

Deaf people and mental well-being: Exploring and measuring mental well-being in  
British Sign Language

A thesis submitted to the University of Manchester for the degree of Doctor of  
Philosophy in the Faculty of Medical and Human Sciences

2013

Katherine Danielle Rogers

School of Nursing, Midwifery and Social Work

## **Contents**

List of tables	10
List of figures	12
List of appendices	13
Abstract	14
Declaration	15
Copyright statement	15
Acknowledgements	16
Dedications	16
The Author	17
Abbreviations	18
Permission to submit a PhD thesis in alternative format	19
 <b>Chapter One: Introduction</b>	 <b>20</b>
1. Introduction	20
1.1. Route map of the component parts of the study on mental well-being in d/Deaf populations across the lifecourse	21
2. My personal narrative: positioning my identity within the thesis	24
3. Rationale for submitting the thesis in an alternative format and an account of how the thesis format has been constructed	24
 <b>Chapter Two: Background</b>	 <b>28</b>
1. Introduction	28
2. How being 'deaf' is conceptualised: the three main models	28
3. Diversity of d/Deaf populations	31
3.1. Deaf community and culture	32
3.2. d/Deaf people and their language	34
3.2.1. Deaf people and British Sign Language	35
3.3. Non-signing deaf people	36
3.3.1. Type of schools and mental health outcomes	37
3.4. Identities in transition	38
4. Inequality issues in d/Deaf populations	39
5. d/Deaf people and mental health	40
5.1. Access to mental health services	41

6. Concept of mental well-being	42
7. Conclusion	43
<b>Chapter Three: Methodology</b>	<b>44</b>
1. Overview	44
2. Aims and objectives of the study	44
2.1. Research design of this study	45
2.1.1. Recruitment strategies employed in these studies	51
2.1.1.1. Follow up study	51
2.1.1.2. Well-being assessment with d/Deaf populations (CORE-OM)	52
2.1.1.3. Validation of the BSL assessments with a Deaf population	52
2.1.1.4. Perspectives on mental well-being	52
3. Ethical approval	53
4. Justification of the research methods used	53
4.1. Perspectives from d/Deaf people on mental well-being	53
4.2. Measuring mental well-being	56
4.2.1. Well-being assessment	56
4.2.2. Deciding which assessment to use to measure mental well-being	57
4.2.3. Measuring well-being	58
4.2.4. Well-being assessments	59
4.2.4.1. Subjective Well-Being Inventory	60
4.2.4.2. Personal Wellbeing Index	60
4.2.4.3. General Health Questionnaire	61
4.2.4.4. Clinical Outcomes in Routine Evaluation – Outcome Measure	61
4.2.4.5. Psychological Well-Being Scales	62
4.2.4.6. World Health Organization Quality of Life Questionnaire – BREF	62
4.2.5. Rationale for the selection of well-being assessment for this study	64
4.2.5.1. Using the CORE-OM in this study	64
4.2.5.2. Procedure	65
5. Specific issues arisen	66
5.1. Researching with d/Deaf people	66
5.1.1. Benefits and ethics of research with d/Deaf people	67

5.1.2. Data collection	69
5.1.3. Researcher as an insider/outsider of the Deaf community	69
5.1.4. Issues in relation to ensuring that the findings represent what participants have said	70
5.2. Longitudinal cohort study	71
5.2.1. Tracing plan for the original cohort	72
5.2.2. Difficulties of tracing the original d/Deaf cohort	72
5.3. Ethics	73
5.3.1. Ethics issues to consider	73
5.3.2. Follow-up study	74
5.3.2.1. Consent issues	74
5.3.2.2. Participants might not have been aware that they were involved in Hindley's study	74
5.3.2.3. Participants' access to their data from 1988	74
5.3.3. Measuring mental well-being with d/Deaf populations	75
5.3.3.1. Concerns arising from the data collection	75
5.4. Translating assessments into British Sign Language	75
5.5. Collecting data remotely	76
6. Summary	78
<b>Chapter Four: Paper A</b>	<b>79</b>
<b>Is there an association between deaf children's mental health difficulties and their adult well-being? The state of the evidence</b>	
1. Introduction	80
2. The Needs for Longitudinal Studies of Mental Health Outcomes	82
3. Comprehensive Literature Search	83
4. Mental Health Outcomes in Adulthood – in the Hearing Population	84
4.1. Mental health difficulties in childhood as a predictive factor for later mental health outcomes	84
4.2. Social, familial and environmental factors in childhood relating to mental health difficulties outcomes in adulthood	85
4.3. Mental health difficulties in childhood and the outcomes in adulthood (other than mental health)	87
4.4. The importance of services for young people with mental health difficulties	88
4.5. Conclusions of the findings from hearing populations	90

5. Longitudinal Studies with d/Deaf populations	90
6. Mental health outcomes in d/Deaf populations	91
6.1. Mental health difficulties in childhood as a predictive factor for later mental health outcomes in d/Deaf populations	93
6.2. Social, familial and environmental factors in childhood relating to mental health difficulties in adulthood in d/Deaf populations	94
6.3. Mental health in childhood and the later outcomes (other than mental health) in d/Deaf populations	96
6.4. Conclusions of the findings from d/Deaf populations	96
7. Current Gaps in Literatures on Mental Wellbeing Outcomes for d/Deaf populations	96
8. Future work	97
References	99

## **Chapter Five: Paper B** **108**

### **The challenges of translating the Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM) into British Sign Language**

1. Abstract	109
2. Purpose of this Study	110
3. Rationale of the Study	110
4. Methods	113
4.1. Clinical Outcomes in Routine Evaluation-Outcome Measure	113
4.2. Translation Procedure Used for This Study	115
4.3. Data Collection Using the Final Draft of the BSL CORE-OM	116
5. Translation Challenges	117
5.1. General Issues	118
5.1.1. Implications of modality	118
5.1.2. Clarify of the frequency anchors: analogical versus digital encoding	118
5.1.3. Pronouns and the direction of the signing	119
5.1.4. Format of the BSL CORE-OM shown on screen	120
5.2. Specific Concepts Within CORE-OM Items	120
5.2.1. Emotional state in BSL	120
5.2.2. The intensity of facial expression in sign language	121
5.2.3. Use of visually motivated signs without giving examples	122
5.2.4. Using the appropriate sign for the specific context	122

