 98 parents (age range 21 to 68) of children aged 3 to 14 years to examine the correlation between coping strategies, stress levels, and demographic characteristics. They found that the child's increased ability to sign correlated significantly with reduced parental stress. The questionnaires were translated and backtranslated for use with Spanish speaking parents. It is unclear how this process was carried out, and more information about this process would enable the validity of the translation process to be assessed.

1.5.3 Psychosocial Stress – life events, disability-related problems, and daily hassles: Only one of the papers reviewed considered life events (Paradise et al, 1999), despite this being measured within the PSI, and did not find a significant relationship between life events and parental stress. Daily hassles emphasise the importance of the cognitive appraisal in determining which events are perceived as stressful (Wallander and Varni, 1998). Pipp-Siegel et al (2002) found that parents experienced more stress if they perceived more intense daily hassles.
1.5.4 Summary of risk factors: The studies suggest that additional disabilities and communication difficulties may all be predictors of parental stress, and therefore, poor parental adaptation. However, small sample sizes and limited research in this area impacts on the generalisability of these findings.

1.6 Resilience Factors for Parental Adjustment

1.6.1 Stress Processing – Parents appraisals: Stress processing is defined as the "appraisal of the experience and implementation of coping strategies to manage it (Lazarus and Folkman, 1984)" (Wallander & Varni, 1998, p40), and is classed as a resilience factor in the model. It has been suggested that denial of a child's hearing-impairment delays the parental adaptation to the disability (Algretti, 2002). These findings are based on a case study, using a series of interviews with one set of parents and cannot therefore be generalised. Research suggests that, on finding out that their child had a disability, parents experience a process of mourning, where denial is common (Horovitz-Darby, 1991), as well as shock, numbness, and disbelief (Kerr & McIntosh, 1999), and a sense of loss of the 'perfect' child (Densham, 1995). Although the limited research so far has suggested similar findings with hearing parents of deaf children, further research is needed.

The stress processing resilience factor was more difficult to distinguish within the research reviewed. Research has looked at parental appraisals of the experience, (Pipp-Siegel et al, 2002; Vostanis et al, 1997) and as a result, this would fit the definition of 'stress processing'. However, if the daily hassles and behavioural and emotional problems were measured more quantitatively, it is
argued that these areas would fit the risk factors of psychosocial stress and child condition respectively. At this time it is therefore difficult to offer support from the literature reviewed for this factor of the disability-stress model of maternal adaptation, but offers an area for further research.

1.6.2 Personal factors: Personal factors include characteristics of the parent such as temperament, competence, motivation, and problem-solving ability. None of the studies reviewed looked at this area, suggesting an area for future research.

1.6.3 Social-ecological factors – social support, annual income, and use of resources: Studies have measured social-ecological factors, which included social support, annual income, and use of early intervention programs (Brand & Coetzer, 1994; Hintermair, 2000a; Lederberg & Golbach, 2002; Mapp and Hudson (1997); Meadow-Orlans, 1995; Mikkelsen, Nielsen & Rasmussen, 2000; Paradise et al, 1999; Pipp-Siegel et al, 2002; Yoshinaga-Itano, 2002; Young, 1999).

Questionnaires returned by 341 parents showed that levels of social support were not found to have any significant relationship with levels of depression (Hintermair, 2000a). However, a recent study argued that less social support is a predictor of parental distress (Pipp-Siegel et al, 2002). The earlier study looked at German children aged 1 – 12 years, whereas the later study considered much younger American children (6 months – 6 years 7 months). Neither study had a control group of hearing parents of hearing children. It
may be suggested that the effect of, and need for, social support may differ as the child gets older, and becomes involved with more activities away from home. It is also suggested that family adaptation to the deaf child will develop as the child grows, with the impact of the hearing loss becoming more apparent with age (Lederberg & Golbach, 2002). The results of this study suggests that, in a sample of 46 children aged 22 months to 4 years, mothers of deaf children did not feel high levels of parental distress or dissatisfaction with their social support networks (Lederberg & Golbach, 2002). A larger study carried out by Hintermair (2000a) found that, when considering three-way interactive effects between contacts with hearing-impaired adults, means of communication, and the hearing status of the child, parents who signed with their child, and who had frequent contact with hearing-impaired adults were less socially isolated and more accepting of their child. Parents provided qualitative reports of the communication methods used within the family and the competency and adequacy of these chosen methods is not measured. Therefore, as the author argues, only an impression of the communication within the family could be gained (Hintermair, 2000a).

The small sample sizes of some of these studies, and the variations in the ages of the children in studies looking at social support, suggests that more research needs to be done in this area to clarify these findings.

Hearing mothers of deaf children have been shown to report significantly greater general life stress, especially with regards to finances and work (Meadow-Orlans, 1995). Lower annual family income has been shown to
predict parental stress (Pipp-Siegel et al, 2002). As already discussed above, this study had a larger sample (n=184) and utilised a number of measures. Similarly, more stress was found amongst parents from socioeconomically disadvantaged groups (Paradise et al, 1999). This study relied on parental appraisals of different situations, and these may be unrealistic appraisals. Also the authors point out that certain ethnic groups were not included in the research, and therefore the findings can not be generalised to all groups (paradise et al, 1999). Meadow-Orlans (1995) suggested that hearing mothers of deaf children might be more reluctant to return to work, increasing financial difficulties. Family income has not been considered in any of the other papers reviewed. Based on the findings of these studies (Meadow-Orlans, 1995; Paradise et al, 1999; Pipp-Siegel et al, 2002) income may serve as an additional variable when measuring parental stress in future research.

Related to this finding, higher levels of parental education were significantly related to less stress (Brand & Coetzer, 1994). Sixty parents (aged 26-52) of 30 children completed questionnaires and were interviewed for this South African study, but were not compared to a control group. Mapp and Hudson (1997), in an American study of 98 parents, found no relationship between parents’ level of education, income, and parental stress. Pipp-Siegel et al (2002), in an American study of 184 hearing mothers, found no relationship between maternal level of education and stress, when the mean level of education was one year at college. The findings of this study were compared but not matched to a sample of 800 parents of hearing children. Although
income has been found to predict parental stress, the relationship with maternal education is unclear.

In many of the papers reviewed, parents were receiving some form of intervention from services. Two of these consider the impact of these programs on the family (Mikkelsen, Nielsen & Rasmussen, 2000; Young, 1999). In several of the studies parental involvement with intervention programs was not measured although present, and was identified as a resilience factor in the disability-stress model. In order to discount the effect of this variable, this would need to be considered in future research.

In a larger study (Mikkelsen et al, 2000) postal questionnaires were returned by 607 parents in Denmark, and the authors concluded that, for the parents' benefit, counselling should be offered immediately after a diagnosis of hearing-impairment has been confirmed, and there is a need for psychological support early on. Postal surveys can create sampling-bias, for example, excluding those with poor literacy skills. The authors have also commented that the qualitative nature of the research indicated what parents want, but not why (Mikkelsen et al, 2000). A more in-depth study of a cultural-linguistic intervention with parents in Britain (Young, 1999) suggested that such a model causes contradictions for the parents, as hearing parents attempt to adapt to a new deaf culture, and integrate this into their lives (Young, 1999), suggesting that consideration of the type of intervention is important. It is suggested that clinicians should not make assumptions about whether the client sees their hearing-impairment as a cultural addition or medical loss, and
they need to decide which model, cultural or medical, is most helpful for the client (Harvey, 1989).

Research that considered the impact of an early intervention program on the child's development found that the intervention led to significantly better language, speech, and social-emotional development (Yoshinago-Itano, 2002). The disability-stress model would suggest that these positive effects on the child condition would reduce the risk of poor maternal adaptation.

1.6.4 Summary of resilience factors: Research suggests that lower family income predicts parental stress (Meadow-Orlans, 1995; Paradise et al, 1999; Pipp-Siegel et al, 2002), as suggested by the disability-stress model. Links between parental adaptation and the resilience factors of social support and use of resources in the form of intervention programs is less conclusive. Further research into these areas is needed.

1.7 Additional research findings not accounted for in the model

1.7.1 Diagnostic process: Although diagnosis is highlighted in the model, this refers to the disability's label, and not the process of diagnosing impairment. The impact of the diagnostic process has been considered in the research into the adaptation of haring parents to a deaf child (Densham, 1995; Kittrell & Arjmand, 1997; Magnuson & Hergils, 2000). It has been argued that severe hearing-impairment is rarely detected in the first year, as the adult-child interactions of hearing-impaired children are similar to those of hearing children (Preisler, 1999). This is explained through a child's use of amodal
perception (the ability to take information received through one sense, and to translate it to another). Preisler (1999) argued that hearing-impairment does not actually impede communication until the age when talking usually begins. If an early diagnosis leads to the introduction of a manual form of communication, this may override the child’s normal everyday methods of communication, preventing the mutual understanding between child and carer, and, as a result, communication may break down.

Densham (1995) suggested that parents go through a process of grieving for the ‘perfect’ child they have lost, and this process enables them to accept the new child. However, any delay in diagnosis can prolong this process. Parents have to realise that there is a problem, before they enter into the diagnostic process. Making the decision to seek clinical advice, making an appointment, and waiting lists can all delay the diagnostic process, and waiting for and receiving a diagnosis has been shown to create tremendous pressure. Research suggests that parents may find themselves besieged by professionals and overwhelmed with information (Densham, 1995). Kittrell and Arjmand (1997) found the mean age of parental suspicion of a hearing-impairment was 12.4 months, but the mean age of diagnosis was 20.2 months. A retrospective analysis of school records was carried out, along with postal questionnaires to parents. It was concluded that the mean age of diagnosis is considered to be unacceptably high, and professionals should take parents’ suspicions seriously. As mentioned before, gathering data through postal responses may bias the sample. The study also used Spanish translations of the questionnaires. Neither details of the translation process,
nor the reliability and validity of the translated scales, were mentioned in the study.

A recent qualitative study (Magnuson & Hergils, 2000) suggested that parents may feel angry, or may blame themselves for a delayed diagnosis. The authors argued that there are distinct phases parents pass through when adapting to the child's hearing-impairment, and that a period of calm precedes parental suspicion. When a hearing-impairment is suspected, anxiety and frustration are often present until the suspicions are confirmed. It was concluded that all the parents who participated would have welcomed screening programs for newborns.

1.7.2 Degree of hearing loss: Although the disability-stress model suggests that the severity of the impairment may be a risk factor for poor parental adaptation, research has suggested that this may not be the case when considering deaf children of hearing parents (Hintermair, 2000a; Pipp-Siegel et al, 2002). Hintermair (2000a) analysed questionnaires returned from 341 parents. He found that parents of children with profound (greater than 90 decibels) and moderate (hearing loss between 40 – 60 decibels) hearing loss reported more problems in establishing a mutual relationship with the child than with children whose hearing loss was severe (61-90 decibels). Similarly Pipp-Siegel et al (2002) found that less severe hearing loss predicted higher parental stress on the parent-child dysfunctional interaction subscale of the PSI. These findings both suggest that severity of hearing loss is not necessarily significantly associated with increased parental stress.
This finding may be explained by parental perceptions and expectations of milder hearing loss, with parents feeling that they are being ignored when the loss is mild, and relationships between parents and child being strained as a result of communication difficulties. This presents an area in which further research is needed.

1.7.3 Types of social support: Although social support has been included as contributing to the social-ecological resilience factor, research shows this to be a complex area. The model does not allow for differentiation between types of social support.

Support from other parents of deaf children has been found to be important for reducing parental stress. Parents who have had parent-to-parent support have shown evidence of a warm, accepting, and trusting relationship with their child (Hintermair, 2000a), and in a longitudinal study by Gregory (1995), out of 122 mothers of children aged 6 and under, 53% rated support from other parents as important.

In a longitudinal study of 46 mothers of both deaf and hearing children, American mothers of younger deaf children (aged 22 months) have been found to have significantly larger professional support networks than mothers of hearing children. In the same study, mothers of hearing children (aged 22 months) were found to have larger general support networks (Lederberg and Goldbach, 2002). This may suggest that it not the presence of social support, but the nature of social support that creates the resilience effect.
Lederberg and Goldbach's (2002) longitudinal research used different measures at different time points in the study. The QRS-F was used when the children were 22 months, and the PSI was used at ages 3 and 4 years. Therefore any age effects between the younger and two older groups may be a result of the different measures.

Lack of spousal support has been considered when looking at parental stress, and research findings have suggested that mothers report insufficient support from their partners (Brand and Coetzer, 1994; Meadow-Orlans, 1995). Support may also be gained through religious organisations, and a correlational study of 98 parents of 138 children in America found that more frequent church attendance predicted lower levels of parental stress in hearing parents of deaf children (Mapp and Hudson, 1997).

Finally, contact with hearing-impaired adults has been linked with evidence of a stronger sense of parents' competence in the upbringing of their child (Hintermair, 2000a).

1.7.4 Cultural differences: Parents from different cultures have been found to employ different coping strategies and different methods of seeking social support to help with adapting to a child's hearing-impairment (Mapp and Hudson, 1997).

Kittrell and Arjmand (1997) reported on questionnaires returned by American parents of 291 children with sensorineural hearing-impairment. They found
that Caucasian children were diagnosed significantly earlier than either Black or Hispanic children, regardless of socio-economic status. However, Pipp-Siegel et al (2002) argued that the child's gender, the age of identification, and ethnicity were not predictors of maternal stress. When considering the findings concerning delayed diagnosis of a hearing-impairment, differences in ethnic group are factors not accounted for in the model.

1.7.5 The introduction of sign language and hearing aids: A Swedish study of 10 parents of 8 children has found that the introduction of hearing aids and/or sign language improved the language and social behaviour of the hearing-impaired child (Magnusson and Hergils, 2000). Unlike some disabilities, the impact of a hearing-impairment on the child and their family can be minimised by the introduction of these, another aspect of hearing-impairment that is not accounted for within the disability-stress model.

1.7.6 Information and preparedness: Questionnaires returned by 607 parents in Denmark found that parents wanted more information about hearing-impairments in order to cope with the impairment (Mikkelson et al, 2001). Parents have reported not understanding what the hearing-impairment would mean in day-to-day terms (Gregory, 1995). Parents of profoundly deaf children were found to receive more information than parents of severely hearing-impaired children, who in turn received more information than parents of children with a moderate hearing-impairment (Mikkelson et al, 2001).
Parents who were more aware that their child may develop a hearing-impairment, (for example, as a consequence of hereditary factors, abnormality around birth, maternal rubella, or meningitis in the child) are argued to be more prepared for the diagnosis of a hearing-impairment. As a result, they may adapt to the impairment more quickly (Densham, 1995).
1.8 Discussion

1.8.1 The adaptation of hearing parents to the deaf child: The research suggest that additional disabilities and communication difficulties may present risk factors for poor adaptation of hearing parents to their deaf child, whereas increased family income provides a resilience factor. Other factors that may be considered to be resilience factors, but are not included within the disability-stress model of adaptation are the type of social support, cultural influences, the provision of information, and parents' preparedness for a diagnosis of a hearing-impairment. However, degree and severity of hearing loss has not been found to have a positive correlation with parental stress, with more stress being found when the hearing loss is either profound or moderate, and a severe hearing loss predicting less stress. A risk factor that is excluded from the model is the diagnostic process, and delays in diagnosis.

The research so far provides partial support for applying the disability-stress model of maternal adaptation (Wallander and Marullo, 1997) to hearing parents of deaf children. Support has been offered for the risk factors of the child condition (additional disabilities) and the resilience socio-economic factor (annual income, and possibly early intervention programs).

When considering the resilience factors outlined, the model is supported by findings that lower income has predicted stress. However, other resilience factors are less clearly supported, with inconclusive findings concerning social support, maternal education, and stress processing.
One possible explanation for these discrepancies is the definition of terms being measured, that is, how 'adaptation' is defined and measured. A number of studies used parental stress as an outcome measure of how parents have adapted to their child's impairment.

The resilience of personal factors would take into account an individual's susceptibility to stress, and other aspects such as depression. The studies reviewed have not considered if these factors were present before the arrival of the child with a hearing-impairment, and therefore it is difficult to distinguish which came first, and whether or not parental stress is truly attributable to the child's condition. This suggests a role for further longitudinal research.