5.2.5. Confirmation of the statement	123
5.2.6 Words in a Deaf social context	123
5.2.7 Challenges of translating English words into BSL	124
6. Discussion	124
7. Conclusion	128
References	130

## **Chapter Six: Paper C** **136**

### **The reliability of British Sign Language and English versions of the Clinical Outcomes in Routine Evaluation – Outcome Measure with d/Deaf populations in the UK: a pilot study**

1. Abstract	137
2. Introduction	139
2.1. Rationale for the study	140
3. Methods	141
3.1. Psychometric properties of the CORE-OM	141
3.2. Phase One: Translating the CORE-OM into BSL	142
3.3. Web hosting of the assessment	145
3.4. Phase Two: Pilot study of the CORE-OM with d/Deaf populations	147
4. Results	149
4.1. Missing Data	152
4.2. Descriptive statistics for CORE-OM	152
4.3. Internal Reliability	153
4.4. Exploratory analysis of items with corrected item-total correlation	155
4.4.1. Comparing the Cronbach's alphas for each version	156
4.5. Exploratory analysis of Phase Three: Pilot study with a small sample of Deaf people for the revised BSL CORE-OM items	157
5. Discussion	158
6. Conclusion	162
References	163

## **Chapter Seven: Paper D** **168**

### **The British Sign Language Versions of the Patient Health Questionnaire, the Generalized Anxiety Disorder – 7 items Scale, and the Work and Social Adjustment Scale**

1. Abstract	169
-------------	-----

2. Methods	171
2.1. Materials	171
2.1.1. The Patient Health Questionnaire	171
2.1.2. The Generalized Anxiety Disorder 7-item scale	172
2.1.3. The Work and Social Adjustment Scale	173
2.1.4. The Clinical Outcomes in Routine Evaluation – Outcome Measure	173
2.2. Procedure	174
2.2.1. Translating the mental health assessments into BSL	174
2.2.2. Pilot study of the PHQ-9, GAD-7, and WSAS with a Deaf population	175
2.3. Recruitment	176
2.3.1. Inclusion criteria	176
2.3.2. Exclusion criteria	176
2.4. Participants	176
2.4.1. Demographics	177
2.5. Statistical Analyses	178
3. Results	179
3.1. Descriptive Statistics	179
3.2. Comparing Means Between Group 1 and Group 2	180
3.3. Psychometric Properties of BSL versions of PHQ-9, GAD-7, and WSAS	181
3.3.1. PHQ-9 BSL version	181
3.3.2. GAD-7 BSL version	182
3.3.3. WSAS BSL version	183
3.3.4. CORE-OM BSL version	184
4. Discussion	184
4.1 Limitations	189
5. Conclusion	190
References	192
 <b>Chapter Eight: Paper E</b>	 <b>199</b>
<b>Deaf people’s perspectives on mental well-being: childhood experience linked to adulthood well-being, the barriers and protective factors</b>	
1. Abstract	200
2. Introduction	201

3. Methods	202
3.1. Recruitment	203
3.2. Procedure	203
3.3. Analysis	204
4. Results	205
4.1. Participants	205
4.2. Deaf perspectives on mental well-being	207
4.2.1. (a) Childhood experiences linked with adult well-being	207
4.2.1.1. Communication	207
4.2.1.2. Managing in school	208
4.2.1.3. Bullying	209
4.2.1.4. Transitions	210
4.2.1.5. Identity	210
4.2.1.6. 'Can do' attitudes	212
4.2.2. (b) Barriers to maintaining positive mental well-being	213
4.2.3. (c) Protective factors relating to the maintenance of mental well-being	215
5. Discussion	218
5.1. Limitations	221
6. Conclusion	221
References	223
 <b>Chapter Nine: Discussion</b>	 <b>227</b>
1. Overview	227
2. Contribution to the knowledge of d/Deaf people and mental well-being as result of this study	228
2.1. Academics contributions: methodological and empirical	228
2.1.1. Literature review on the association between childhood and adulthood mental well-being outcomes in d/Deaf populations	228
2.1.2. Translating the mental health assessments into BSL	231
2.1.3. Pilot study of the CORE-OM (BSL and English) with d/Deaf populations	232
2.1.4. Validation of the four mental health assessments	233
2.1.5. Deaf people's perspective on mental well-being	235
2.2. Theoretical contributions	237
3. Policy and practice implications	238



4. Future research	241
4.1. Identify normal distributions for the Deaf population	241
4.2. Early intervention and preventative measures	241
4.3. Longitudinal study	242
4.4. Collecting data remotely	242

<b>Reference</b>	<b>243</b>
------------------	------------

**Word count:** 61,447

## List of tables

### Chapter Three

Table 1. Table of assessments with information.	63
---	----

### Chapter Six

Table 1. Demographic details of the d/Deaf participants who did either the BSL or English version of the CORE-OM.	150
Table 2. Means and standard deviations (SD) for all domains of the BSL and English CORE-OM in present study and non-clinical populations in Evans et al. (2002).	153
Table 3. Cronbach's alpha ( $\alpha$ ) values for the internal consistency of the items in each domain, with confidence intervals in brackets (95% CI), All Items, and Non-risk domain for a d/Deaf sample using the BSL version, a d/Deaf sample using the English version, and a non-clinical sample using the English version, from the Evans et al. (2002) study.	154
Table 4. CORE-OM items with corrected item-total correlation values less than 0.3 with the overall score in each of the domains for both BSL and English versions completed by d/Deaf people in this study.	156

### Chapter Seven

Table 1. Number of participants in each mental well-being group, including those whose GPs had been contacted.	178
Table 2. Participants' scores for the Patient Health Questionnaire (PHQ-9), Generalized Anxiety Disorder (GAD-7), Work and Social Adjustment Scale (WSAS), and Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM) by mental well-being group.	180
Table 3. Component loadings of the Patient Health Questionnaire (PHQ-9) British Sign Language (BSL) items after principal components analysis with Varimax rotation.	182
Table 4. Component loadings of the Generalized Anxiety Disorder (GAD-7) British Sign Language (BSL) items after principal components analysis.	183

Table 5. Component loadings of the Work and Social Adjustment Scale (WSAS) British Sign Language (BSL) items after principal components analysis.	184
---	-----

## **Chapter Eight**

Table 1. Demographic information of the participants.	206
---	-----

## List of figures

### Chapter One

Figure 1. A diagram of the route map of the overall work	23
--	----

### Chapter Three

Figure 1. A diagram of the route map of the overall work	46
Figure 2. An image of the website developed for this study	78

### Chapter Five

Figure 1. Example of the Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM) English version.	114
Figure 2. Example of the British Sign Language (BSL) version of the CORE-OM in the survey tool (shown in SelectSurvey.NET software implementation).	117

### Chapter Six

Figure 1. Translation procedure for translating the CORE-OM into BSL.	143
Figure 2. Example of the BSL version of the CORE-OM in the SelectSurvey tool.	146
Figure 3. Example of the English version of the CORE-OM in the SelectSurvey tool.	147
Figure 4. CONSORT-type diagram of participants who took part in the pilot study.	149
Figure 5. Cronbach's alpha ( $\alpha$ ) values with 95% confidence intervals for the internal consistency of the items in each domain, All Items, and Non-risk domain for a d/Deaf sample using the BSL version, d/Deaf sample using the English version, and a non-clinical sample using the English version in Evans et al.'s (2002) study.	155

### Chapter Eight

Figure 1. Diagram of a bird's eye view of the focus group with the researcher and the participants in a circle. Outside the circle where the participants are seated, are two camcorders which are positioned so that each one faces half of the participants and the researcher.	204
---	-----

## List of appendices

Appendix 1.	A critique of the Hindley (1993) study	272
Appendix 2.	Materials for the pilot study of CORE-OM with d/Deaf populations	274
Appendix 3.	Materials for the pilot study in relation to the validation of the BSL assessments with the Deaf population	278
Appendix 4.	DVD of the BSL versions of CORE-OM, PHQ-9, GAD-7, and WSAS	Backcover
Appendix 5.	Materials for the study on d/Deaf people's perspective of mental well-being	284
Appendix 6.	Descriptive statistics of the scores on CORE-OM and TEIQue-SF from the focus groups' participants	287
Appendix 7.	Ethical approval letters	288

## **Abstract**

### **Background:**

The prevalence of mental health difficulties in d/Deaf populations is higher than that of the hearing population. The association between mental health difficulties in childhood and well-being in adulthood amongst d/Deaf populations, including as perceived by Deaf people themselves, has been little explored. Access by d/Deaf people to mental health services is poor. In addition, there is a paucity of mental health assessments available in British Sign Language.

### **Aims:**

The aims of this thesis were; (i) to understand the association between childhood and adulthood mental well-being in d/Deaf populations; (ii) to find out how well the standardised mental health assessments can be used with d/Deaf populations; and (iii) to explore Deaf people's perspectives on mental well-being.

### **Methods:**

BSL versions of four mental health assessments (the Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM), the Patient Health Questionnaire (PHQ-9), the Generalized Anxiety Disorder (GAD-7), and the Work and Social Adjustment Scale (WSAS)) were produced by carrying out a translation process to ensure that the statements in the assessments are linguistically and culturally meaningful to a Deaf population. The reliability and validation of the mental health assessments were examined by piloting them with d/Deaf populations. In order to gain Deaf people's own perspectives on mental well-being, four focus groups were set up in England.

### **Results:**

Thematic analysis of the focus group data identified pre-disposing factors in childhood that Deaf participants believed would affect adult mental well-being.

The CORE-OM BSL, PHQ-9 BSL, GAD-7 BSL, and WSAS BSL were found to be reliable and have been validated. The pilot study which compared the reliability between the BSL and English version of one mental health assessment (CORE-OM) as completed by d/Deaf people found that two domains had lower reliability in English in comparison with the BSL version.

### **Conclusions:**

Reliable standardised instruments in BSL are required to identify and assess common mental health problems amongst Deaf people. These are now available. Deaf people identified a number of factors that are important to well-being, for example, ease of communication with others, a strong sense of identity, a 'can do' attitude, and a firm sense of belonging. These factors are of importance if we are to attempt to reduce the prevalence of mental health difficulties in d/Deaf populations in the future.

The University of Manchester

Katherine Danielle Rogers

Doctor of Philosophy

Deaf people and mental well-being: Exploring and measuring mental well-being in British Sign Language

2013

## Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

## Copyright statement

- i. The author of this thesis (including any appendices and/or schedules to this thesis) owns certain copyright or related rights in it (the "Copyright") and s/he has given The University of Manchester certain rights to use such Copyright, including for administrative purposes.
- ii. Copies of this thesis, either in full or in extracts and whether in hard or electronic copy, may be **only** in accordance with the Copyright, Designs and Patents Act 1988 (as amended) and regulations issued under it or, where appropriate, in accordance with licensing agreements which the University has from time to time. This page must form part of any such copies made.
- iii. The ownership of certain Copyright, patents, designs, trade marks and other intellectual property (the "Intellectual Property") and any reproductions of copyright works in the thesis, for example graphs and tables ("Reproductions"), which may be described in this thesis, may not be owned by the author and may be owned by third parties. Such Intellectual Property and Reproductions cannot and must not be made available for use without the prior written permission of the owner(s) of the relevant Intellectual Property and/or Reproductions.
- iv. Further information on the conditions under which disclosure, publication and commercialisation of this thesis, the Copyright and any Intellectual Property and/or Reproductions described in it may take place is available in University IP Policy (see <http://documents.manchester.ac.uk/DocuInfo.aspx?DocID=487>), in any relevant Thesis restriction declarations deposited in the University Library, The University Library's regulations (see <http://www.manchester.ac.uk/library/aboutus/regulations>) and in the University's policy on Presentation of Theses.