Another explanation for the variety in findings is the differences in age groups studied. Although Paradise et al (1999) found that there were no differences in parental stress levels in the first three years of the child's life, Lederberg and Golbach (2002) did find that parental concerns changed with the child's age, with concerns for the child's future being more likely with parents of children aged 2 months than those whose children were 3 and 4 years old. The overall conclusions of this research were that, in general, mothers of deaf children did not feel a high level of stress. Although hearing loss can change with age, which may affect levels of adaptation, all the children in this study had severe to profound hearing loss, so it is possible that developmental changes in the impairment would be minimal. In light of this, it is considered important to consider the child's age as a separate variable in future research.
Further explanation for the variety of findings may be the varying sample sizes and statistical power of the smaller samples, and the different measures used.

1.8.2 A revised model of parental adaptation to a child with a hearing-impairment: Figure 1.2 suggests a revised version of the disability-stress model of adaptation, which is considered to be more applicable to hearing parents of deaf children. This revised model has an additional resilience factor that is connected to functional care strain, which considers the introduction of sign language and/or hearing aids to minimise communication problems and/or the hearing deficit. The revised model also shows a link between psychosocial stress and stress processing. This aims to clarify how parental perceptions of psychosocial stresses impact on their adaptation to the child's hearing impairment. However, further research is necessary which considers these factors individually and in more depth.
Figure 1.2: A revised version of the disability-stress coping model of adaptation in parents with children with a hearing-impairment

Single lined boxes indicate risk factors, and double lines indicate resilience factors.
1.9 Future research

Seventeen studies have been considered within this chapter. Of these, only four studies took place in the United Kingdom (Densham, 1995; Gregory, 1995; Vostanis et al, 1997; Young, 1999). Research has shown that there are cultural differences in the adaptation and coping styles of parents who have a child with a physical disability, and cultural differences in how a disability is viewed (Goldin-Meadow & Saltzman, 2000; Mapp & Hudson, 1997). All of the UK studies are small, and it is suggested that more research is needed in this country in order to identify the culturally specific adaptation styles, and factors involved in the adaptation of hearing parents to having a deaf child.

Additional disabilities have been suggested to be a predictor of increased parental stress (Hintermair, 2000; Pipp-Siegel et al, 2002), but further research is needed in this area to clarify this link. Any future research needs to clarify the nature and severity of the additional disability, taking into account any cognitive or additional sensory impairment. Additional disabilities should be considered as an interacting variable when research is carried out that considers parental adaptation to the deaf child.

Further work into the effects of the introduction of sign language, and its relationship with age and the adaptation of parent and child to a hearing-impairment, may also be valuable. Communication methods have not been measured in much of the research reviewed, and data about this would be simple to include in further research.
The relationship between psychosocial stress and adaptation is unclear, and an explanation for this may be that psychosocial stress is difficult to distinguish from the stress processing resilience factor. There is limited research in this area so far, and further research that considers the impact of disability-related problems, daily hassles, and major life events on the adaptation of parents to a deaf child is recommended.

Wallander and Marullo (1997) have developed the Handicap-related Problems for Parents Inventory (HPPI). This measure has been devised from the disability-stress model, and preliminary research suggests this measure has excellent internal consistency, and good test-retest reliability (Wallander and Marullo, 1997). As this measure corresponds to the disability-stress model, this would be an appropriate measure to use in future research. However, the HPPI would need to be standardised first with a population of hearing parents with deaf children, presenting another area where research is advised.

1.10 Clinical implications

Based on the findings to date, it is clear that professionals should be aware of the risk factors predicting poor adaptation, and resilience factors for better adaptation, of hearing parents to a deaf child in the family. Providing hearing parents of deaf children with information has been considered important (Gregory, 1995; Mikkelsen et al, 2000), and subjective reports from parents have suggested they can feel ignored by professionals during the diagnostic process (McNeil and Chabassol, 1984).
One finding that does emerge is the importance of early intervention with parents. Early intervention was considered to be important in providing protection for parents against stress. Family art therapy (Horovitz-Darby, 1991) and systemic therapy (Harvey, 1989; Warner, 2000) have both been suggested as good interventions when working with a hearing family with a deaf child. A family centred approach, encouraging a partnership between parents and professionals, support and respectful treatment, and an exchange of information, has been shown to be effective in helping parents to adapt to their child’s disability (King, King, Rosenbaum & Goffin, 1999). An area of further interest not considered within this chapter is the role of hearing siblings within the family with a deaf child. One study (Magnuson and Hergils, 2000) suggested that siblings became the 'middlemen' between hearing parent and deaf child. More work in this area is needed.

The findings from this chapter suggest that clinical psychologists have much to offer parents whose child has received a diagnosis of a hearing-impairment. The disability-stress model suggests that areas such as problem-solving, family environment, use of resources, and cognitive appraisal all provide resilience factors against poor adaptation. The research reviewed suggests that early intervention is preferable to no intervention. Other sources recommend systemic family therapy (Harvey, 1989; Warner, 2000) as one role for the Clinical Psychologist. However, there are many other professionals who may be involved with the family – for example, interpreters, audiologists, Deaf professionals, health visitors, teachers, and speech and language therapists – and a multidisciplinary approach has been advised.
(Golberg, 1995). Self-reports from parents have suggested they feel besiegged by professionals (Densham, 1995), and those designing intervention should acknowledge this. Parent-to-parent support has also been considered important (Gregory, 1995; Hintermair, 2000) suggesting a role for support groups or networks.

1.11 Conclusion

From the literature reviewed it is suggested that the disability-stress model of parental adaptation (Wallander and Marullo, 1997) has some applicability to the area of the adaptation of hearing parents to a deaf child. Specific factors have been shown to have some power to predict a risk of poor adaptation, these being communication difficulties, additional disabilities, the diagnostic process, and social-ecological factors.

Additional factors drawn from the literature reviewed suggest that a new model of parental adaptation may be more applicable for this area. This revised model needs to be tested fully, and further research is necessary.
1.12 References


2. Chapter 2: Empirical paper 1 - Creating a scale to measure the interruption of the social identity of Deaf people.
2.1 Abstract

This paper describes the development of the Identity Interruption Scale for Deaf People (IISDP). This scale will be used in a larger research project (Marriott, O'Rourke, and Forshaw, 2003, unpublished paper) that will aim to consider links between identity interruption (as described by Burke, 1991), social identification by people with hearing loss, and psychological distress.

Initially qualitative data was collected through Internet newsgroups for deaf people. Nine respondents returned data, from which ten themes emerged. From these twenty questions were developed, which were each coded into one of four identity interruption types, and face validity tested. Questions were translated into a written form of British Sign Language, and then back-translated.

Following a pilot of the questionnaire, Cronbach's alpha coefficients revealed acceptable internal consistency for all but one of the questionnaire items (α=.8415). Factor analysis extracted five factors with eigenvalues of 1.2 or higher. Four items were removed from the final version of the IISDP. A discussion of the process and findings, and general conclusions are made.
2.2 Introduction

This paper describes the development of the Identity Interruption Scale for Deaf People (IISDP), a measure based on the theory of identity interruption and psychological distress (Burke, 1991). Any work carried out with deaf people, clinically or academically, may encounter both language differences, and a Deaf subculture (Glickman, 1986; Harris, 1995; Hindley, Hill and Bond, 1993; Thomas, 1981). This paper will introduce briefly the concept of Deaf culture, and then consider the problems that may arise when designing and translating questionnaires across cultures. The development of the IISDP will then be described.

'Deafness' can indicate membership to a cultural group (Barnet and Franks, 2002; Harris, 1995; Young, Monteiro, and Ridgeway, 2000). Individuals identifying themselves as members of the Deaf culture are likely to view their deafness as a positive part of their lives, instead of seeing it as a medical loss (Barnet and Franks, 2002; Harris, 1995; Young, Monteiro, and Ridgeway, 2000). This view of Deafness is that of a linguistic and cultural minority and contrasts with the traditional medical or disability model (Baker and Cokely, 1980. In Glickman, 1996).

British Sign Language (BSL) syntax differs significantly from spoken English language (Hindley, Hill, and Bond, 1993). Research suggests that the reading age of d/Deaf\(^1\) school-leavers is considerably lower than that of their hearing

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\(^1\) Conventionally members of the Deaf community, who take on a Deaf identity, have been referred to using 'Deaf' with a capital 'D'. This convention will be maintained. The Deaf
counterparts (Young, Monteiro, and Ridgeway, 2000). As a result, it is inappropriate to use measures that are presented in written English alone (Braden, 1994; Childs, 2000).

Research suggests that deaf people who adopt a hearing identity, experience higher levels of psychological distress (Ridgeway, 1997; Weinberg and Sterritt, 1986). Based on a cognitive view that considers how interruption of an action or thought results in stress (Mandler, 1982. In Burke, 1991), Burke's notion of identity interruption offers a means of understanding this finding. Burke (1991) proposes a feedback loop of social identity. Interruption of this loop leads to psychological distress.

Burke's theory views identity as a continuous process. An identity standard is reinforced or modified as the individual behaves within, and perceives input from, the chosen social group. Adjustments to the identity standard may become automatic over time, and are continuously made to balance the identity standard and reflected self-appraisals. However, when there is a large discrepancy between the perceived input, or effects of the output, and the identity standard, this causes interruption of the loop. Burke identifies four types of identity interruption. The loop can be broken by external events that interrupt the normal, automatic process (the broken loop). Identities can interfere with each other when time constraints, or over-commitment to community may consist of hearing people (family and friends of a Deaf person, workers with deaf people, and so on).
another identity, can prevent another identity from being prominent, for example, the roles of wife, mother, and a career identity (interference from other identities). An over-controlled identity system is seen when an individual tries to match input signals from the group identified with too rigidly, for example, a rigid gender identity, religious identity, or sexual identity. Finally, identity interruption can occur when a role is episodic, therefore meaning that there is less time to rehearse the role (Burke, 1991).

It is proposed that this model can be applied to deafness, specifically that adoption of a hearing identity, may in some cases, result in identity interruption, and therefore psychological distress. In order to measure the degree of identity interruption d/Deaf people may experience, this paper describes the development of a new measure, based on the four identity interruption types identified above. In order to overcome difficulties that may arise through cultural differences, a qualitative approach was used to collect information from the d/Deaf target population. In order to overcome issues of language and translation, a system of forward and back-translation was used (Bowling, 1997; Brislin, 1970). The questionnaire was piloted within the Deaf community.
2.3 Ethical approval

The research was granted approval through Coventry University Ethics Board (see Appendix 1).

2.4 Method

Design

2.4.1 Stage One - Developing questionnaire items through a qualitative approach: For this stage of the research, the Internet was used for data collection. The aim was to gain as much information as possible about the experiences Deaf people have in a hearing world. From this common themes were identified, and questionnaire items developed. The Internet offers access to specific groups through specific web sites. This is particularly helpful when accessing smaller groups within a larger population, allowing a better chance at obtaining a larger sample. Research has suggested that the Internet offers a feasible means of data collection (Ross, Tikkanen, and Månsson, 2000). For the purpose of this research, web sites specifically for deaf people were used.

The first posting was put out in May 2001 and a second posting was put out in June 2001 (see Appendix 2 for a copy of the posting). Data collection stopped when qualitative data stopped being received from respondents, and postings stopped being added to the newsgroups at a point when no new themes were identified in the data being received.

Participants: Replies were received from 21 deaf people. Although the web sites accessed originated within the United Kingdom, many replies
were received from people in America. As British Deaf culture and experiences were required, these were not included. As a result, 9 people were included in this stage of the research (n=9; males=4, females=5; ages unknown).

Procedure: Thematic analysis (Smith, 1995) was used to extract themes from the data. The nine written responses to the data were read and reread. Statements that represented a theme were drawn from each posting, and written down (a total of 45 statements). These 45 statements were then read, and broader themes identified. Ten themes were identified from the 45 identified statements (See Appendix 3a for examples of raw data, and Appendix 3b for the statements and themes identified).

Results: Table 2.1 outlines the main themes identified (see Appendix 3b for data contributing to each theme).
<table>
<thead>
<tr>
<th>Theme</th>
<th>Number of statements from data for each theme</th>
</tr>
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<tbody>
<tr>
<td>Transport</td>
<td>2</td>
</tr>
<tr>
<td>Health Services</td>
<td>7</td>
</tr>
<tr>
<td>Emotional</td>
<td>1</td>
</tr>
<tr>
<td>Labels</td>
<td>1</td>
</tr>
<tr>
<td>Employment</td>
<td>3</td>
</tr>
<tr>
<td>Invisible disability</td>
<td>5</td>
</tr>
<tr>
<td>Aids</td>
<td>4</td>
</tr>
<tr>
<td>Family</td>
<td>4</td>
</tr>
<tr>
<td>Communication</td>
<td>13</td>
</tr>
<tr>
<td>Social</td>
<td>5</td>
</tr>
</tbody>
</table>

Table 2.1: Main themes identified from Internet data collection, with the number of statements made in total relating to each theme.

2.4.2 Stage Two – Creating questionnaire items: Five questions were developed for each type of the 4 identity interruption types proposed by Burke (1991) (twenty questions in total), these being based on the themes identified from the first stage of the research (see Appendix 6a for the original questionnaire items).

Test of face validity – Coding: Before translating the question items into British Sign Language, the questions were given to three coders, who
were asked to identify which of the four identity interruption types they considered each question belonged to. This approach was used to test the face validity of the questionnaire items (see Appendix 4 for the outline of each identity interruption type given to coders).

**Results:** All three coders correctly coded eleven of the question items (Questions 1, 3, 5, 8, 11, 13, 14, 15, 17, 18, and 20). Two out of three coders correctly coded an additional four of the questions (questions 2, 7, 9, and 19). Four questions were correctly coded by one of the three coders (questions 4, 6, 12, and 16). All coders incorrectly coded one of the questions (question 10), but all three coders coded this item the same (see Appendix 5 for coding data).
2.4.3 Stage Three – Forward and back-translation of the scale: The twenty scale items were translated into BSL. They were then presented to a bilingual Deaf health professional, who wrote down the translation in spoken English. This system of forward and back-translation was used to ensure that the semantics of the questions were not altered once translated into BSL.

Results: As a result of the back-translation process, changes were made to the BSL translations to attempt to reduce any ambiguity. An example of this is as follows:

The question “Because I am deaf, employers do not think I can do the job as well as hearing people” was translated into BSL as “Boss think me rubbish work - why? me deaf – boss thinks hearing people better”. This was back-translated as follows: “The boss thinks my work is rubbish because I am Deaf, the boss thinks hearing people are better at their work” Through translation, the concept of ‘doing a job less well’ became ‘being rubbish at a job’. As a result, the BSL translation was changed thus: “Boss think me work less good – why? Me deaf – boss thinks hearing people better”.

Following on from the process of forward and back-translation, the wording of 2 BSL versions of the questions were altered (see Appendix 6a – 6d for original questions, BSL translations, back-translations, and amended BSL questions).
It was felt that, to reduce the risk of translation errors, both the written English and BSL translations of the questions would be included on the final questionnaire.

2.4.4 Stage four – piloting the questionnaire:

Participants: Initially the questionnaire was taken to a small Deaf Club (25 members) in the Midlands. Deaf members were invited to complete the questionnaire, and information and instructions were presented in both written English and BSL (see Appendices 7 and 8). Five members (20%) volunteered to take part. In order to increase the sample size, one copy of the questionnaire was sent to a lip reading tutor, and a contact at a larger Deaf Club. These two people distributed an unknown number of questionnaires, and from this, an additional 39 respondents completed the questionnaire (total sample: n=44).

Materials - Scoring system for IISDP: Questions are scored on a five-point Likert scale. Respondents are asked to identify to what degree they agree or disagree with each of the twenty questionnaire statements. Responses are scored as follows:

<table>
<thead>
<tr>
<th>Response</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly agree</td>
<td>5</td>
</tr>
<tr>
<td>Agree</td>
<td>4</td>
</tr>
<tr>
<td>Neither agree nor disagree</td>
<td>3</td>
</tr>
<tr>
<td>Disagree</td>
<td>2</td>
</tr>
<tr>
<td>Strongly disagree</td>
<td>1</td>
</tr>
</tbody>
</table>

All questions are positively weighted.
2.5 Results

2.5.1 Descriptive findings: The pilot sample consisted of 18 males and 26 females, aged between 16 and 79 (mean age = 52.68). Of these, 31.8% identified Sign Language as their first language, 56.8% identified spoken English as their first language, and 11.4% identified a combination of sign language and spoken English. Sixteen participants (36.4%) had no educational qualifications and 29.5% identified O'-level grade or equivalent as their highest achieved qualification. When identifying employment status, 45.5% were retired, 22.7% were in full-time employment, and 20.4% of participants were unemployed. All participants identified themselves as white (see Table 2.2 for demographic information).