## **Acknowledgements**

I would like to thank the following people:

My supervisors Professor Alys Young and Professor Karina Lovell for their support, guidance, patience, encouragement and for their belief in me.

Malcolm Campbell for his statistical advice.

Chris Evans for his time and input relating to the CORE-OM work.

The teams of translators for their input in producing the mental health assessments in British Sign Language.

The staff at the Faculty of Medical and Human Sciences Web team for their technical support, especially Simon Wheeldon and Mike Pigram.

My colleagues at the Social Research with Deaf People (SORD) group, University of Manchester, for their support.

The National Institute for Health Research (NIHR) for awarding me a NIHR Doctoral Research Fellowship.

I would like to thank especially those d/Deaf people who have taken part in this study. Their participation has enabled this thesis to be completed and has added to knowledge regarding mental well-being and d/Deaf people.

I am grateful to my family and friends for their encouragement, support, patience and understanding.

## **Dedications**

To my parents and my family.



## **The Author**

Upon completion of my BSc in Psychology at the University of Central Lancashire in 2004, I became a youth service co-ordinator, working with d/Deaf young people in the East Lancashire area. I then decided to return to university to study at Masters level and took the opportunity to be a research assistant at the University of Manchester in 2006. My first project involved carrying out an evaluation of a pilot project on parenting deaf children. While completing my MRes in Psychology at the University of Manchester, I also worked on various research projects on a part time basis. These projects included research into Deaf role models, resilience as well as forward translating the Trait Emotional Intelligence Questionnaire into British Sign Language (BSL).

Between 2006 and 2008, I delivered lectures on the social construction of deafness to Social Work students at Manchester Metropolitan University and to trainee audiologists at the University of Manchester.

In 2009, I went to the National Technical Institute for the Deaf, Rochester Institute of Technology in New York, on a six-month internship. During this time I worked, alongside Assistant Professor Peter Hauser and his team in the Deaf Studies Laboratory, on a project studying the psychosocial and academic achievements of deaf young people. This primarily focussed on cultural capital and community cultural wealth in relation to the education of deaf children.

Since 2009, I have been employed as a doctoral research fellow, funded by the National Institute for Health Research. During my fellowship, I have also obtained a grant from the British Society for Mental Health and Deafness (BSMHD) working on the validation of BSL versions of the Patient Health Questionnaire (PHQ-9), the Generalized Anxiety Disorder 7-Item scale (GAD-7), and the Work and Social Adjustment Scale (WSAS).

## Abbreviations

American Sign Language	ASL
Black and Minority Ethnic	BME
British Sign Language	BSL
British Society for Mental Health and Deafness	BSMHD
Child and Adolescent Mental Health Services	CAMHS
Clinical Outcomes in Routine Evaluation – Outcome Measure	CORE-OM
Generalized Anxiety Disorder 7-Item Scale	GAD-7
Improving Access to Psychological Therapies	IAPT
International Congress on Education of the Deaf	ICED
National Health Service	NHS
National Institute for Health Research	NIHR
Patient Health Questionnaire	PHQ-9
Sign Supported English	SSE
Social Research with Deaf People	SORD
Trait Emotional Intelligence Questionnaire	TEIQue
Work and Social Adjustment Scale	WSAS
United Kingdom	UK

## Permission to submit a PhD thesis in alternative format

### THE UNIVERSITY OF MANCHESTER

#### Faculty of Medical and Human Sciences

#### PERMISSION TO SUBMIT A Ph.D. THESIS IN ALTERNATIVE FORMAT (SUITABLE FOR PUBLICATION OR DISSEMINATION)

We confirm that the following student in the Faculty of Medical and Human Sciences, has been granted permission by his/her supervisor to submit a Ph.D. thesis in alternative format approved under the regulations, including sections which are in a format suitable for submission for publication or dissemination.

Name: \_\_\_\_\_ Katherine ROGERS \_\_\_\_\_

Degree programme: \_\_\_\_\_ PhD Nursing \_\_\_\_\_

Registration Number: \_\_\_\_\_ 7072969 \_\_\_\_\_

School: \_\_\_\_\_ School of Nursing, Midwifery & Social Work

**This form should be submitted with the thesis.**



Signed:

\_\_\_\_\_  
Graduate Education Manager  
Faculty of Medical and Human Sciences Graduate Office

Date 13/9/11

**TWO COPIES OF THIS FORM SHOULD BE GIVEN TO THE STUDENT, WHO SHOULD SUBMIT ONE COPY WITH THE THESIS AND RETAIN THE OTHER COPY. FURTHER COPIES SHOULD BE HELD BY THE FACULTY GRADUATE OFFICE AND BY THE SUPERVISOR.**

## CHAPTER ONE: INTRODUCTION

### 1. Introduction

d/Deaf<sup>1</sup> people across their lifespan are more likely than hearing people to experience mental well-being difficulties whether in terms of mental ill health or more broadly in relation to feelings of positivity and negativity about one's self (Fellinger et al., 2012; Hindley et al., 1994). These studies have largely investigated prevalence or involved d/Deaf people at a single point in time (Rogers and Young, in press). There have been no longitudinal studies undertaken in the context of mental health and d/Deaf people, and very few in relation to d/Deaf people more generally. Little is known, therefore, about the association between mental well-being difficulties in d/Deaf people's childhood and their later adulthood mental well-being outcomes. Furthermore, there is little research into how d/Deaf people themselves perceive their mental well-being or how they view the way in which their life experiences during their childhood or adult life may have impacted on their well-being. Research has found that mental well-being difficulties in d/Deaf populations<sup>2</sup> are more common than in hearing populations and access to primary and secondary mental health services is poor. In addition there is a lack of appropriate mental health assessments that are suitable for d/Deaf people. Having mental health assessments that are linguistically accessible and culturally appropriate for Deaf people would mean that mental health difficulties could be identified at an earlier stage and appropriate services put in place. As a consequence of inadequate mental health assessment tools for d/Deaf people, and in particular the population of people who use sign language, the normative distribution of mental health among d/Deaf people is unclear.