2.5.2 Data analysis:

Reliability testing: The internal reliability of the Identity Interruption Scale for Deaf People was examined statistically using Cronbach's alpha. Item-total correlation ranged from .1864 to .6842. Cronbach's alpha coefficients revealed acceptable internal consistency for 19 out of the 20 questionnaire items (α = .8415). If item 12 is removed, validity will increase (Alpha if item removed: α= .8479) (see Appendix 9).
<table>
<thead>
<tr>
<th></th>
<th>Percentage of sample</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender (n = 44)</strong></td>
<td></td>
</tr>
<tr>
<td>male</td>
<td>18</td>
</tr>
<tr>
<td>female</td>
<td>26</td>
</tr>
<tr>
<td><strong>Age (n = 38)</strong></td>
<td></td>
</tr>
<tr>
<td>mean</td>
<td>52.68</td>
</tr>
<tr>
<td>s.d. = 18.704</td>
<td>range = 16 – 79</td>
</tr>
<tr>
<td>median</td>
<td>56.5</td>
</tr>
<tr>
<td><strong>First language (n = 44)</strong></td>
<td></td>
</tr>
<tr>
<td>sign language (n=14)</td>
<td>31.8%</td>
</tr>
<tr>
<td>spoken English (n=25)</td>
<td>56.8%</td>
</tr>
<tr>
<td>both (n=5)</td>
<td>11.4%</td>
</tr>
<tr>
<td><strong>Highest educational qualification (n = 44)</strong></td>
<td></td>
</tr>
<tr>
<td>none (n=16)</td>
<td>36.4%</td>
</tr>
<tr>
<td>CSE/GCSE/GCE O’-level (n=13)</td>
<td>29.5%</td>
</tr>
<tr>
<td>A’-level (n=7)</td>
<td>15.9%</td>
</tr>
<tr>
<td>Degree (n=5)</td>
<td>11.4%</td>
</tr>
<tr>
<td>Other (n=3)</td>
<td>6.8%</td>
</tr>
<tr>
<td><strong>Occupation (n = 44)</strong></td>
<td></td>
</tr>
<tr>
<td>Employed full-time (n=10)</td>
<td>22.7%</td>
</tr>
<tr>
<td>Employed part-time (n=5)</td>
<td>11.4%</td>
</tr>
<tr>
<td>Retired (n=20)</td>
<td>45.5%</td>
</tr>
<tr>
<td>Unemployed (n=9)</td>
<td>20.4%</td>
</tr>
<tr>
<td><strong>Ethnicity (n = 44)</strong></td>
<td></td>
</tr>
<tr>
<td>White (n=44)</td>
<td>100%</td>
</tr>
</tbody>
</table>

Table 2.2: Demographic information for pilot study of Identity Interruption Scale for Deaf People (sample n=44)
**Factor Analysis:** Principal component factoring on a correlation matrix with varimax rotation and Kaiser normalisation was performed with the 20 questionnaire items on the sample of 44 respondents, with some missing data. Eigenvalues and scree plots were examined to determine the number of factors. The factor analysis extracted five factors with eigenvalues of 1.2 or higher, and these accounted for 71.8% of the variance. These five factors comprised of all 20 items of the IISDP. The first three factors represented questions contributing to three of the identity interruption types – the broken loop, the over-controlled identity, and episodic identity. Questions pertaining to the final identity interruption type, interference from other identities, was split across factors four and five, with factor 4 comprising of questions about family, and factor 5 comprising questions about work (see Table 2.3 and Appendix 10).

<table>
<thead>
<tr>
<th>Broken Loop</th>
<th>Factor Loading</th>
<th>Over-controlled</th>
<th>Factor Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q5</td>
<td>.810</td>
<td></td>
<td>Q17</td>
</tr>
<tr>
<td>Q20</td>
<td>.808</td>
<td></td>
<td>Q4</td>
</tr>
<tr>
<td>Q11</td>
<td>.793</td>
<td></td>
<td>Q1</td>
</tr>
<tr>
<td>Q6</td>
<td>.700</td>
<td></td>
<td>Q10</td>
</tr>
<tr>
<td>Q12</td>
<td>.577</td>
<td></td>
<td>Q13</td>
</tr>
<tr>
<td>Episodic Factor 1</td>
<td>Interference from other identities Factor 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------</td>
<td>---------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q14</td>
<td>.735</td>
<td>Q16</td>
<td>.888</td>
</tr>
<tr>
<td></td>
<td>Q8</td>
<td>Q15</td>
<td>.795</td>
</tr>
<tr>
<td>Factos 3</td>
<td></td>
<td>Q7</td>
<td>.727</td>
</tr>
<tr>
<td>Q9</td>
<td>.816</td>
<td>Q2</td>
<td>.483</td>
</tr>
<tr>
<td>Q3</td>
<td>.809</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q19</td>
<td>.652</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q18</td>
<td>.563</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 2.3: Factor loadings for items on the Identity Interruption Scale for Deaf People by identity interruption type.

Reliability testing and factor analysis suggest the removal of four questionnaire items – questions 2, 12, 13, and 14 (lowest factor loadings in each factor). Although coded correctly as an episodic identity interruption type by all coders, question 14 had a higher factor loading in the Broken Loop identity interruption type, and so was removed (see Appendix 11 for the final version of the Identity Interruption Scale for Deaf People).
2.6 Discussion

Cronbach's Alpha identified that removal of one item from the original scale would increase validity. The results of the factor analysis suggest removal of three further items. Following these adjustments, the scale contains 16 items.

Factor analysis identifies three factors based on three of the four identity interruption types - the broken loop, episodic identities, and the over-controlled identity type. Questions designed to measure interference from other identities load over two factors, and becomes a less clearly defined identity type. Due to time constraints, test-retest was not carried out, and would have added to the validity of the scale. Reliability of the scale needs to be confirmed through a repeat factor analysis on a larger sample size.

A sample size of 44 was used for the pilot of the scale. When conducting factor analysis, a sample size of 100 is considered acceptable, but over 200 is considered more favourable (Coakes and Steed, 1999). The sample used for this research is small, and may be considered too small for the findings to be acceptable. More research is necessary to ensure validity and reliability of the scale. Thus caution is advised when using the IISDP in the clinical setting. However, careful analysis of higher scores on the scale may identify areas for which further assessment with an individual may be necessary, such as difficulties within the family. Those items which receive a particularly high score (that is, a score of 4 or 5), may be considered to indicate an area in which an individual's identity loop may be at a higher risk of interruption, and, as a result, a increased possibility of psychological distress.
At the initial stages, qualitative data was gathered from 9 people, via the Internet. This method of data collection may create a sample bias. Firstly, by excluding those without access to the Internet, secondly, by excluding those whose literacy and computer skills are limited, and finally, by only accessing people who feel an affiliation to the web group being accessed, and possibly excluding deaf people with a hearing identity.

Question items are weighted in one direction, and therefore the results may be affected by response bias, with respondents being inclined to answer in one direction. When used clinically, it is suggested that the scale be administered face-to-face with an individual, in order to ensure that each question is understood properly and thought about by the respondent.

When devising a measure aimed to be used within a specific cultural group, the target group should be accessed when developing questionnaire items. When working in a qualitative way, interviewing would gain the perspectives of the target group. To do this within the Deaf population, and when the researcher is not fluent in Sign Language, it is necessary to use Sign Language interpreters. In order to gain a reliable transcript of interviews, they should be videoed, and any spoken interpretation recorded. When devising the IISDP, the Internet was used as an alternative source of data, with the intention that a larger number of d/Deaf people could be accessed, in a shorter amount of time, and with minimal costs.
The over-controlled identity interruption type considers only an over-controlled hearing identity, and fails to consider an over-controlled Deaf identity. The model of identity interruption suggests that a rigid identity may result in psychological distress. As such, an over-controlled Deaf identity may be hypothesised to result in psychological distress in the same way that an over-controlled hearing identity may. This is important to bear in mind if the scale were to be used in the clinical setting. As it stands currently, the scale would only identify psychological distress if an individual's identity were at one pole of the deaf/hearing identity continuum. As a result, the IISDP would benefit from further modification to include items that may account for a rigid Deaf identity.

As mentioned above, it has been argued that the majority of Deaf people who use BSL as their first language are likely to have poor English literacy skills (Young, Monteiro, and Ridgeway. 2000) Difficulties were experienced when recruiting subjects for the questionnaire pilot, and many participants remarked that they felt unable to read the questions and were unwilling to become involved for this reason. In the past research with Deaf people has overcome this difficulty by using tools such as a BSL video of the instructions (de Graaf and Bijl, 2002). It was felt that, by offering a written BSL translation of the questionnaire, this would overcome problems an individual may encounter with written English. However, presenting the questionnaire in paper format still created difficulties, and put off many potential participants. Ideally, in order to overcome language and translation issues, a BSL version of the questionnaire should also be available.
2.7 Clinical uses of the IISDP

The IISDP has many limitations due to the small sample size of the pilot study, item weighting, and the lack of retest. Caution is advised when using the scale clinically. Preliminary research using the IISDP (Marriott, O'Rourke, and Forshaw, 2003, unpublished paper) indicates a significant positive correlation between total scores on the IISDP, and total scores on the General Health Questionnaire – 28 (GHQ-28, Goldberg, 1981), suggesting that higher scores on the IISDP may correlate with higher levels of psychological distress.

The IISDP may help identify areas such as poor self-esteem, and perceived difficulties with family, work, and social situations, and may also serve as an indicator of elevated levels of psychological distress, which can then be measured with additional scales. However, the IISDP will gain greater validity and reliability if a visual signed version becomes available.

Further development of the IISDP needs to take place before it can be used clinically.

2.8 Conclusions

The IISDP has many limitations due to the small sample size of the pilot study, item weighting, and the lack of retest, and further research should be carried out before it is used clinically.

The development of the IISDP has presented many cultural, linguistic, and methodological challenges, some of which it has not been possible to deal
with. However, these early stages of development have proved worthwhile, and it is hoped that, with further development, the IISDP will provide a measure of identity interruption that can be used with health measures as a means of identifying specific areas within an individual's life that may cause difficulties, impacting on psychological distress.
2.9 References


Word count: 5,696
3.1 Abstract

Social identification taps into what is considered to be a human desire to search for things that reflect positively on an individual's self-esteem (Hayes, 1993). Links have been made between social identity and psychological distress (Burke, 1991; Large and Marcussen, 2000; Thoits, 1991), and research suggests that deaf people who adopt a hearing identity have higher levels of psychological distress (Ridgeway, 1997; Weinberg and Sterritt, 1986). The interruption theory of social identity and psychological distress (Burke, 1991) proposes that disruption or incongruence within an identity loop results in psychological distress. Four types of identity interruption are defined – the broken loop, episodic identities, interference from other identities, and an over-controlled identity system. This research hypothesises that there will be correlations between d/Deaf identity, psychological distress, and identity interruption.

The Identity Interruption Scale for Deaf People (IISDP; Marriott, O'Rourke, Forshaw, and Coleman, 2003, unpublished paper), Deaf Attitude and Identity Questionnaire (DATIQ; Ridgeway, 1997) and the General Health Questionnaire-28 (GHQ-28; Goldberg, 1981) were distributed to deaf and hard-of-hearing people (n=130). Pearson's product-moment correlation coefficients were carried out between each combination of these scales, and these were found to be significant, suggesting that a stronger deaf identity leads to less identity interruption, and less psychological distress. When considering identity interruption types, interruption as a result of a broken loop, episodic identity, or interference from other identities is significantly
correlated with higher levels of psychological distress. The findings of this research, and clinical implications, are discussed.
3.2 Introduction

This paper considers the links between social identity, psychological distress, and deafness, and considers a means of identifying in more detail the causes of increased psychological distress in deaf people who adopt a hearing identity. The paper will use the theory of identity interruption (Burke, 1991) as an explanation for the presence of psychological distress.

Social identity refers to an understanding of one’s own self within a social system (Hayes, 1993). It is argued that, in modern society, social identity is determined by situational appraisals rather than background or achievements (Côté, 1996).

Tajfel first mentioned social identity theory in 1972 (Turner, 1996). An individual’s social identity consists of “those aspects of his self-image, positively or negatively valued, which derive from his membership of various social groups to which he belongs” (Tajfel, 1978; p443). Social identities are considered to be descriptive, prescriptive, and a means of evaluating self and others (Hogg, 1996).

Research has suggested that threat to our social identity may lead to psychological distress (Burke, 1991; Large and Marcussen, 2000; Thoits, 1991). Specifically, Burke (1991) proposes a feedback loop of social identity (see Figure 3.1). Burke’s theory views identity as a continuous process, in which an identity standard is automatically adapted according to perceived feedback from the environment. However, when there is a large discrepancy
between the perceived feedback and the identity standard, this causes interruption of the loop. It is this interruption of this loop that leads to a threat to the identity standard, and as a result, psychological distress (such as anxiety or depression) (Burke, 1991).

Figure 3.1 shows the processes involved in the feedback loop model of social identity. The identity standard involves the meanings an individual has attached to his or her social roles. Input is taken from social situations and the environment, and this part of the loop describes the perceptions an individual has of him/herself as implied by the behaviour of others. The identity standard and input have a similar content, and the comparator compares the degree of congruence between the two. The output to the environment (that is, meaningful behaviour) will then be dependent on this comparison. Incongruence between the standard and the input will result in distress, and this distress will increase with the level of incongruence (Burke, 1991).
This theory of identity interruption identifies four interruption types:

- The broken loop - the loop may be broken by external events that prevent the continuous process. This can occur at either the output, or the input stage. When interruption occurs at the output stage, an individual's behaviour in a given situation may have limited or no effect on that situation - that is, others may not change their way of interacting with the individual, or attempts at interaction with others fail. An example of this would be an individual being ignored by the social group. This results in feelings of, for example, alienation or isolation.
Interruption at the input stage considers how the individual may perceive the situation, and how these perceptions may be unclear or incorrect. An individual's behaviour may affect the environment, but the individual does not perceive this effect, and may feel misunderstood. This situation may occur when an individual joins a new social group, and does not know how to read the reactions of others to his/her behaviour.

- Interference from other identities - The loop may be interrupted when two or more identities conflict. For example, a particular identity may be more important, and may detract from other identities. As a result, one identity process is continued, whilst another is interrupted, for example, the roles of women who work and have children.

- An over-controlled identity system - When an individual tries to match the input signals exactly to the identity standard it is described as being 'tightly controlled'. An example of this may be an individual who feels that they must behave in a particularly rigid way to match their gender identity – for example, a strong masculine identity - or a rigid hearing identity of a deaf person. Such a rigid identity will result in more frequent occurrences of incongruence, and as a result, higher levels of distress. Frequent adjustment of the identity standard can interrupt the other processes within the loop.

- Episodic identities - In order to change incongruence within the identity loop it is necessary for an individual to rehearse the changes, and to have feedback from this. This is seen with the anxiety experienced when
performance is being evaluated, such as in work reviews. When a role and
identity is infrequently taken up, rehearsal and feedback is limited. The more
infrequent the rehearsal and feedback occurs, the more likely distress will
result due to extended interruptions in the rehearsal and feedback.

The concept of 'deafness' can be defined in two ways. Firstly, deafness is
defined as a medical and audiological condition, where hearing loss is viewed
on a scale ranging from mild to profound, and can be measured in terms of
the quietest sounds audible in the better ear (in decibels) (Royal National
Institute for Deaf People (RNID) website, http://www.rnid.org.uk/). Secondly,
'Deafness' can also indicate membership to a cultural group, and is often
distinguished from the audiological definition of deafness by the use of a
capital 'D'. Individuals who identify themselves as members of the Deaf
culture adopt sign language as their first language, have a shared history,
culture, and values, and will view their deafness as a positive part of their
lives, instead of seeing it as a medical loss (Baker and Cokely, 1980. In
Glickman, 1996). This view of Deafness is that of a linguistic and cultural
minority (Barnet and Franks, 2002; Harris, 1995; Young, Monteiro, and
Ridgeway, 2000).

Ninety per cent of deaf babies are born to hearing parents (Childs, 2000;
Hindley, 1997; Muth, Emerson, and Williams, 1998). In this situation it is
argued that, in many cases, effective communication does not develop
between parent and child, and this results in the individual being unable to
develop a healthy identity (Holcomb, 1997).
Shared identities are often centred round a shared difference (Taylor, 1999). It is proposed that, if 'Deafness' is a difference that plays an important part in an individual's identity, this may result in a clear separation from other deaf people who adopt a hearing identity. Research has suggested that individuals with a negative attitude towards their deafness are more likely to suffer from anxiety and depression, and that a high sense of Deaf identity results in higher self-esteem and self-image, leading in turn to better mental health (Ridgeway, 1997; Weinberg and Sterritt, 1986). However, a dual identity involves a balance of both hearing and Deaf identity. Research has suggested that a dual identity is the most adaptive form of identity (Cole and Edelmann, 1992; Weinberg and Sterritt, 1986). However, definitions of 'Deaf', 'hearing' and 'dual' identity vary across the research.

As mentioned above, a stronger Deaf identity is considered to lead to better psychological health. When considering Burke's model of identity interruption, an individual's identity standard may be based on their sense of belonging to, and desire to be part of, the Deaf and/or hearing social identity. The more incongruence that exists between input and the identity standard, the higher the level of psychological distress (Burke, 1991). Therefore it is proposed that an individual whose identity standard is based within a hearing identity (so perhaps preferring spoken English and lip-reading to sign language), but whose perceptions of self as implied by the behaviour of others leads more towards a deaf identity (for example, hearing people shouting or gesturing to communicate), may experience higher levels of incongruence between input
and identity standard, and therefore, according to the model, higher levels of psychological distress.

3.3 Research aims

The following research aims to consider links between the level of hearing identity adopted by a deaf person, degree and type of identity interruption to the identity loop, and psychological distress. These will be measured using the Deaf Attitude and Identity Questionnaire (DATIQ; Ridegeway, 1997), the Identity Interruption Scale for Deaf People (IISDP; Marriott, O'Rourke, Forshaw, and Coleman, 2003, unpublished paper), and the General Health Questionnaire – 28 (GHQ-28; Goldberg, 1981).

3.4 Research hypotheses

H1: There will be a correlation between the level of Deaf social identity and psychological distress.

H2: Deaf people with a hearing identity will experience interruption to this identity, which is different in terms of frequency and level of distress, than their counterparts with a Deaf identity.

H3: There will be a relationship between degree of identity interruption and levels of psychological distress.
3.5 Method

3.5.1 Design: A repeated measures, correlational design will be used to examine the relationships between the three measures. Data is normally distributed. The research will look for correlations between degree of Deaf or hearing identity, levels of psychological distress, and identity interruption (separated into type and degree). These three variables will be looked at under the following conditions. Firstly, the dependent variable will be level of psychological distress, and this will rely on two independent variables - strength of Deaf identity, and nature and degree of identity interruption. Secondly, a correlation will be looked for between strength of Deaf identity and identity interruption, with the former being the independent variable, and the latter the dependent variable. Data for each variable will be collected through a series of closed-ended questionnaires and standardised measures.

3.5.2 Participants: Participants were adults (age 18 or over), and members of either Deaf clubs, Hard-of-hearing groups, or students on lipspeaking classes. Contacts within each group distributed questionnaires, and participation was voluntary.

3.5.3 Measures: The DATIQ (Ridgeway, 1997) consists of thirty-two items, with a minimum score of zero and a maximum score of thirty-two. Each item gives a statement that the respondent is asked to either agree or disagree with (A or D). No instructions were available for the DATIQ, and, as a result, the instructions used were written by the author (see Appendix 14). Scoring of
the scale is either 1 or 0 for each item. The higher an individual's score (maximum of 32), the stronger their Deaf identity is considered to be.

In addition, respondents were asked to indicate their self-rated degree of deafness according to a linear representation (see figure 3.2). This line was measured in millimetres, and was used to give additional support to the DATIQ, for which data regarding reliability and validity was not available.

![Additional linear scale to measure perceived d/Deaf/hearing identity](image)

**Figure 3.2:** Additional linear scale to measure perceived d/Deaf/hearing identity (not to scale - actual total line length = 121mm).

The IISDP (Marriott, O'Rourke, Forshaw, and Coleman, 2003, unpublished paper) has been piloted with a sample of forty-four d/Deaf people, and has been shown to have acceptable internal consistency (α=. 8479). Factor analysis identified five factors, with questions pertaining to interference from other identities spreading out over two factors. Each of the three other identity interruption types accounted for the three other factors identified (see Appendix 10).
The GHQ-28 (GHQ-28; Goldberg, 1991) comprises four sections, somatic difficulties, anxiety and insomnia, social dysfunction, and severe depression (see Appendix 15). The GHQ-28 can be scored in one of three ways - by using a 0-0-1-1 method, a 0-1-2-3, or a 0,1,1,1 method (Goldberg and Williams, 1991; Goodchild and Duncan-Jones, 1985). When scoring for psychological caseness, it is recommended that the 0-0-1-1 scoring method be used. However, if subscales are required, the use of the 0-1-2-3 method has advantages (Goldberg and Williams, 1991). For the purpose of this research, a 0,1,2,3 method was used. The GHQ-28 has had several studies carried out, and is considered to have good reliability and validity (Goldberg, 1991). Although it has been reported that the GHQ has been translated into sign language, and the written version of this is reported to have good sensitivity and specificity levels (Ridgeway and Checinski, 1991), at the time of this research no published version of the BSL GHQ was available, and therefore the original GHQ was used.

3.5.4 Procedure: Letters were sent out to Deaf clubs, Hard-of-hearing groups, and lip speakers (n=45) explaining the research, and offering them the opportunity to be involved (see Appendix 12). Of these, 25 people requested questionnaires that they would distribute within their group. These included 6 Deaf Clubs (74 questionnaires sent), 10 hard-of-hearing groups (156 questionnaires sent), and 4 lip speakers (80 questionnaires). In total 310 questionnaires were posted out, with instructions (see Appendix 13). Of these, 135 were returned (43.5% return rate). Five of these were incomplete, and
therefore 130 questionnaires were used in the final data collection. Questionnaires were returned anonymously.

3.6 Results

3.6.1 Descriptive data: The sample consisted of 49 (37.7%) males and 81 (62.3%) females. Of the 130 respondents, 62 gave their age (mean age=63; S.D.= 18.19), with a large percentage of this being over the age of 60 (62.9%). This can be accounted for due to the fact that a larger proportion of questionnaires were sent to hard-of-hearing groups than any other group accessed for the sample, and organisers of these groups reported that the members were often older adults. The majority of respondents (n=89; 68.5%) identified spoken English as their first or main language. A large number of respondents reported having no qualifications (n=53; 40.8%), and 85 (65.4%) were retired. All but six of the sample (n=124; 95.4%) identified their ethnic group as white. Of the sample, 128 reported the age at which hearing loss occurred. Thirty-four (26.6%) respondents are prelingually deaf (hearing loss before the age of 2 (Denmark, 1966)), 21 (16.4%) acquired hearing loss in childhood or adolescence (age 3-18), 55 (42.9%) acquired hearing loss as adults (age 19-64), and 18 (14.1%) acquired hearing loss in later life (age 65+). Thirty-seven of the respondents (28.5%) reported being profoundly deaf, with the 41 respondents (31.5%) identifying themselves as severely deaf (Table 3.1).
<table>
<thead>
<tr>
<th><strong>Gender (n=130)</strong></th>
<th>Male = 49 (37.7%)</th>
<th>Female = 81 (62.3%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (n=62)</strong></td>
<td>Mean age = 63</td>
<td>Std. deviation = 18.19</td>
</tr>
<tr>
<td></td>
<td>Median = 68</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Minimum = 18</td>
<td>Maximum = 90</td>
</tr>
<tr>
<td><strong>Language (n=130)</strong></td>
<td>Sign language = 18 (13.8%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Spoken English = 89 (68.5%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sign language and spoken English = 23 (17.7%)</td>
<td></td>
</tr>
<tr>
<td><strong>Highest qualification (n=130)</strong></td>
<td>None = 53 (40.8%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>CSE/GCSE/GCE O'-levels = 31 (23.8%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>GCE A'-level = 6 (4.6%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Degree = 12 (9.2%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Higher degree = 4 (3.1%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other = 24 (18.5%)</td>
<td></td>
</tr>
<tr>
<td><strong>Employment (n=130)</strong></td>
<td>Employed full-time = 16 (12.3%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Employed part-time = 13 (10%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Unemployed = 16 (12.3%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Retired = 85 (65.4%)</td>
<td></td>
</tr>
<tr>
<td><strong>Ethnicity (n=130)</strong></td>
<td>White = 124 (95.4%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Indian = 2 (1.5%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Asian other = 1 (0.8%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Black Caribbean = 3 (2.3%)</td>
<td></td>
</tr>
</tbody>
</table>
Table 3.1: Demographics for research sample (n =130).

3.6.2 Data analysis: The data were analysed with the Statistical Product and Service Solution 11.0 (SPSS 11.0.0) computer programme.

Table 3.2 shows the mean scores and standard deviations for the IISDP, DATIQ, and GHQ-28.
<table>
<thead>
<tr>
<th>Scale</th>
<th>N</th>
<th>Mean</th>
<th>S.D.</th>
<th>Min</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>DATIQ</td>
<td>117</td>
<td>20</td>
<td>3.89</td>
<td>3</td>
<td>29</td>
</tr>
<tr>
<td>IISDP – Total</td>
<td>123</td>
<td>52.72</td>
<td>9.88</td>
<td>12</td>
<td>80</td>
</tr>
<tr>
<td>Broken Loop</td>
<td>124</td>
<td>13.06</td>
<td>3.52</td>
<td>2</td>
<td>20</td>
</tr>
<tr>
<td>Episodic identity</td>
<td>124</td>
<td>12.77</td>
<td>3.17</td>
<td>1</td>
<td>20</td>
</tr>
<tr>
<td>Interference from other identities</td>
<td>124</td>
<td>13.67</td>
<td>3.55</td>
<td>0</td>
<td>20</td>
</tr>
<tr>
<td>Over-controlled identity</td>
<td>124</td>
<td>12.89</td>
<td>3.31</td>
<td>4</td>
<td>20</td>
</tr>
<tr>
<td>GHQ-28 – Total</td>
<td>121</td>
<td>19.91</td>
<td>11.67</td>
<td>5</td>
<td>55</td>
</tr>
<tr>
<td>Somatic</td>
<td>125</td>
<td>5.13</td>
<td>3.99</td>
<td>0</td>
<td>18</td>
</tr>
<tr>
<td>Anxiety</td>
<td>125</td>
<td>4.86</td>
<td>3.99</td>
<td>0</td>
<td>18</td>
</tr>
<tr>
<td>Depression</td>
<td>121</td>
<td>2.27</td>
<td>3.63</td>
<td>0</td>
<td>15</td>
</tr>
<tr>
<td>Social dysfunction</td>
<td>121</td>
<td>7.67</td>
<td>2.681</td>
<td>3</td>
<td>17</td>
</tr>
</tbody>
</table>

**Table 3.2:** Descriptive statistics for DATIQ, IISDP, and GHQ-28

Two-tailed Bivariate Pearson product-moment coefficients of correlation were used to determine if there were any significant relationships between the DATIQ and GHQ-28 (H₁: There will be a correlation between the level of Deaf social identity and psychological distress), the DATIQ and the IISDP (H₂: Deaf people with a hearing identity will experience interruption to this identity, which is more frequent and more distressing than their counterparts with a Deaf identity), and the IISDP and the GHQ-28 (H₃: More frequent identity interruption will be associated with higher levels of psychological distress).
These coefficients were found to be -0.25, -0.316, and 0.329 respectively, indicating a significant correlation between all three pairs (see Table 3.3).

<table>
<thead>
<tr>
<th></th>
<th>Pearson's r</th>
<th>p (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>$H_1$: DATIQ and GHQ-28</td>
<td>-0.25</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>$H_2$: DATIQ and IISDP</td>
<td>-0.316</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>$H_3$: IISDP and GHQ-28</td>
<td>0.329</td>
<td>&lt;0.01</td>
</tr>
</tbody>
</table>

Table 3.3: Statistically significant Pearson Product-Moment correlations between the three research scales.

The results show a negative correlation between the DATIQ and GHQ-28, and also between the DATIQ and IISDP, suggesting that a lower score on the DATIQ (that is, a stronger hearing identity) is linked to higher psychological distress, and higher levels of identity interruption. The results show a positive correlation between the IISDP and the GHQ-28, suggesting that higher levels of identity interruption are linked to higher levels of psychological distress.

Two-tailed Bivariate Pearson Product Moment coefficients of correlations were conducted between the self-rated linear scale (line mm) and the DATIQ (see Table 3.4).

The results indicate that the relationship between the self-rated scale and the DATIQ is not significant, suggesting that the self-rated perception of deafness does not relate to degree of Deaf identity. A positive correlation is shown
between the self-rated line and scores on the GHQ28, suggesting that an individual's perception of their hearing status is positively correlated with increased levels of psychological distress.

<table>
<thead>
<tr>
<th></th>
<th>Pearson's r</th>
<th>p (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Line (mm) and DATIQ</td>
<td>-.011</td>
<td>Not significant</td>
</tr>
<tr>
<td>Line (mm) and GHQ-28</td>
<td>.208</td>
<td>&lt;0.05</td>
</tr>
</tbody>
</table>

Table 3.4: Pearson's Product Moment Coefficient Correlations between Line (mm), DATIQ, and GHQ-28.

Identity interruption types and psychological distress: Two-tailed Bivariate Pearson product-moment coefficients of correlation were conducted between each identity interruption type and total scores on the GHQ-28. A positive correlation was found between three out of the four identity interruption types, and scores on the GHQ-28 (see Table 3.5). No significant relationship was found between scores on questions pertaining to an over-controlled identity system, and GHQ-28 scores (r = .056).
Identity interruption type | Pearson’s r | p (2-tailed)
---|---|---
Broken loop / GHQ-28 | .344 | <0.01
Episodic identity / GHQ-28 | .291 | <0.01
Interference from other identities / GHQ-28 | .281 | <0.01

Table 3.5: Significant Pearson’s Product Moment Coefficient Correlations between specific identity interruption types and total GHQ-28 scores.

Identity interruption and anxiety, depression, and social dysfunction

Two-tailed Bivariate Pearson product-moment coefficients of correlation were used to determine if there were any significant relationships between total scores on the IISDP and the four GHQ-28 subscales, and also identity interruption types and GHQ-28 subscales. A significant positive correlation was found between three of the four subscales of the GHQ-28 and IISDP scores (see Table 3.6). No significant relationship was found between identity interruption and somatic symptoms \( (r = .157) \).

Significant relationships between identity interruption type and GHQ-28 subscales are given in table 3.7.
Table 3.6: Significant Pearson's Product Moment Coefficient Correlations between GHQ-28 subsets and IISDP totals

<table>
<thead>
<tr>
<th>GHQ-28 subscale</th>
<th>Pearson's r</th>
<th>p (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety / IISDP</td>
<td>.346</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Depression / IISDP</td>
<td>.330</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Social dysfunction / IISDP</td>
<td>.241</td>
<td>&lt;0.01</td>
</tr>
</tbody>
</table>

Table 3.7: Significant Pearson product-moment coefficient correlations between identity interruption types and GHQ-28 subsets (* p<0.05; ** p<0.01).
Age of onset of hearing loss

Two-tailed Bivariate Pearson product-moment coefficients of correlation identified that there were no significant correlations between the age at which hearing loss occurred and scores on any of the three measures.

The GHQ-28

As mentioned above, this research did not intend to consider scores of caseness when scoring the GHQ-28. However, in retrospect, the GHQ-28 was rescored using a 0,0,1,1 scoring system. Caseness (scores > 5) was identified in 30.5% of the sample (n=121). In the sample, 25.5% of the males, and 33.8% of the females, were found to have scores above 5.