---

<sup>1</sup> Deaf (with a capital 'D') refers to the community of people who use sign language as their first or preferred language and for whom being Deaf is akin to a cultural-linguistic identity (Padden & Humphries, 1988). When deaf is written with a small 'd' it refers to those who use spoken language and/or have a view of deafness as an impairment or disability for example those who have lost their hearing in later life. d/Deaf is an all inclusive term and often is used with respect to children where their core identity is not yet formed or is unclear.

<sup>2</sup> Whilst it is recognised that the Deaf population consists of a diverse range of people, for consistency in this thesis, the term Deaf populations (plural) refers to the full range of d/Deaf people whereas the term Deaf population (singular) refers to those people who identify as a specific cultural and linguistic minority group.

This thesis addresses the above issues by investigating associations between childhood and later mental well-being status from the perspectives of d/Deaf people, producing and piloting standardised mental health assessments in BSL, testing their reliability and exploring the feasibility of their use with d/Deaf populations. The research aims and objectives are as follows:

**Aims:**

- i. To gain an understanding from the literature of the association between mental well-being in childhood and later adulthood outcomes in d/Deaf populations;
- ii. To establish how well the standardised mental health assessments can be used with d/Deaf populations; and
- iii. To gain an understanding of d/Deaf people's perceptions of their own mental well-being since leaving school, and their view about the risks and protective factors in the pathway from childhood to adult well-being.

**Objectives:**

- i. To examine the literature in order to understand the association between childhood and adulthood mental well-being outcomes in d/Deaf populations;
- ii. To translate four standardised mental well-being assessments into BSL;
- iii. To test the reliability of the CORE-OM (in BSL and English) with d/Deaf populations;
- iv. To validate the BSL mental health assessments in British Sign Language; and
- v. To explore Deaf people's perspectives on their mental well-being since childhood and to examine how this relates to their adult mental well-being outcomes using a qualitative approach.

### **1.1. Route map of the component parts of the study on mental well-being in d/Deaf populations across the lifecourse**

In 1988 a study had been carried out to establish the mental health difficulties of young deaf people in England at the time (Hindley<sup>3</sup>, 1993). In order to identify factors from childhood which may influence adulthood mental well-being, it was

---

<sup>3</sup> Hindley originally reported his findings in a comprehensive and detailed report in 1993. This was later published Hindley, Hill, McGuigan, & Kitson (1994) in *Journal of Child Psychology and Psychiatry*. For consistency in this thesis, Hindley's work will be cited as 1993, as this report contains the comprehensive findings from his research.

the intention of this thesis to undertake a follow-up study of the people who had originally been involved in Hindley's study. This would include establishing their current well-being once traced and comparing it with the original data. However, because of the lack of standardised mental health assessments available for d/Deaf people, it was first necessary to identify a suitable assessment and translate it into British Sign Language (BSL) using a rigorous protocol before piloting the translated versions with d/Deaf populations outside of the original cohort. This was a necessary first step; to establish the reliability of BSL and English versions of the standardised mental health assessment identified, when used with d/Deaf people.

Unfortunately, for a variety of reasons, it proved difficult to recruit participants from the original cohort of Hindley's 1988 study (see chapter three for a discussion of the methodological significance of this failure to trace and recruit). Nonetheless, the expertise gained in translating and testing the reliability of one standardised mental health assessment in BSL could be applied to other assessment tools associated with mental well-being. An opportunity arose to do this in association with the national IAPT (Improving Access to Psychological Therapies) programme (Department of Health, 2011) which was, at the time developing more accessible services for d/Deaf people in England. Early identification of common mental health problems and their treatment in primary care is another component of supporting d/Deaf people's well-being over the lifecourse. Finally, in order to gain a broad understanding of Deaf people's perspectives on mental well-being and how it might be associated with their childhood experiences, d/Deaf people who had not been involved in Hindley's study were invited to take part in focus groups. They discussed their perceptions and experiences of growing up d/Deaf and the factors that they thought had either positively or negatively influenced their current well-being. They also completed a standardised mental well-being assessment in their preferred language (BSL or English). Figure one below represents in diagrammatic form how the different components of the thesis fit together within an overarching investigation of mental well-being over lifecourse and in light of changes that had to be made to the initial intention of the study.

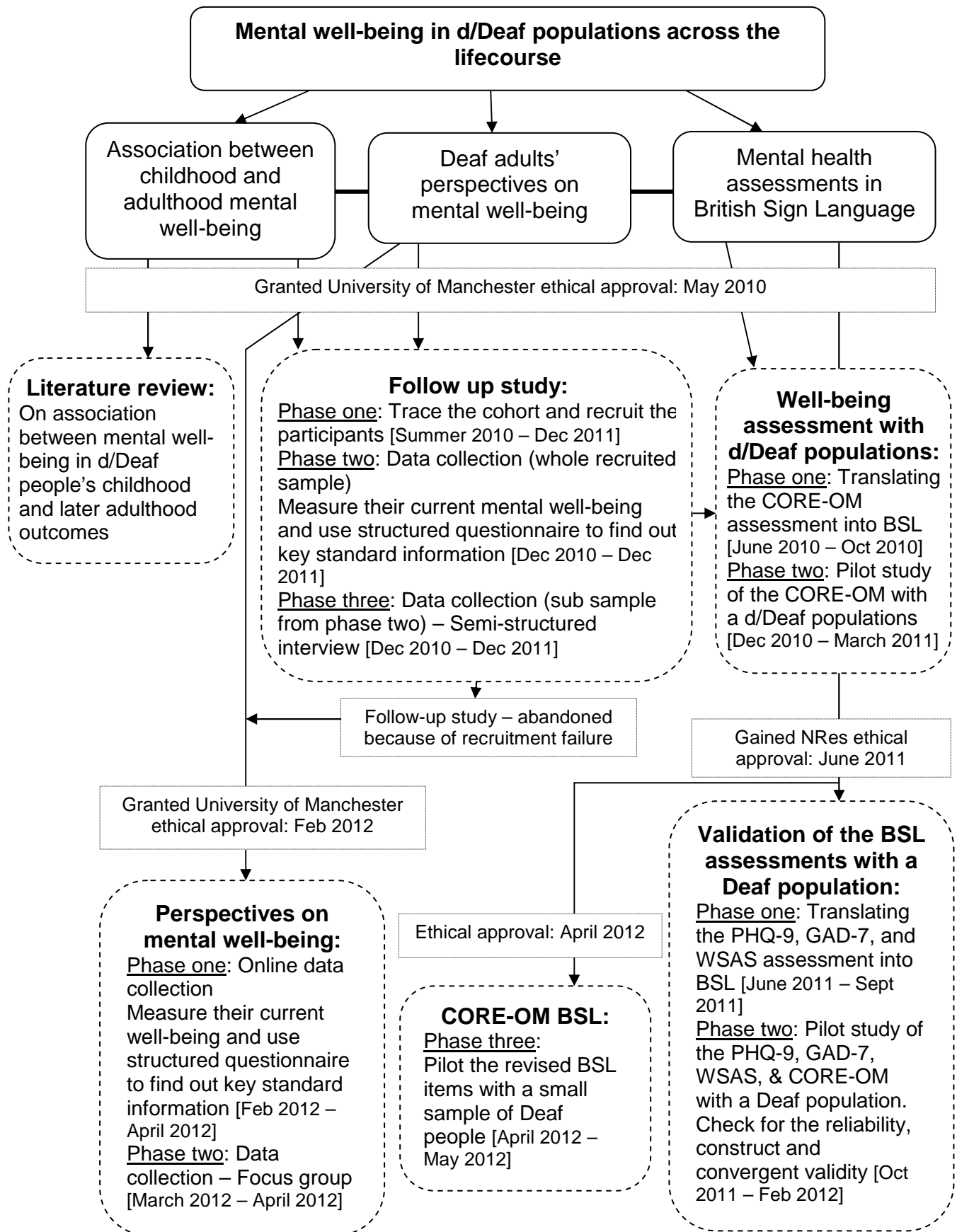


Figure 1. A diagram of the route map of the overall work

## **2. My personal narrative: positioning my identity within the thesis**

I have been Deaf since birth although both my parents are not deaf. I identify as a culturally Deaf person and am bilingual in BSL (British Sign Language) and written English as well as being able to use ASL (American Sign Language) fluently. As a result of my parents' belief that I should mix with other Deaf people, I have been part of the Deaf community all my life and attended deaf boarding schools from the age of five. It was around this time that I learned sign language although this was from friends, as the deaf schools I attended forbade the use of sign language in the classroom. I am aware of the impact of my own position as a researcher who happens to be Deaf. As a Deaf person who belongs in the Deaf community I have a high degree of insight into the diverse life experiences of d/Deaf people and also have a good understanding of some of the issues raised by Deaf people themselves. My ontological (what is reality for me) and epistemological (how that reality is known) position is that of a Deaf person.

I am also aware, as a Deaf person, of the frustrations associated with, for example, communication barriers and a feeling of exclusion which can, in turn, have an impact on mental well-being. Not being included, although not intentionally, in family conversations, and not being able to express oneself freely in sign language can be a frustrating experience, for example.

As a researcher who has held a staff position within the University of Manchester for the past seven years, my research interests primarily involve issues pertaining to d/Deaf communities. I am part of the Social Research with Deaf People (SORD) group at the University of Manchester and am a member also of Deaf Academics UK and Ireland. I was awarded a doctoral research fellowship by the National Institute for Health Research (NIHR).

## **3. Rationale for submitting the thesis in an alternative format and an account of how the thesis format has been constructed**

This is a PhD by "alternative format" and includes, as required, 5 publications. There are three principal reasons for deciding to submit the thesis in this manner, rather than in a traditional format. Firstly, I wanted to ensure that the research findings were made available as quickly as possible to the research and practice communities. The work in particular that relates to the production of standardised assessments in BSL (papers B, C and D) was of immediate interest and use.



Secondly, the research studies underpinned products which were of immediate clinical use, such as the BSL versions of the IAPT instruments. It could have been regarded as unethical to wait to use the instruments until after I had finished my PhD and the work had been published. Thirdly, producing a thesis in alternative format was a more efficient way to support my personal development in writing for academic publications and my future research career. The NIHR award which was given to support this work was made in respect of my potential to become a leader in health sciences research and as a Deaf person I would be one of the few people internationally who are qualified and experienced to do this.

The thesis is structured as follows:

- Chapter One: Introduction.
- Chapter Two provides the background to the study, and introduces the key information relating to d/Deaf people, such as how they are viewed by society, the diversity of d/Deaf populations, language preferences, culture and identity(ies) and how these factors relate to mental well-being for d/Deaf people.
- Chapter Three describes the overall methodology including specific methodological considerations of wider interest that have arisen from different parts of this study. It raises issues such as the challenges of research involving d/Deaf people, ethical implications and a perspective on mental well-being. The methods used for each of the studies are included in the individual publications.
- The five papers/ book chapters (published, in press, submitted or in preparation for submission) included in this thesis are:

Paper A (Chapter Four): Rogers, K. D., & Young, A. (In press). Is there an association between deaf children's mental health difficulties and their adult well-being? The state of the evidence. In: L. Leeson and M. Vermeerbergen (Eds.), "Working with the Deaf community: Education, Mental Health & Interpreting". Dublin, Ireland: Intersources Group (Ireland) Limited.

Paper B (Chapter Five): Rogers, K. D., Young, A., Lovell, K., & Evans, C. (2013). The challenges of translating the Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM) into British Sign Language. *Journal of Deaf Studies and Deaf Education*. Advance online publication. doi:10.1093/deafed/ent002

Paper C (Chapter Six): Rogers, K. D., Evans, C., Campbell, M., Young, A., & Lovell, K. (2013) *The reliability of British Sign Language and English versions of the Clinical Outcomes in Routine Evaluation – Outcome Measure with d/Deaf populations in the UK: a pilot study*. Manuscript submitted for publication.