Research the d/Deaf population has used the GHQ-30 (Bridgeman, Macpherson, Rako, Campbell, Manning and Norman-Kelly, 2000; de Graaf and Bijl, 1998; Ridgeway, 1997). These studies have found levels of caseness higher than those found in the general population (see Table 3.8). The findings of this research show levels of caseness lower than those in these three studies.
<table>
<thead>
<tr>
<th>Study</th>
<th>Sample size</th>
<th>Country</th>
<th>% caseness (males)</th>
<th>% caseness (females)</th>
<th>% sample caseness</th>
<th>GHQ cut-off score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ridgeway, United Kingdom (1997)</td>
<td>97</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>37.3%</td>
<td>&gt;5</td>
</tr>
<tr>
<td>de Graaf and Bijl, Netherlands (1998)</td>
<td>523</td>
<td>Netherlands</td>
<td>27.3%</td>
<td>36.8%</td>
<td>-</td>
<td>&gt;2</td>
</tr>
<tr>
<td>Bridgeman, New Zealand (et al 2000)</td>
<td>198</td>
<td>New Zealand</td>
<td>-</td>
<td>-</td>
<td>42.4%</td>
<td>&gt;5</td>
</tr>
<tr>
<td>Current research, UK (2003)</td>
<td>121</td>
<td>UK</td>
<td>25.5%</td>
<td>33.8%</td>
<td>30.5%</td>
<td>&gt;5</td>
</tr>
</tbody>
</table>

Table 3.8: Findings of studies with a d/Deaf population using the GHQ-30 showing caseness percentages.
3.7 Discussion

The present findings support the research hypotheses. Firstly, it suggests that there is a relationship between the level of Deaf social identity and psychological distress. Secondly, that deaf people with a hearing identity may experience interruption to this identity, and the findings suggests that this interruption may be more frequent and more distressing than for their counterparts with a Deaf identity. Finally, that there is a relationship between identity interruption and psychological distress, and it is suggested that higher identity interruption is related to higher psychological distress.

Burke's model of identity interruption is based on a cognitive view of stress, and follows the basic idea that "autonomic activity results whenever some organized action or thought process is interrupted" (Burke, 1991, p.836). Within this model, the process being interrupted is that of identity. Identity processes operate continuously, maintaining congruence between the identity standard and the reflected self-appraisals. Meaningful behaviour links with the perceived self-meanings through the social environment (Burke, 1991). Within this research, the identity that is being considered is that of Deaf identity. The social environment in which the identity is operating is either that of Deaf culture, or hearing culture. This research suggests that a deaf individual who adopts a hearing identity may have this continuous loop interrupted when within the social environments of both hearing culture and Deaf culture. Within both environments, the individual's self-appraisals may be incongruent with the identity standard. For example, if the meaningful behaviour (output) for an individual is to successfully communicate using speech rather than
BSL, maintaining an identity as a hearing person, yet the perceptions of self as reflected by others (input) are incongruent with the identity standard (the speech is for example, unclear or misunderstood, and communication fails), interruption may occur if the process is not adjusted. If the incongruence is small, interruption may not occur. However, larger discrepancies will attract an individual's attention, and the process becomes more conscious and less automatic.

This research suggests that interruption may occur as a result of the identity loop being broken, an episodic identity, or interference from other identities. However, this research suggests that interruption to the identity process may be less likely to result from an over-controlled identity. These four types of interruption will be considered in greater depth.

The identity process is a continuous, closed loop. If this loop is broken, the process ceases to operate normally (Burke, 1991). The loop can be broken at the either output or the input. The findings of this research suggest that, when an identity loop is broken, an individual may suffer higher levels of anxiety, depression, social dysfunction, and, to a lesser extent, somatic symptoms. The broken loop may occur when the deaf individual acts as a hearing person, but is unable to fulfil this identity standard, and/or perceives themselves as treated as a deaf person by other people. So, for example, the deaf person may attempt to lip-read in social situations, and will use spoken English to communicate. However, communication may fail when lip-reading is not possible (for example, the speaker may look away, or cover their mouth with
their hands text removed), and the individual is unable to follow a conversation. This may result in feelings of isolation. It might be suggested that a conflict may arise between an individual's need to enter these situations to maintain the hearing identity, and the individual's reluctance to enter these situations due to previous experience of failure, and this conflict may increase psychological distress.

Interruption may occur as a result of the episodic performance of a role. A role needs to be practised, and feedback given to help develop congruence between the standard and self-meanings (Burke, 1991). If a role is episodic, and there is a restricted amount of time to rehearse it, it will become harder to maintain congruence. Continuous feedback will not be received, and the process will be interrupted. This research suggests that this may be more likely if a deaf person adopts a hearing identity, and this may result in higher levels of psychological distress. For example, an individual may have limited opportunities to be with hearing people, or to practise lip-reading skills. It is suggested from the results of this research that this form of identity interruption may result in increased levels of anxiety and depression.

When several identities interfere with each other, this research has suggested that the individual may experience anxiety, depression, and somatic symptoms. Specifically questions from the IISDP pertaining to this interruption type ask about work and family roles, and therefore it can be suggested that a deaf person who adopts a hearing identity within the family or at work, or a person with a Deaf identity within a hearing work or family environment, may
find that this chosen identity is interrupted by other identities, for example, that of worker or parent.

No significant relationship was found between an over-controlled identity system and psychological distress. It is possible that deaf people with a rigid hearing identity who experience this type of identity interruption would be less likely to be involved with Deaf clubs, groups for the hard-of-hearing, and would be less likely to want to answer questionnaires for 'deaf' people. However, the range of scores for the over-controlled identity type is normally distributed, suggesting that this identity interruption type has been tapped into. It is also likely that within this population, individuals with a rigid hearing identity may be included. Therefore this research implies that, of the four types of identity interruption, an over-controlled identity system may be less likely to result in psychological distress amongst d/Deaf people.

As mentioned above, research suggests that if an individual adopts a negative attitude towards their deafness, they are more likely to possess lower self-esteem, a more negative self-image, and higher psychological distress (Ridgeway, 1997; Weinberg and Sterritt, 1986). This research supports these findings, suggesting a correlation between a stronger deaf identity, as measured with the DATIQ, and psychological well being, as measured with the GHQ-28. However, this research has attempted to look for explanations for findings of lower self-esteem, more negative self-image, and higher psychological distress, by considering the model of identity interruption. The structure of identity has been considered in more detail, and consideration has
been given to how this structure may be compromised if an individual's identity is not reinforced by the social group they identify with. Specifically, this research suggests that there are three types of interruption to an individual's identity loop, the presence of which may have a direct correlation with increased psychological distress.

A dual identity is considered to be the most adaptive form of identity (Cole and Edelmann, 1992; Weinberg and Sterritt, 1986). Within the model of identity interruption, this would be achieved when two identities are held side-by-side, without causing interruption to each other. Each identity has its own continuous loop that remains intact, and both hearing and Deaf identity loops are automatically adjusted to maintain congruence between the self-meanings and identity standard. Interruption of the processes becomes less likely, as the two identities would come into play within both environments as appropriate, balancing each other, and supporting congruence within both loops. When a d/Deaf person adopts a dual identity, this may be seen in, for example, the use of BSL within the Deaf community, and spoken language combined with lip-reading in the hearing culture.

3.7.1 Methodological limitations of the current study: The research used a linear scale to measure identity. This scale is unclear, in that participants may interpret the terms 'Deaf' and 'Hearing' according to their own definition of these terms. Therefore, a culturally Deaf individual may view these terms as cultural groups, whereas someone who regards him or herself as medically deaf may define these terms medically. As a result, an individual who does
not identify with the Deaf culture may still indicate themselves as 'Deaf' on this scale, as they may consider this term to indicate a medical degree of hearing impairment. This difficulty may have been overcome by the use of the terms 'Deaf world' and 'Hearing world'.

The use of written postal questionnaires in this study has created a sampling bias. More data was collected from hearing-impaired clubs, where the members were much older. Even with the presentation of the questionnaires in BSL, the measures were still not appropriate for people with BSL as a first language. Therefore the culturally Deaf population was more likely to be excluded. Therefore the results cannot be generalised to the wider population without further research.

The IISDP has many limitations. It has been piloted on a small sample (n=44) without a retest, and question items are weighted in one direction, creating a possibility of response bias (Marriott, O'Rourke, Forshaw and Coleman, 2003, unpublished paper).

3.7.2 Future research: The written nature of the measures used in this study created a sampling bias. Future research that looks at the validity and reliability of BSL translations of the measures used may offer the first step for future research in this area. Once this is done, it would seem worthwhile repeating this research.
This study has suggested that there is a relationship between deafness, identity interruption, and psychological distress. In order to investigate this further, research carried out with younger adults would be important. In order to gain a less biased sample, a BSL version of the questionnaires should be presented to d/Deaf adults. An additional area from which participants could be accessed would be Audiology clinics, offering an area where both medically and culturally deaf adults may be found.

3.7.3 Clinical Implications: This research suggests that there are links between hearing status, identity, and psychological distress, and provides directions for therapy. When working with d/Deaf and hard-of-hearing clients, the IISDP may be a useful tool to identify the causes of psychological distress, and to identify the specific difficulties that an individual may experience with their identity and sense of self. High scores on the IISDP may indicate an increased risk of anxiety, depression, and social dysfunction.

The IISDP offers a means of considering individual aspects of the experiences of a d/Deaf person. As such, it is possible that it could be used as a tool for identifying specific areas of difficulty for an individual that are particular to having a hearing impairment, areas that could be explored therapeutically if appropriate.

Specialised Clinical psychology services for d/Deaf people are limited across England, being mainly focused in Birmingham, London, and Manchester. It could be argued that few mainstream services have the specialised
knowledge and skills to work with d/Deaf clients. It can be proposed that d/Deaf people are no less likely to experience psychological distress than their hearing counterparts. Few psychological measures are available that have been developed for d/Deaf people, and it is suggested that the IISDP is one measure that may be positively correlated with the GHQ-28, and could therefore be used in clinical settings. However, the IISPD does have limitations, and needs further research (Marriott, O'Rourke, Forshaw and Coleman, 2003, unpublished paper).

3.8 Conclusions

Analysis of the research data suggests that we should accept the three research hypotheses. The results indicate that individuals who adopt a hearing identity may experience more interruption to their identity loop, and this identity interruption may lead to higher levels of psychological distress. It is suggested from this research that the identity interruption types that have a significant relationship with increased psychological distress are the broken loop, episodic identities, and interference from other identities. The research also suggests that an over-controlled identity system does not have a significant relationship with increased psychological distress.

In this research, interruption of identity through the broken loop, episodic identity, or interference from other identities, are suggested to be positively correlated with higher levels of anxiety and depression. This research suggests a broken identity loop has a significant relationship with social dysfunction and somatic symptoms, and that interference from other identities
may also be significantly correlated to somatic symptoms. These findings may have implications for clinical psychologists working with d/Deaf people. However, due to the limitations of the study, the findings cannot be generalised.
3.10 References


4. Chapter 4: Reflective paper – A journey into research, language, and Deaf culture

Word count: 3,289
4.1 Introduction

The following paper aims to outline the process of my research into deafness, social identity, identity interruption, and psychological distress. It will tell the story of this research, from early, unformed ideas, through to the final drafts of the three research papers. Along the way I will consider methodological issues, and highlight the significant issues that were encountered throughout the research process.

4.2 Developing an area of interest

As an assistant psychologist I completed a qualification in British Sign Language. I began to meet culturally Deaf people, a group who used BSL as a first language, and shared a common history and set of values. As I became more involved in this culture, I discovered that, for some, the concept of a 'psychologist' was unknown. Even the sign for 'psychologist' gave no clues to its meaning – the sign for 'psychiatrist' is a combination of 'head' and 'doctor', the sign for 'psychologist' involves touching the head, and then forming the symbol used to represent psychology with the hands. Through conversations with Deaf people, it was suggested that, for them, getting help for psychological complaints was a real challenge. Many would rely on either a spouse or family member to interpret between themselves and their doctor. Often, if an interpreter from the locality were used, this would be someone who attended the Deaf Club socially. People were reluctant to discuss psychological problems in front of these people, and, as a result, would not attempt to seek help. Some of the people I met were describing difficulties throughout their lives, and were relating times of poor mental health, when
they felt a psychologist could have offered them help. Working within Psychology departments, I was made aware that clients who used BSL as a first language were seldom referred. Although three specialist units exist in the country for the Deaf, I began to feel that a need was not being met.

Before entering my Clinical Psychology training, I had decided that this was an area that I would like to research further.

4.3 Planning the research

The research process was mentioned during the first few months of training. I do not consider research to be my strongest area. Already having an area of interest, in hindsight, made me perhaps over-confident, reducing my own perceived need to think about exactly what I was going to do. I was interested in Deafness and psychological distress. When asked what theoretical model I would be using to underpin my research, I became unstuck.

On reflection, I can now see why this happened. I had a broad area of interest, with many general questions and concerns. I was working as a 'practitioner' and forgetting the 'scientist'. I needed to reduce my field of vision, and to come up with a research question, but I was thinking in a very generic way – I could see the whole picture, but that was too big to research.

My initial plan was to use a model of social support. This was pulled out as a plausible model to research a social group. But at this stage I was following an unclear route, not linking different parts of the research together in a logical
way. My own personal circumstances at the time meant that I could not place the research as a priority. I had been bereaved only months beforehand, and needed to devote time and energy to a series of anniversaries and important dates. With the deadline for the research proposal imminent, I threw together my ideas in a very unstructured way, producing a plan for research that made little sense, and did not follow a logical progression. Not surprisingly, the research proposal failed.

This failure was a turning point in the research story. The feedback I received was invaluable. With the emotional trial of one stage of my grief process behind me, I was able to prioritise my research again. It was at this point I was able to move away from the general, unfocused standpoint, and take on a more selective viewpoint, moving to the concept of social identity, and building up a research question from this. It was at this point it felt that the research began to take shape.

When I reflect back on this time, my mistakes in the process seem so obvious. I feel I have learnt a great deal about the early stages of planning research, and am much more aware of the route to take when generating a research question. I had questions that were not theoretically grounded, but was over-confident in my ability to answer these. I had a sense of what I wanted to find out, but did not adequately put this into words. As a result my progress was hampered by vague ideas and a lack of a theoretical model on which to develop my work.
4.4  Researching a specialist area

As mentioned above, there are few clinical psychologists who specifically work with Deaf people, and it is an area that has a relatively small interest group. It was important to me that I had supervision from people that had some interest in deafness, and could help with the cultural and language issues. As a result, I had to travel some distance to for clinical supervision, devoting a whole day for supervision meetings in order to take travel into account. When reflecting on choosing such long-distance supervision, I feel that these meetings were invaluable and made the travel worthwhile. The time was, I believe, used more efficiently. An effort was made to travel some distance, and I had to be extremely well organised, as forgetting to take some paperwork could be costly in terms of time. This skill became particularly important when combining research with looking after a baby.

4.5  Qualitative data collection

During the early stages it became apparent that I would be looking at a previously unmeasured concept, and with a target population culturally and linguistically different to my own. I was keen to develop a measure that incorporated the views and experiences of culturally deaf people (the 'Deaf'). I chose the Internet as a means of collecting data. It felt like a risk, and my concerns were centred on this not being considered a credible means of data collection. It became what one clinician described as a 'hybrid grounded theory approach'.
I was overwhelmed by the responses I did receive. Although small in number, the quality and depth of information was immense. I was touched by the openness of respondents, and by the difficulties they described in everyday life. One respondent, when describing being called from the waiting room at the doctors', explained:

"...the doctors don't always know what I look like so they tend to come out shouting and waving, and I feel a prat."

Another remarked that:

"...a lot of people are willing to help but a lot of them think I am stupid when they drag the w...o...r...d...s out I get annoyed at times once I said to a young shop assistant "look mate I am deaf not bloody stupid""

I found myself feeling frustrated for the people I was hearing from. In some way it reassured me that my research could be useful, if only to highlight some of these issues.

At first my intention had been to run small focus groups as a means of collecting qualitative data. In order to do this with BSL users, I would need interpreters, and would need video recording equipment, set up in several places, so that all the signers would be recorded clearly. The order of the discussion would need to be noted down. Collecting data from the Internet is restrictive in that it accesses only those people who are computer-literate. Focus groups would reduce this sampling bias by allowing more Deaf people access to this early stage of the research. However, as with many of the qualitative methods of data collection, it would have been costly in terms of
time and money, and as a result became unfeasible within the time frame of
the research.