Paper D (Chapter Seven): Rogers, K. D., Young, A., Lovell, K., Campbell, M., Scott, P. R., & Kendal, S. (2013). The British Sign Language Versions of the Patient Health Questionnaire, the Generalized Anxiety Disorder 7-Item Scale, and the Work and Social Adjustment Scale. *Journal of Deaf Studies and Deaf Education*, 18(1), 110-122. doi:10.1093/deafed/ens040

Paper E (Chapter Eight): Rogers, K. D., Young, A., & Lovell, K. (2013). *Deaf people's perspective on mental well-being: childhood experience linked to adulthood well-being, the barriers and protective factors*. Manuscript to be submitted for publication.

Paper A is a book chapter on the association between mental well-being in d/Deaf people's childhood and later adulthood outcomes. Paper B identifies the challenges of translating standardised mental health assessments into British Sign Language. Paper C details the findings of a pilot study using the CORE-OM with d/Deaf populations; Paper D shows the results of translating the PHQ-9, GAD-7, WSAS and CORE-OM into BSL with a signing Deaf population. Paper E focuses on Deaf people's perspectives on mental well-being. All papers (A, B, C, D, and E) are of my own work; I designed the studies, determined the methods and analysed all the data, my academic supervisors contributed to the overall design of the thesis and commented on all publications, Malcolm Campbell contributed and commented on the statistical analysis in papers C and D, and Chris Evans commented on the work related to the CORE-OM (Paper B and C). The percentage of my contribution to each paper is 85%. The presentation of the papers that have been published (Paper A, B, and D) are in the versions that have been accepted for publication, these have been inserted in the thesis as one whole document with page numbers added for the continuation of the pagination sequence of this thesis.

The final chapter (Chapter Nine) is a synthesis which brings together the entire thesis. This chapter also provides an overview of the findings: how they relate to

theoretical perspectives, policy and practice issues in relation to mental well-being in d/Deaf populations and recommendations for future research.

## **CHAPTER TWO: BACKGROUND**

### **1. Introduction**

People who are born deaf or become deaf in infancy or childhood have different life experiences from those who acquire deafness later in life (Young, 2006). This thesis concerns the former. The incidence of people in England who are born with a bilateral, permanent deafness of 40dB or greater is 1.01 per 1000 (NHS, 2011) and by the age of 10, the prevalence of deafness increases to 2 in 1000 (Fortnum, Stacey, Barton, & Summerfield, 2007).

The chapter will provide brief background information about deafness in terms of 'deaf' perspectives and models of deafness, the Deaf community and Deaf culture, British Sign Language (BSL) and d/Deaf people and mental health. Firstly however it is useful to clarify the terminology used in this literature. It is common to refer to culturally Deaf sign language users as Deaf with a capital 'D' and those who are not culturally Deaf with a lower case 'd' (Padden & Humphries, 1988). When both populations are included in a discussion this is marked by 'd/D'. These distinctions are discussed in detail below. However, it is important to note at the outset that d/Deaf people are diverse as they do not all share the same characteristics as they do not all share the same language, community, and identity (Leigh, 2009). Furthermore, being 'deaf' is not just about the function of hearing, it is more than that. An appreciation of this will assist in understanding the relationship between deafness and mental well-being of d/Deaf people throughout their lives.

### **2. How being 'deaf' is conceptualised: the three main models**

The identity and representation of d/Deaf people is dependent on the perspective or conceptual framework that is applied. There are three main models of how d/Deaf people are viewed in society; namely the medical, social and linguistic models. The medical model primarily considers deafness as an impairment of bodily functioning. It problematizes the person who is deaf as it is focussed on the 'diagnosis', the degree of hearing, and treatments or interventions such as hearing aids, cochlear implants and more recently brain implants. All are concerned with what is regarded as the restoration of hearing and 'curing' the deaf person. The main focus of the medical model is to 'reduce' or minimise the effects of the 'hearing loss' as it is considered that this makes a person different from that which

is thought to be the norm, and to integrate them into hearing society (Lane, 1992). Bauman and Murray (2009) emphasised how the concept of non-normal emerged in the context of normalcy:

Within this context of a normal distribution of human populations, the concept of disability emerged. Society interprets disabled people as outliers, as statistical anomalies that need to be elevated to normalcy. It is this interpretation that underlies Deaf people's long struggle with "normal". The frame of normalcy has shaped the Deaf community's fraught relationships with the field of education, with the medical profession, and with mainstream society. It has established a statistical ideal – the perfect "normal" person – toward which all Deaf people are exhorted to strive. But, upon achieving the heights of normalcy, one can see that the landscape below is actually quite dismal. It is one of hearing loss, of genetic tests, and of medical technology, i.e. of a purely audiological view of deafness. (Bauman & Murray, 2009, p. 1)

The medical model suggests that d/Deaf people, regardless of the degree of hearing loss can be studied as one group (Munoz-Baell & Ruiz, 2000). Thus the medical model with its focus on pathology ignores the greater complexities of being d/Deaf including those of a social nature and identity.

Contrary to the medical model, the social model of disability does not focus on the individual and their impairment. Rather it uncovers how barriers within society create disabling effects. For example, a deaf person is not disabled because they cannot hear an announcement on a train. They are disabled because trains are not fitted with visual display boards which ensure announcements can be seen, not just heard. The social model of disability attempts to ensure that all members of society have an equal right to participate fully in society; failure to provide this is seen as discrimination. The focus of the social model is, therefore, on issues of exclusion, access and participation. It has its origins primarily in the struggles faced by people with a physical impairment (Ladd, 2003) and d/Deaf people are viewed as disabled because they have a 'medically defined hearing impairment' and they experience inequalities in access and participation in the same way as other disabled people. However as Obasi (2008) points out, not all d/Deaf people necessarily view themselves as disabled and often do not place as much emphasis on the physical impairment (of deafness) and its effects on hearing as others might. The social model assumes that there is a shared emphasis on

overcoming the barriers which enable d/Deaf people to function as hearing people and this may not necessarily be the case. The linguistic model (see below) on the other hand emphasises that not all Deaf people recognise such barriers in the first place.