Without such time restraints, I certainly would have considered running focus
groups. Many of the replies I received through the Internet commented on
experiences at work, and on reflection I have considered the possibility that
some relationship may exist between being employed and having access to
the Internet — for example, the financial benefits of employment may increase
the possibility of affording Internet access, or employment and computer-
literacy may be correlated. Only 22.3% of the participants in the main
research were employed, meaning that for the large majority of participants,
questions regarding work were not applicable.

4.6 Questionnaire design

4.6.1 Issues of translation: The most appropriate way of conducting research
with people whose first language is different to that of the researcher would be
to present questions in the target population's language. If this is a written
language, the questionnaire can remain written. When the language is visual,
this presents new difficulties. I wanted to include as many participants as
possible, to enable me to gather data from a variety of people with differing
degrees of social identity. The most appropriate method of conducting
research with BSL users would be to present the questions in BSL, either
through a video, or in person. Again, I encountered time and monetary
constraints. I had also been let down by local groups who had originally
agreed to help with the research, and had to access groups from further
outside the locality. My compromise was to translate the questions into a written form of BSL, hoping that people would sign the words to themselves, and understand the meaning.

At this stage I felt quite helpless and frustrated. My own level of BSL was not adequate enough for the translation process. I had to rely on the skills of other people for the whole of this process, and, as a result, worked at their pace, which was slower than I hoped for. It was a time of thumb twiddling during which I felt unable to do much. I had a sense of being at the start of a race, waiting for the gun to go off. As soon as the translation was completed, I could send out the questionnaires. My time was focused on writing my literature review, but I was aware that the longer I waited to send the questionnaires out, the less time I would have at the end. When the translation process was finally completed, I was suddenly busier than at any other stage of the research, printing out and sending over 300 questionnaire packs.

4.6.2 Lessons learnt: In hindsight, it seems that there are possibly two changes I would make to the scale I developed. The first is to include a ‘not applicable’ option. Using the Internet for qualitative data collection meant that I did not gain any demographic information about the respondents. From the responses it is assumed that many were culturally Deaf, as many spoke about using BSL. Therefore, questions developed around using sign language, and concepts of Deaf and hearing social groups. For many participants from hard-of-hearing groups, they did not need to use BSL, and only had hearing friends. For many whose hearing loss was acquired in later life,
questions that were developed were irrelevant to their situation. As a result, the Identity Interruption Scale that I developed seems appropriate only for those whose hearing loss developed at an early age, and particularly for the prelingually deaf (that is, hearing loss before the age of 2). If it were to be used with a wider group, the wording of many of the questions would need to be changed.

The second change I would make is to change the direction of some of the questions. All questions are positively weighted, and the research may have been affected by response bias.

4.7 Participants

One of my research aims was to gather data from as many prelingually deaf adults as was possible. I particularly wanted to find prelingually deaf people who had adopted a hearing identity. The culturally Deaf could be accessed through Deaf clubs. However, finding prelingually deaf adults with a hearing identity seemed a real challenge. It was felt that, in order to increase the possibility of reaching this group of people, I would need to distribute as many questionnaires as possible. As a result I contacted a large number of different groups to which deaf people may belong. As already mentioned, this resulted in receiving data from people for whom the questions were less appropriate. At some level I felt it important to include these people in the research, partly because I was interested in considering if there may be any relationships between age of hearing loss and psychological distress, and partly because
they had taken the time to fill in the questionnaires, and showed interest in the research and my findings.

The mean age of the main research sample was 63, and the distribution of age was skewed towards older adulthood. There could be many reasons for this. Firstly, that the largest number of questionnaires were sent to hard-of-hearing groups, whose membership tended to consist of older adults. Secondly, those who had lost their hearing in later life were more able to understand a questionnaire in a written format. Research has suggested that Deaf students leave school with a lower reading age to their hearing counterparts (Conrad, 1979. In Young, Monteiro, and Ridgeway, 2000). When piloting the questionnaire several people were reluctant to even look at the questionnaire, stating that they avoided things that were written. This raised again the issue of format of presentation, and suggests that the costs of a smaller sample size would be outweighed by the validity of the data gathered from a more representative sample of the Deaf community.

4.7.1 Misunderstandings and ethical issues: In general the response to the research was favourable. However, at some level it did strike a chord with one or two respondents, who felt they needed to contact me with their concerns. One respondent felt that the questions were trying to highlight the failings of Deaf people. Another contact felt that I was conducting research without any understanding of Deaf people. These concerns were dealt with personally, and misunderstandings clarified. A comment was made that:
"I feel it is important to say that if a person is brow beaten and discriminated against for years and years they can start to internalise the attitudes of those that oppress them"

I experienced a sense of a hearing society abusing Deaf people, and a feeling of inequality. On reflection, I also have wondered whether people did not want to become involved with the research when they discovered that I was hearing – it was reported by some of the contacts within the Deaf clubs that this was a question that was often asked of them. This may be a further explanation for why fewer prelingually deaf adults took part.

When considering ethical issues, this is something that should be taken into consideration. Although my details were made available to all participants, it was not made explicit that, if any concerns arose from the questions, they could contact me. I did not consider that I would be viewed as an outsider, having felt accepted within the Deaf community. On reflection that is a very narrow viewpoint. Having made every effort to include Deaf people throughout the questionnaire development, I failed to see any reason why the questions may cause offence. Again, this may have been avoided if I took the time to present the questionnaire in the respondents’ first language, so that misunderstandings of intention could be reduced.

4.8 Suggestions for future research

This research has highlighted for me many aspects about future research that can be divided into two areas – further research, and how (not) to do it.
4.8.1 Further research: The findings of the research suggest positive correlations between hearing identity, identity interruption, and psychological distress. Firstly, it is important to consider repeating the research with a BSL version of the Identity Interruption Scale for Deaf People (IISDP), and reviewing the findings. It is also important to use the current research data to retest the reliability of the scale, something that was omitted from the main data analysis process.

An area of research that is considered important would consider how the identity of deaf children is formed, and the processes that lead to a healthy identity formation. This could have important clinical implications, particularly when supporting hearing parents with a deaf child.

4.8.2 Learning from mistakes: When reflecting on my research story, there are some aspects that I would change in order to create a smoother process. I do believe that, although time-consuming and costly, focus groups with Deaf people would have allowed a more representative collection of views. I feel that this is something that applies to all research within a cultural group different to that of the researcher. When developing ideas the concepts that will be measured should come from the group under investigation.

Time constraints meant corner cutting, and, on reflection, this has had a detrimental effect on the research process. A visual language was being used, and writing this down was a compromise that was not adequate. Again, time should have been taken to produce a visual format of the questionnaires.
4.9 Clinical implications

With further research, the IISDP may become a scale that has some use within clinical settings. It is a measure that has been shown to correlate with psychological distress. The causes of this distress can be identified from the scale items, and may offer directions for therapy. With further research into the identity formation of Deaf children, further implications for working with families may be highlighted.

4.10 Concluding remarks

For me the research process has been a long road, along which I have met many obstacles. I have felt helpless when relying on others, and have felt the frustration and anger of some of the Deaf people who have become involved. I have felt the relief of finishing a paper, only to be told that it needs to be rewritten, or reminded that I have forgotten a vital part of the process.

Research is a lengthy and difficult process, and when working with a different cultural group and a different language, the process becomes even longer. Perhaps the challenge I took on was too great for the time available. However, there are some important findings that can inform clinical practise and future research.

Part of the aims of the research have been to highlight a group of people who do not access mainstream Clinical Psychology services very often, and to help develop awareness of some of the issues that may be present. Many Clinical Psychology departments do not have the resources to work with Deaf
clients – from the intercom at the door, to the knowledge of, and access to, interpreters. I have experienced a Deaf client being told that, unless she agreed to work with a local interpreter, a person who was a friend from the local Deaf Club, she would only be able to have 3 sessions, the explanation being that it was too expensive to pay the travel expenses of an out of area interpreter that she did not know. It is hoped that this research will at least go some way towards helping clinicians to consider how to improve the clinical setting for Deaf people.
4.11 References

Appendices
Appendix 1 – Ethical approval form
COVENTRY UNIVERSITY - SCHOOL OF HEALTH & SOCIAL SCIENCES

STUDENT SUBMISSION TO SCHOOL RESEARCH ETHICS COMMITTEE

1. Student's name: Emma Marriott
2. Course: Doctorate in Clinical Psychology
3. Title of project: Social Identity Theory, Psychological Distress, and the Deaf Community: Does Having a Weak Deaf Identity Lead to More Frequent Identity Interruption and Higher Levels of Psychological Distress?
4. Summary of the project in jargon-free language and in not more than 120 words:

Sample: Pilot study - maximum 20 prelingually deaf people from Staffordshire Deaf Club, an equal number of prelingually deaf people on a Warwickshire Social Services caseload. Main research: TPARTICIPANTS FROM DEAF CLUBS AND SOCIAL SERVICES CASELAOD.

Research sites: Deaf clubs in Staffordshire and West Midlands; Social Services caseload in West Midlands.

Design (e.g., experimental):
Non-experimental correlational design.

Methods of data collection:
Scale of identity interruption developed by researcher - the four types of identity interruption identified by Burke (1991) will be measured. Questionnaire items will be developed after looking at common experiences deaf people have that may threaten their identity.

Deaf attitude and identity questionnaire (Kocsway, 1993) and the General Health Questionnaire - 28 (Goldberg, 1981) will measure deaf identity and psychological distress.

Questionnaires will be distributed by hand and returned either by hand or postal returns.

Access arrangements (if applicable):

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

Student's signature: 
Supervisor's signature: 
Date: 21/03/10

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: 
Date: 4/4/10
Appendix 2 – Internet posting to newsgroups

Do you have some degree of hearing impairment?
Do you have experience of being deaf or hoh in a hearing world?

If you answered yes to these two questions you can help me. Below are some situations that people with a hearing impairment may encounter in everyday life.

I would like to get a bit of information from people like yourselves about what experiences you have had in these situations to help me develop a questionnaire.

It may be an example of something that has happened or happens a lot. You may only be able to talk about one area that applies to you and just answer one question. Or you may have a lot of experiences that you want to share. I would appreciate even the smallest bit of help. You can e-mail me directly on <<e-mail address>>. All responses will be treated confidentially.

Thanks for your time.

1. Communicating:
   a. What are the good and bad points about lip-reading, using interpreters, notetakers, etc?
   b. What are your experiences of using sign language in a hearing world?
   c. What are your experiences of communicating with a hearing world?
   d. How do others communicate with you? What helps, and what doesn't?
   e. How much deaf awareness is there in the hearing world?
2. Health services:
   a. What are your experiences of using health services - doctor, dentist, optician, etc.?

3. Transport:
   a. What are your experiences of using public transport - buses, trains, planes, etc.?

4. Adaptive technology:
   a. What are your positive and negative experiences of using e.g. Hearing aids, minicoms/phones, etc?

5. An 'invisible disability':
   a. What are your experiences of having an 'invisible disability'?

6. Employment:
   a. What are your experiences of work - getting work, keeping work, and being at work?

7. Socially:
   a. What are your experiences when out - pubs, clubs, cinema, shops etc.?

8. Other experiences:
   a. What other experiences can you tell me about - times when you have felt treated particularly well, being treated differently, being labelled, being part of a group, being left out, emotional aspects, family life etc.
Appendix 3a – Examples of thematic analysis of data

“I’m (......) a university student and severely deaf in both ears. I wear 2 over the ear hearing aids which I hate as they amplify the wrong noises.

My main problem being deaf is social isolation - I can not communicate as well as I like to nor can I hear that well. I rely on lip reading all the time which leaves me tired at the end of the day and in no mood to go out in the evening (which students do!). The main problem being deaf or hoh in the hearing world is that often it's not visible, for example you see a person in a wheelchair and know they have mobility problems. Deafness is not something that sticks out a mile ......

Aids: Hearing aids amplify the wrong noises

Social: Social isolation because communication difficult

Communication: Lip-reading is tiring

Invisible disability
".....I get as far as the interview all the time then they see my hearing aids and say either sorry the position filled or I am afraid that we cannot take you on due to your disability....."

".....My biggest problem is travelling I go on the busses and I find the bus drivers no help at all, over charging on fares and when I ask them to tell me to get off at a certain place when it is a new area, they are no help....."

".....There is not alot of deaf awareness in shops and I think that big places should put their staff on deaf awareness courses so that they then can help us....."

**Employment** : Discrimination when applying for jobs

**Transport**: Drivers on buses unhelpful / overcharge

**Social**: Not a lot of deaf awareness in shops
Appendix 3b - Themes arising from qualitative data gained through internet postings.

Transport:
Unable to hear tannoy announcements
Drivers on buses unhelpful / overcharge

Health Services:
GPs talk too quietly
Difficulty with health service
Difficulty making appointments over the telephone
Partner has to make GP appointments
Difficulty knowing when the GP calls you
Feel stupid when the GP waves and shouts
Audiology serves good – staff are trained to deal with hearing impairments, and it is effortless.

Emotional:
depression

Labels:
People think that I am stupid

Employment:
Can't get a job
Difficulty keeping a job
Discrimination when applying for jobs

Invisible disability:
Need to make disability known to people
Have to be outspoken all the time
Have to explain disability all the time to avoid problems
Wearing a badge identifying deafness doesn't help
Have to tell people

Aids:
Hearing aids amplify the wrong noises
Need adaptive technology
Can't talk on the phone
Unable to use the phone

Family:
Wife unsure what to do to get my attention or to tell others about my deafness.
Need the support of my spouse
Challenges parental role – not being able to hear my daughter
Can't hold a normal conversation

Communication:
Complications of listening – not just sitting and hearing
Tracking conversations hard – swivelling around
Lip-reading requires a lot of concentration and can give me a headache
Unclear speakers
If I ask people to repeat they tend to clarify rather than repeat what they said
Lip-reading is tiring
I feel awkward and expose because I have difficulties keeping up
with conversations

Lecturers mumble and look away – hard to lipread

People talk with their hands in front of their mouths

I don't pick up all of the conversation

People talk at once

People speak slowly or shout

People drag out the words

Social:

Can't understand theatre and cinema

Not a lot of deaf awareness in shops

Signing misinterpreted as threatening gestures (in pubs, etc.)

Social isolation because communication difficult

If I use a notetaker in lectures it discourages people from making

friends with me.
Appendix 4 - Identity interruption types – for coding

1. The broken loop – an individual holds an identity standard, and the output (behaviour) towards others, and input (perceptions) of others, reinforces this standard. When the input or effect of the output does not match the standard, this causes interruption: e.g. ignored by others, meaningful interaction fails, behaviour doesn't influence how others label or treat individual (output); meanings in situations misunderstood (input).

2. Interference from other identities – one identity interrupts another e.g. role of wife, mother, and worker. Time constraints, or over commitment to an identity, can prevent another identity from being prominent.

3. Over-controlled identity system – trying to match input signals to tightly, e.g. a rigid gender identity; rigid religious identity.

4. Episodic identity – the role is episodic, therefore there is less time to rehearse the role, or there is extended interruption in feedback e.g. restricted opportunities to practise that desired identity.
### Appendix 5 - Results of coding

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**Key:**
- BL = Broken Loop
- IO = Interference from other identities
- OC = Over controlled Identity
- E = Episodic Identity
Appendix 6a - Identity Interruption Scale for Deaf People (first draft)

1. I want to be able to speak clearly so that I am the same as hearing people.
2. It is harder for me to do my job because I am deaf.
3. I prefer to be with my hearing friends, but do not have many opportunities to do so.
4. I like people to think I am hearing, but I can't hide my deafness.
5. Because I am deaf, hearing people think I am stupid.
6. People react differently to me when they find out I can't hear.
7. Because I am deaf, employers do not think I can do the job as well as hearing people.
8. I want to fit in with my hearing family, but my deafness makes it hard.
9. It is important to me that I get to know more hearing people, but I don't get the chance to do this.
10. I am really pleased if people think that I am hearing and feel upset if they think that I am deaf.
11. I want to join in with conversations, but a lot of the time hearing people give up trying to talk to me.
12. I would like to talk to hearing people, but they have problems knowing what I say to them.
13. I do not want to use sign language because it will make people realise I am deaf.
14. I want to be able to follow conversations when I am with hearing people, but find it difficult.
15. I want to do my job as well as hearing people, but it is difficult being a deaf person in a hearing work environment.

16. I do not fit in well with the hearing people in my family.

17. It is important to me that I can lip-read so that I am like hearing people.

18. My deafness stops me from going out when I want with my hearing friends.

19. I want to be able to lip-read, but cannot find the time to practise.

20. No matter how hard I try, I can be left out of conversations with my hearing friends.
Appendix 6b - Identity Interruption Scale (BSL translation first draft)

1. Me want speak good be same hearing.
3. Me want with friends hearing but difficult no time.
4. I like people see me hearing but deaf - easy see.
5. Hearing think me stupid, - why? me deaf.
6. People different behaviour with me - why? found out me deaf.
9. Me want more with hearing important but time can’t.
10. People think me hearing, me think great but if they say me deaf me upset.
11. I want talk hearing people but all the time they stop or finish talk with me.
12. I want talk hearing, they understand me can’t.
13. I don’t like sign – why? make people think me deaf.
14. Me want talk hearing but difficult understand what happen.
16. I have hearing family - me with family not good.
17. Me must lipread – why? important me same hearing.
19. Me want lipread good but time practise can’t.
20. Hearing friend talk, me try try try still not understand.
Appendix 6c – Backtranslation of BSL first draft

1. I want to be able to speak as well as hearing people
2. My job is really difficult because I am deaf
3. I want hearing friends but it's difficult because of lack of time
4. I would like hearing people to think I could hear, but they can tell I am Deaf
5. Hearing people think I am stupid because I am Deaf
6. Hearing people behave differently with me because I am Deaf
7. The boss thinks my work is rubbish because I am Deaf, the boss thinks hearing people are better at their work
8. My family is hearing which is difficult for me because I am Deaf
9. I would like to be with hearing people more, I think it is important but I don't have enough time
10. When people think I can hear I feel really proud, but when they know I am deaf I feel upset.
11. I want to talk to hearing people but they put up barriers and end conversations too quickly
12. I want to talk to hearing people but they don't understand me
13. I don't like using sign language because hearing people will know that I am deaf
14. I would like to talk to hearing people but it's difficult to know what is happening
15. I want the same equality of work as hearing people, but it's difficult as there are so many hearing people and I am the only deaf person
16. I have a hearing family but our relationship is not good
17. I must lipread it is important as hearing people use speech
18. My hearing friends want to go out, I can't go with them because I am deaf
19. I want to be good at lip-reading but even though I practise I still can't
20. I try to communicate a lot with hearing friends but still misunderstand what is being said
Appendix 6d - Identity Interruption Scale (BSL revised version following back-translation)

1. Me want speak good be same hearing.
3. Me want with friends hearing but difficult no time.
4. I like people see me hearing but deaf - easy see.
5. Hearing think me stupid, - why? me deaf.
6. People different behaviour with me - why? found out me deaf.
7. Boss think me work less good – why? Me deaf – boss thinks hearing people better
9. Me want more with hearing important but time can't.
10. People think me hearing, me think great but if they say me deaf me upset.
11. I want talk hearing people but all the time they stop or finish talk with me
12. I want talk hearing, they understand me can't.
14. Me want talk hearing but difficult understand what happen.
16. I have hearing family - me with family not good.
17. Me must lipread – why? important me same hearing.
19. Me want lipread good but time practise hard

20. Hearing friend talk, me try try try still not understand.
Appendix 7 - Information sheet for pilot study (written English and BSL versions)

Research into social identity, deafness, and psychological distress – pilot of Identity Interruption Scale for Deaf people.

Hello, my name is << >>. I am a student at Coventry and Warwick universities, and I am studying for a Doctorate in Clinical Psychology. As part of this degree I am doing research. I hope that when the research is finished it will show how Clinical Psychologists can help deaf people in the future. First, I have written a questionnaire that I want to use in my research. Before I use it, I need to test it out (this is called a pilot study) to make sure it is asking the right questions and that people understand it.

It would help me if you would be able to fill in the questionnaire for me. All information you give will be confidential.

If you would like more information about this research, you can contact me at:

<< >>

Thank you for your help.
Research into social identity, deafness, and psychological distress – pilot of Identity Interruption Scale for Deaf people.

Hello!

My name what? <<<>

Work what? Student

Where? Coventry and Warwick universities

Study what? Degree – Clinical Psychology.


If you can do questionnaire can help me. You give me information, I keep confidential.

If you want know more information about my research, you can write:

<<<  >>>

Or telephone:

<<<  >>>(voice and minicom)

Or e-mail:

<<<  >>>

Thank you for your help.
Appendix 8 – Pilot study demographics information sheet

General information.

Gender: (Tick one)

☐ male
☐ female

Age: ______________________

First language: (Tick one)

☐ Sign language
☐ Spoken English
☐ Other (please state) ______________________

Qualifications: (Tick all that apply)

☐ CSE/GCSE / GCE O'levels
☐ GCE A' – Levels
☐ Degree
☐ Higher degree

☐ Other (please specify) ______________________

Employment: (Tick one)

☐ Employed full-time
☐ Employed part-time
☐ Unemployed

Ethnicity: (Tick one)

☐ White
☐ Black Caribbean
☐ Black African
☐ Black other
☐ Indian
☐ Pakistani
☐ Bangladeshi
☐ Chinese
☐ Asian other
☐ Other (please state) ______________________

Area you live in: ______________________
Appendix 9 - Reliability analysis

<table>
<thead>
<tr>
<th>Q1</th>
<th>Scale Mean if Item deleted</th>
<th>Scale Variance if Item Deleted</th>
<th>Corrected Item-Total Correlation</th>
<th>Squared Multiple Correlation</th>
<th>Alpha if Item Deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q2</td>
<td>58.4359</td>
<td>122.3576</td>
<td>.4633</td>
<td>.8469</td>
<td>.8324</td>
</tr>
<tr>
<td>Q3</td>
<td>58.7949</td>
<td>120.0621</td>
<td>.5983</td>
<td>.5948</td>
<td>.8263</td>
</tr>
<tr>
<td>Q4</td>
<td>59.1795</td>
<td>122.8354</td>
<td>.5630</td>
<td>.7623</td>
<td>.8288</td>
</tr>
<tr>
<td>Q5</td>
<td>59.2308</td>
<td>122.2874</td>
<td>.4355</td>
<td>.7730</td>
<td>.8339</td>
</tr>
<tr>
<td>Q6</td>
<td>58.6923</td>
<td>123.0081</td>
<td>.4646</td>
<td>.8268</td>
<td>.8324</td>
</tr>
<tr>
<td>Q7</td>
<td>58.0513</td>
<td>128.2078</td>
<td>.3513</td>
<td>.7023</td>
<td>.8373</td>
</tr>
<tr>
<td>Q8</td>
<td>58.4615</td>
<td>126.3077</td>
<td>.3982</td>
<td>.7695</td>
<td>.8354</td>
</tr>
<tr>
<td>Q9</td>
<td>58.9487</td>
<td>124.4184</td>
<td>.3634</td>
<td>.8235</td>
<td>.8375</td>
</tr>
<tr>
<td>Q10</td>
<td>59.0769</td>
<td>125.3887</td>
<td>.4497</td>
<td>.7334</td>
<td>.8334</td>
</tr>
<tr>
<td>Q11</td>
<td>58.4103</td>
<td>120.9325</td>
<td>.5271</td>
<td>.7553</td>
<td>.8294</td>
</tr>
<tr>
<td>Q12</td>
<td>58.8205</td>
<td>128.6248</td>
<td>.1864</td>
<td>.6395</td>
<td>.8479</td>
</tr>
<tr>
<td>Q13</td>
<td>59.7179</td>
<td>125.3131</td>
<td>.4173</td>
<td>.7226</td>
<td>.8346</td>
</tr>
<tr>
<td>Q14</td>
<td>57.8462</td>
<td>128.6599</td>
<td>.4533</td>
<td>.7661</td>
<td>.8348</td>
</tr>
<tr>
<td>Q15</td>
<td>58.4359</td>
<td>127.6734</td>
<td>.3986</td>
<td>.5389</td>
<td>.8356</td>
</tr>
<tr>
<td>Q16</td>
<td>59.1538</td>
<td>125.5020</td>
<td>.3084</td>
<td>.7878</td>
<td>.8406</td>
</tr>
<tr>
<td>Q17</td>
<td>58.1795</td>
<td>125.6775</td>
<td>.3683</td>
<td>.8299</td>
<td>.8370</td>
</tr>
<tr>
<td>Q18</td>
<td>59.5128</td>
<td>121.0985</td>
<td>.5461</td>
<td>.5523</td>
<td>.8286</td>
</tr>
<tr>
<td>Q19</td>
<td>59.3585</td>
<td>127.9393</td>
<td>.3128</td>
<td>.5724</td>
<td>.8390</td>
</tr>
<tr>
<td>Q20</td>
<td>58.1282</td>
<td>119.5884</td>
<td>.6842</td>
<td>.7520</td>
<td>.8234</td>
</tr>
</tbody>
</table>

Reliability Coefficients

20 items

Alpha = .8415  Standardized item alpha = .8482

N of Cases = 23

Statistics for Scale:

Mean=61.7391  Variance=145.2925  Std Dev=12.0537
### Appendix 10 – Factor analysis data

<table>
<thead>
<tr>
<th>Question</th>
<th>Identity interruption type</th>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
<th>Factor 4</th>
<th>Factor 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I want to be able to speak clearly so that I am the same as hearing people</td>
<td>Over controlled</td>
<td></td>
<td></td>
<td>.762</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. It is harder for me to do my job because I am deaf</td>
<td>Interference from other identities</td>
<td></td>
<td>.442</td>
<td></td>
<td>.483</td>
<td></td>
</tr>
<tr>
<td>3. I prefer to be with my hearing friends, but do not have many opportunities to do so</td>
<td>Episodic</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.809</td>
</tr>
<tr>
<td>4. I like people to think I am hearing, but I can’t hide my deafness.</td>
<td>Over controlled</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.854</td>
</tr>
<tr>
<td>5. Because I am deaf, hearing people think I am stupid.</td>
<td>Broken Loop</td>
<td></td>
<td></td>
<td>.810</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. People react differently with me when they find out I can’t hear.</td>
<td>Broken Loop</td>
<td></td>
<td></td>
<td></td>
<td>.700</td>
<td></td>
</tr>
<tr>
<td>7. Because I am deaf, employers do not think I can do the job as well as hearing people</td>
<td>Interference from other identities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.727</td>
</tr>
<tr>
<td>8. I want to fit in with my hearing family, but my deafness makes it hard.</td>
<td>Interference from other identities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.835</td>
</tr>
<tr>
<td>9. It is important to me that I get to know more hearing people, but I don’t get the chance to do so.</td>
<td>Episodic</td>
<td></td>
<td></td>
<td>.816</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. I am really pleased if people think that I am hearing, and feel upset if they think I am deaf.</td>
<td>Over controlled</td>
<td></td>
<td></td>
<td></td>
<td>.750</td>
<td></td>
</tr>
<tr>
<td>11. I want to join in with conversations, but a lot of the time hearing people give up trying to talk to me.</td>
<td>Broken Loop</td>
<td></td>
<td></td>
<td>.793</td>
<td>.353</td>
<td></td>
</tr>
<tr>
<td>12. I would like to talk to hearing people, but they have problems knowing what I say to them.</td>
<td>Broken Loop</td>
<td></td>
<td></td>
<td>.577</td>
<td>-.384</td>
<td>.433</td>
</tr>
<tr>
<td>13. I do not want to use sign language because it will make people realise I am deaf.</td>
<td>Over controlled</td>
<td></td>
<td></td>
<td>.480</td>
<td>.434</td>
<td>.329</td>
</tr>
<tr>
<td>14. I want to be able to follow conversations when I am with hearing people, but find it difficult.</td>
<td>Episodic</td>
<td></td>
<td></td>
<td>.735</td>
<td>.451</td>
<td></td>
</tr>
<tr>
<td>15. I want to do my job as well as hearing people, but it is difficult being a deaf</td>
<td>Interference from other identities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.795</td>
</tr>
<tr>
<td>Number</td>
<td>Statement</td>
<td>Other Identities</td>
<td>Interference from other Identities</td>
<td>Over controlled</td>
<td>Episodic</td>
<td>Episodic</td>
</tr>
<tr>
<td>--------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>------------------</td>
<td>-----------------------------------</td>
<td>-----------------</td>
<td>----------</td>
<td>----------</td>
</tr>
<tr>
<td>16</td>
<td>I do not fit in well with the hearing people in my family.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>It is important to me that I can lipread so that I am like hearing people.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>My deafness stops me from going out when I want to with my hearing friends.</td>
<td>Episodic</td>
<td></td>
<td></td>
<td>.563</td>
<td>.455</td>
</tr>
<tr>
<td>19</td>
<td>I want to be able to lipread well, but cannot find the time to practise.</td>
<td>Episodic</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>No matter how hard I try, I can be left out of conversations with my hearing friends.</td>
<td>Broken Loop</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 11 - Identity Interruption Scale for Deaf people

Spoken English Instructions:

On the next few pages are a list of statements that sometimes apply to deaf people. Each statement is written in spoken English (left-hand column) and British Sign Language (right-hand column). For each one, decide if you strongly agree (5), agree (4), neither agree nor disagree (3), disagree (2), or strongly disagree (1) with that statement. Circle the answer that most applies to you. Please answer all questions.

BSL instructions:

Next few pages – what? List of questions – Deaf people sometimes think some these questions true.
Left side – question written spoken English. Right side question written BSL.
Each question – read. Decide if you really agree (strongly agree – 5), agree little bit (agree – 4), don’t agree, don’t disagree (neither agree nor disagree – 3), disagree a little bit (disagree – 2), really disagree (strongly disagree – 1).
Circle number you feel true for you.
Please answer every question.
<table>
<thead>
<tr>
<th>Spoken English</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I want to be able to speak clearly so that I am the same as hearing people.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>2. I prefer to be with my hearing friends, but do not have many opportunities to do so.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>3. I like people to think I am hearing, but I can't hide my deafness.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>4. Because I am deaf, hearing people think I am stupid.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>5. People react differently with me when they find out I can't hear</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>6. Because I am deaf, employers do not think I can do the job as well as hearing people.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>British Sign Language</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Me want speak good be same hearing.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Me want with friends hearing but difficult no time.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I like people see me hearing but deaf - easy see.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. People different behaviour with me - why? found out me deaf.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td></td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neither agree nor disagree</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
<tr>
<td>7.</td>
<td>I want to fit in with my hearing family, but my deafness makes it hard.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>8.</td>
<td>It is important to me that I get to know more hearing people, but I don't get the chance to do so.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>8.</td>
<td>Me want more with hearing important but time can't.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>I am really pleased if people think that I am hearing, and feel upset if they think I am deaf.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>9.</td>
<td>People think me hearing, me think great but if they say me deaf me upset.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>I want to join in with conversations, but a lot of the time hearing people give up trying to talk to me.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>10.</td>
<td>I want talk hearing people but all the time they stop or finish talk with me</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>I want to do my job as well as hearing people, but it is difficult being a deaf person in a hearing work environment.</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>
12. I do not fit in well with the hearing people in my family.

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

12. I have hearing family - me with family not good.

13. It is important to me that I can lipread so that I am like hearing people.

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>


14. My deafness stops me from going out when I want with my hearing friends.

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>


15. I want to be able to lipread well, but cannot find the time to practice.

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

15. Me want lipread good but time practise hard

16. No matter how hard I try, I can be left out of conversations with my hearing friends.

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

16. Hearing friend talk, me try try try still not understand.

Thank you for your time
Dear Sir/Madam

I am currently doing research for my doctorate in clinical psychology, at the universities of Coventry and Warwickshire. I am looking at deafness, identity, and psychological distress. I am particularly looking at the effects of an individual holding an identity that is not supported and maintained by the actions of others (for example, a deaf person who chooses to have a hearing identity (oral, lipreads) but is treated as a deaf person (is shouted at, ignored during conversation, gestured at, etc)).

I am wondering if you would be able to help with distributing questionnaires? At the moment I am trialling a questionnaire I have designed, but will be ready to carry out my main research in the next 4-8 weeks. My questionnaires are in both written English and BSL.

I hope that the results from this research will help to raise awareness among psychologists about deaf issues, improve access to services, and help to identify areas that may result in psychological problems that can be worked with.

I can send questionnaires to you, and will cover any postage costs that may result. If you know of any other groups that may help, I would appreciate any help you can give. I am accessing some Deaf clubs already. If you would like any more information, or would like a copy of the questionnaires, or the research proposal, please do not hesitate to contact me.

Any help would be gratefully received.

With thanks

Emma Marriott

Clinical Psychologist in Training
Hello, my name is Emma Marriott. I am a student at Coventry and Warwick universities, and I am studying for a Doctorate in Clinical Psychology. As part of this degree I am doing research. I hope that when the research is finished it will show how Clinical Psychologists can help deaf and hard of hearing people in the future.

I am asking people to complete these 3 short questionnaires – this will take about 10 to 15 minutes. If you have any concerns that arise from the questions, please contact either myself, or a health professional, such as your GP, to discuss these.

All information you give will be confidential.

If you would like more information about this research, you can contact me at:

Emma Marriott  
Clinical Psychology Doctorate  
School of Health and Social Sciences  
Coventry University  
Priory Street  
Coventry CV1 5FB

Or telephone on:  

<<telephone number>>

Or e-mail me at:  

<<e-mail address>>

Thank you for your help.
Research into social identity, deafness, and psychological distress.

Hello!

My name what? Emma Marriott.

Work what? Student

Where? Coventry University and Warwick University

Study what? Degree – called Clinical Psychology.

Mean what? Do many things.

Research. I hope when finish research show how Clinical Psychologists can help deaf people.

I ask people answer 3 short questionnaires – how long? about 10 - 15 minutes. Please - if when read questions you worry - contact either 1) myself, 2) health professional, e.g. your GP, why? talk about this.

You give me information, I keep confidential.

If you want know more information about research, you can write:

Emma Marriott
Clinical Psychology Doctorate
School of Health and Social Sciences
Coventry University
Priory Street
Coventry CV1 5FB

Or telephone:

<<telephone number>>

Or e-mail:

<<e-mail address>>

Thank you for your help.
Appendix 14

Deaf Attitude and Identity Questionnaire

Instructions

Read the following 32 statements and decide if you agree (A) or disagree (D) with the statement.

Circle either A or D as your answer.
Deaf Attitude and Identity Questionnaire (DATIQ)

| A  | D  | I would be a better person if I could hear. |
| A  | D  | My best friends are deaf. |
| A  | D  | I am most relaxed when I am with deaf people. |
| A  | D  | I feel I have a hard life because I am deaf |
| A  | D  | I feel nervous because I am deaf. |
| A  | D  | My deafness is a problem for other people but it is not a problem for me. |
| A  | D  | Deaf people understand me best. |
| A  | D  | I blame my deafness for my problems. |
| A  | D  | Sometimes I pretend to understand other people when really I don’t. |
| A  | D  | People dislike me because I am deaf. |
| A  | D  | I don’t like it when I have to tell other people I am deaf. |
| A  | D  | I feel quite confident. |
| A  | D  | Deaf people make more mistakes in life because they are deaf. |
| A  | D  | Deaf people can be just as equal as hearing people. |
| A  | D  | Being deaf is absolutely terrible. |
| A  | D  | I feel rejected by the hearing world. |
| A  | D  | Hearing people often put down deaf people. |
| A  | D  | I am angry because I was born deaf. |
| A  | D  | I lead a normal life just like anyone else. |
| A  | D  | I worry when I see people talking because I wonder if they are talking about me. |
| A  | D  | My close friends are hearing. |
| A  | D  | I feel embarrassed signing in public. |
| A  | D  | I feel uncomfortable if I am the only deaf person in a group. |
| A  | D  | I feel nervous if I miss something said and I have to ask people to repeat. |
| A  | D  | I have a strong feeling of identity as a deaf person. |
| A  | D  | It is ideal for deaf people to marry other deaf people. |
| A  | D  | I really wish I was hearing. |
| A  | D  | I prefer being with hearing people. |
| A  | D  | I feel angry towards hearing people. |
| A  | D  | I have a strong sense of belonging to the Deaf community. |
| A  | D  | I don’t like mixing with deaf people. |
| A  | D  | I am satisfied that I am deaf. |

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The General Health Questionnaire
GHQ 28
David Goldberg

Please read this carefully.

We should like to know if you have had any medical complaints and how your health has been in general, over the past few weeks. Please answer ALL the questions on the following pages simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

It is important that you try to answer ALL the questions.

Thank you very much for your co-operation.

<table>
<thead>
<tr>
<th>Question</th>
<th>Better than usual</th>
<th>Same as usual</th>
<th>Worse than usual</th>
<th>Much worse than usual</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1 – been feeling perfectly well and in good health?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A2 – been feeling in need of a good tonic?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>A3 – been feeling run down and out of sorts?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>A4 – felt that you are ill?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>A5 – been getting any pains in your head?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>A6 – been getting a feeling of tightness or pressure in your head?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>A7 – been having hot or cold spells?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>B1 – lost much sleep over worry?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>B2 – had difficulty in staying asleep once you are off?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>B3 – felt constantly under strain?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>B4 – been getting edgy and bad-tempered?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>B5 – been getting scared or panicky for no good reason?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>B6 – found everything getting on top of you?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
</tbody>
</table>

Please turn over
<table>
<thead>
<tr>
<th>Question</th>
<th>Rating Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you recently C1 - been managing to keep yourself busy and occupied?</td>
<td>More so than usual, Same as usual, Rather less than usual, Much less than usual</td>
</tr>
<tr>
<td>C2 - been taking longer over the things you do?</td>
<td>Quicker than usual, Same as usual, Longer than usual, Much longer than usual</td>
</tr>
<tr>
<td>C3 - felt on the whole you were doing things well?</td>
<td>Better than usual, About the same, Less well than usual, Much less well</td>
</tr>
<tr>
<td>C4 - been satisfied with the way you've carried out your task?</td>
<td>More satisfied, About same as usual, Less satisfied than usual, Much less satisfied</td>
</tr>
<tr>
<td>C5 - felt that you are playing a useful part in things?</td>
<td>More so than usual, Same as usual, Less useful than usual, Much less useful</td>
</tr>
<tr>
<td>C6 - felt capable of making decisions about things?</td>
<td>More so than usual, Same as usual, Less so than usual, Much less capable</td>
</tr>
<tr>
<td>C7 - been able to enjoy your normal day-to-day activities?</td>
<td>More so than usual, Same as usual, Less so than usual, Much less than usual</td>
</tr>
<tr>
<td>D1 - been thinking of yourself as a worthless person?</td>
<td>Not at all, No more than usual, Rather more than usual, Much more than usual</td>
</tr>
<tr>
<td>D2 - felt that life is entirely hopeless?</td>
<td>Not at all, No more than usual, Rather more than usual, Much more than usual</td>
</tr>
<tr>
<td>D3 - felt that life isn't worth living?</td>
<td>Not at all, No more than usual, Rather more than usual, Much more than usual</td>
</tr>
<tr>
<td>D4 - thought of the possibility that you might make away with yourself?</td>
<td>Definitely not, I don't think so, Has crossed my mind, Definitely have</td>
</tr>
<tr>
<td>D5 - found at times you couldn't do anything because your nerves were too bad?</td>
<td>Not at all, No more than usual, Rather more than usual, Much more than usual</td>
</tr>
<tr>
<td>D6 - found yourself wishing you were dead and away from it all?</td>
<td>Not at all, No more than usual, Rather more than usual, Much more than usual</td>
</tr>
<tr>
<td>D7 - found that the idea of taking your own life kept coming into your mind?</td>
<td>Definitely not, I don't think so, Has crossed my mind, Definitely has</td>
</tr>
</tbody>
</table>

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First published 1978
Appendix 16 – Journal guidelines for contributors
British Journal of Clinical Psychology

Notes for Contributors

The British Journal of Clinical Psychology publishes original contributions to scientific knowledge in clinical psychology. This includes descriptive comparisons, as well as studies of the assessment, aetiology and treatment of people with a wide range of psychological problems in all age groups and settings. The level of analysis of studies ranges from biological influences on individual behaviour through to studies of psychological interventions and treatments on individuals, dyads, families and groups, to investigations of the relationships between explicitly social and psychological levels of analysis.

The following types of paper are invited:

- Papers reporting original empirical investigations;
- Theoretical papers, provided that these are sufficiently related to the empirical data;
- Review articles which need not be exhaustive, but which should give an interpretation of the state of the research in a given field and, where appropriate, identify its clinical implications;
- Brief Reports and Comments (see below).

1. Circulation

The circulation of the Journal is worldwide. There is no restriction to British authors; papers are invited and encouraged from authors throughout the world.

2. Length

Pressure on Journal space is considerable and papers should be as short as is consistent with clear presentation of the subject matter. Papers should normally be no more than 5,000 words, although the Editor retains discretion to publish papers beyond this length.

3. Refereeing

The journal operates a policy of anonymous peer review. Papers will normally be scrutinised and commented on by at least two independent expert referees (in addition to the Editor) although the Editor may process a paper at his or her discretion. The referees will not be made aware of the identity of the author. All information about authorship including personal acknowledgements and institutional affiliations should be confined to a removable front page (and the text should be free of such clues as identifiable self-citations ("In our earlier work..."))

4. Submission requirements

- Four copies of the manuscript should be sent to the Editor (Professor Karin Mogg/Professor Brendan Bradley, BPS Journals Department, St. Andrews House, 48 Princess Road East, Leicester, LE1 7DR, UK). Submission of a paper implies that it has not been published elsewhere and that it is not being considered for publication in another journal. Papers should be accompanied by a signed letter indicating that all named authors have agreed to the submission. One author should be identified as the correspondent and that person’s title, name and address supplied.
- Contributions must be typed in double spacing with wide margins and on only one side of each sheet. All sheets must be numbered.
- Tables should be typed in double spacing, each on a separate piece of paper with a self-explanatory title. Tables should be comprehensible without reference to the text.
They should be placed at the end of the manuscript with their approximate locations indicated in the text.

- Figures are usually produced direct from authors' originals and should be presented as good black or white images preferably on high contrast glossy paper, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Paper clips leave damaging indentations and should be avoided. Any necessary instructions should be written on an accompanying photocopy. Captions should be listed on a separate sheet.

- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusion. Review articles should use these headings: Purpose, Methods, Results, Conclusions (more details on Structured Abstracts can be obtained by contacting the Journals Department).

- Bibliographic references in the text should quote the author's name and the date of publication thus: Smith (1994). Multiple citations should be given alphabetically rather than chronologically: (Jones, 1998; King, 1996; Parker, 1997). If a work has two authors, cite both names in the text throughout: Page and White (1995). In the case of reference to three or more authors, use all names on the first mention and et al. thereafter except in the reference list.

- References cited in the text must appear in the list at the end of the article. The list should be typed in double spacing in the following format:

- Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.

- SI units must be used for all measurements, rounded off to practical values if appropriate, with the Imperial equivalent in parentheses

- In normal circumstances, effect size should be incorporated.

- Authors are requested to avoid the use of sexist language.

- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations etc for which they do not own copyright.

For more information on submission requirements, please refer to the online Guide to Preparing Manuscripts for Journal Publication at:

5. E-mail and Web submissions

Manuscripts may also be submitted via e-mail and the BPS website (http://www.bps.org.uk/publications/ submissions.cfm). The main text of the manuscript, including any tables or figures, should be saved as a Word 6.0/95 compatible file. The file must be sent as a MIME-compatible attachment. E-mails should be addressed to journals@bps.org.uk with 'Manuscript submission' in the subject line. The main body of the e-mail should include the following: title of journal to which the paper is being submitted; name, address and e-mail of the corresponding author; and a statement that the paper is not currently under consideration elsewhere. Web and e-mail submissions will receive an e-mail acknowledgement of receipt.

6. Brief reports and comments

These allow publication of research studies and theoretical, critical or review comments with an essential contribution to make. They should be limited to 2000
words, including references. The abstract should not exceed 120 words and should be structured under these headings: Objective, Method, Results, Conclusion. There should be no more than one Table or Figure, which should only be included if it conveys information more efficiently than the text. Title, author, name and address are not included in the word limit.

7. Ethical considerations

The code of conduct of The British Psychological Society requires psychologists 'Not to allow their professional responsibilities or standards of practice to be diminished by consideration of religion, sex, race, age, nationality, party politics, social standing, class or other extraneous factors. The Society resolves to avoid all links with psychologists and psychological organizations and their formal representatives that do not affirm and adhere to the principles in the clause of its Code of Conduct. In cases of doubt, the Journals Department may ask authors to sign a document confirming the adherence to these principles. Any study published in this journal must pay due respect to the well-being and dignity of research participants. The British Psychological Society's Ethical Guidelines on Conducting Research with Human Participants must be shown to have been scrupulously followed. These guidelines are available at http://www.bps.org.uk/about/rules5.cfm

8. Supplementary data

Supplementary data too expensive for publication may be deposited with the British Library Document Supply Centre. Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the Editor together with the article, for simultaneous refereeing.

9. Proofs

Proofs are sent to authors for correction of print but not for rewriting or the introduction of new material. Fifty complimentary copies of each paper are supplied to the senior author, but further copies may be ordered on a form accompanying the proofs.

10. Copyright

To protect authors and journals against unauthorised reproduction of articles, The British Psychological Society requires copyright to be assigned to itself as publisher, on the express condition that authors may use their own material at any time without permission. On acceptance of a paper submitted to a journal, authors will be requested to sign an appropriate assignment of copyright form.

11. Checklist of requirements:

- A signed submission letter
- Correspondent's title/name/address
- A cover page with title/author(s)/affiliation
- Double spacing with wide margins
- Tables/figures at the end
- Complete reference list in APA format
- Four good copies of the manuscript (or an e-mail attachment)
British Journal of Psychology

Notes for Contributors

The Editorial Board of the *British Journal of Psychology* is prepared to consider for publication:

(a) reports of empirical studies likely to further our understanding of psychology;
(b) critical reviews of the literature;
(c) theoretical contributions.

Papers will be evaluated by the Editorial Board and referees in terms of scientific merit, readability, and interest to a general readership.

1. Circulation

The circulation of the Journal is worldwide. There is no restriction to British authors; papers are invited and encouraged from authors throughout the world.

2. Length

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4. Submission requirements

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5. E-mail and Web submissions

Manuscripts may also be submitted via e-mail and the BPS website (http://www.bps.org.uk/publications/isubmission.cfm). The main text of the manuscript, including any tables or figures, should be saved as a MS Word compatible file. The file must be sent as a MIME-compatible attachment. E-mails should be addressed to journals@bps.org.uk with 'Manuscript submission' in the subject line. The main body of the e-mail should include the following: title of journal to which the paper is being submitted; name, address and e-mail of the corresponding author; and a statement that the paper is not currently under consideration elsewhere. Web and e-mail submissions will receive an e-mail acknowledgement of receipt.

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7. Supplementary data
All articles should be preceded by an Abstract of between 100 and 200 words, giving a concise statement of the intention and results or conclusions of the article.

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Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations etc for which they do not own copyright.

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For Guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association, Washington DC, USA (http://www.apastyle.org)

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7. Supplementary data
Notes for Contributors

The British Journal of Social Psychology publishes original papers in all areas of social psychology. We encourage submissions addressing a variety of issues, and employing a variety of approaches and methods, both quantitative and qualitative. Topics covered include attitudes, group processes, intergroup relations, self and identity, social cognition, social influence, and social psychological aspects of affect and emotion, and of language and discourse.

The following types of paper are invited:

- empirical papers that have theoretical significance or implications;
- theoretical papers, which may be analyses or commentaries on established theories in social psychology, or presentations of theoretical innovations, extensions, or integrations;
- review papers, which should aim to provide systematic overviews and evaluations of research in a given field of social psychology, and identifying issues requiring further research;
- methodological papers dealing with any methodological issues of particular relevance to social psychologists.

1. Circulation

The circulation of the Journal is worldwide. There is no restriction to British authors; papers are invited and encouraged from authors throughout the world.

2. Length

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4. Submission requirements

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7. Supplementary data

Supplementary data too expensive for publication may be deposited with the British Library Document Supply Centre. Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the Editor together with the article, for simultaneous refereeing.

8. Proofs

Proofs are sent to authors for correction of print but not for rewriting or the introduction of new material. Fifty complimentary copies of each paper are supplied to the senior author, but further copies may be ordered on a form accompanying the proofs.

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