Although the social model of disability has given Deaf people some benefits, “many are uncomfortable with their inclusion in the disability social model” (Ladd, 2003, p. 15) as it fails to acknowledge Deaf people as visually oriented beings. In fact both the medical and the social models fail to recognise Deaf people as a cultural group who share the use of sign language. Instead they are viewed within the social model as a minority group that need ‘help’ or ‘support’.

The linguistic model, extended by Ladd (2003) to the culturo-linguistic model, incorporates not only the importance of Deaf culture but also that of language. The linguistic model recognises that for many Deaf people it is language that draws them together as a group, not the fact that they cannot hear. A survey which examined how Deaf people wished to be seen found that Deaf people wanted to be accepted as a linguistic and cultural minority group rather than a disabled group (Jones & Pullen, 1989).

Research involving d/Deaf people has been conducted over the past century. However it is only in recent decades that there has been a growth in research that acknowledges Deaf people and their language. The differing models of deafness led researchers to “focus on different concerns within the same constituency of interest” (See Young & Hunt, 2011, p. 4, for examples of an area of focus from each model). It can be argued that the models of deafness and the understandings of d/Deaf people that researchers bring to their work influences the questions they address, the methods they use and the conclusions they reach. For example in the study of early intervention for d/Deaf children, the research questions across the models would take a different focus. The medical model may for example consider the importance the lack of access to sound has on a d/Deaf child's development whereas a cultural perspective is more likely to focus on the importance of the exposure to visual language on a child's development. The medical model, and to some extent the social model, with their emphasis on impairment and disability, largely ignore the essential essence of being Deaf. To focus on such models does

not allow exploration of those very aspects which are of importance to any minority group, such as language, cultural and social experiences (Ladd, 2003).

In the context of improving the quality of life for d/Deaf people, each model takes a different perspective in terms of what is considered to be a priority. For example, from a medical perspective the emphasis would be to ensure that a d/Deaf person is as much like a hearing person as possible, which means they should be able to maximise their hearing, to speak and to interact with hearing people. From a cultural perspective however, one of the priorities would be to ensure group identification to allow the development of a positive sense of self, e.g. having d/Deaf youth services available.

### **3. Diversity of d/Deaf populations**

There is a common misconception that d/Deaf people are a homogenous population. In fact, d/Deaf people are a heterogeneous group of people. Diversity includes the age of onset when a person was first recognised as being deaf, language usage, identity, educational experience and the life experiences of being d/Deaf. Leigh (2008, p. 24-25) stated that “cultural and linguistic background, the existence of concomitant disabling conditions, as well as linguistic, social, personality, and cognitive developmental issues are all influencers of diversity within this population”. Changes in policies as well as the technical aids, for example cochlear implants, influence the increase in diversity for d/Deaf people (Leigh, 2008). Those people who identify themselves as culturally Deaf view themselves as being part of the Deaf community, are sign language users and are usually described as Deaf (with a capital D) (Padden & Humphries, 1988). They have their own social structures, organisations, attitudes, values, culture, history and Deaf political structure. Those who do not identify themselves as culturally Deaf are referred to as deaf (with small d), and may consider themselves as belonging to the hearing community i.e. they are culturally hearing.

Furthermore, it is not only a matter of whether one identifies as belonging to the Deaf community or the hearing community (or for some, both). d/Deaf people are also diverse for reasons not associated with being d/Deaf. This may include factors such as ethnicity or affiliation with other minority communities (such as the gay community). Nevertheless, it is important to use being d/Deaf as an organising category in considering well-being and to make distinctions between, for example,

Deaf people who use sign language and/or deaf people who do not use sign language. Without such distinctions, it would not be possible to understand the varied life experiences of d/Deaf people, how identities are developed (as a deaf or Deaf person), and what is valued by individuals in relation to mental well-being.

### **3.1. Deaf community and culture**

Different communities inevitably hold differing values and perspectives about what is important. In order to understand the factors which promote an individual's well-being it is essential to give some thought to the community or communities to which they belong. There remains considerable debate in sociology as to what constitutes a community (Ladd, 2003). The term 'community' can be defined as an area where people live, a neighbourhood, or composed of social relationships between people (Gusfield, 1975). Although there are islands and villages in the world where there are high numbers of Deaf people (and hearing people who can sign) these are rare (see Kusters, 2010 for review); in general, Deaf people are not physically bound to an area, they are geographically dispersed. There is no Deaf nation state in the way in which other linguistic and cultural groups might usually have a territory or state e.g. the French in France, Flemish speakers in Belgium.

It has been argued that a sense of community has four elements: membership (feeling of belonging); influence (sense of mattering); integration and fulfilment of needs (reinforcement); and shared emotional connection (McMillan & Chavis 1986). These elements can influence how an individual perceives their own sense of well-being and value. Woll and Ladd (2003) stated that the Deaf community is based on deafness, communication and mutual support. Deaf people often meet at events including Deaf clubs, social events, art/theatre shows, sporting and political events. Historically, Deaf people were less visible in society as they were not seen as often as today in public settings and in the media. Education for d/Deaf children was segregated, for example, and as adults Deaf people tended to meet at Deaf-specific venues such as Deaf clubs. Nowadays, however, Deaf people are more likely to be seen in shared public settings such as cafes and pubs and participate in the same social spaces, such as theatres and cinemas. There has been a growth of Deaf people and sign language reflected in mainstream media, such as the regular signing of national news programmes, soap operas, children's programmes and other broadcast media as a matter of course. As a



result, Deaf communities and signed languages are now more visible within mainstream society.

Being culturally Deaf can be seen as being akin to an ethnic grouping (Lane, Pillard, & Hedberg, 2011). The Deaf community is a close knit community, where most members know one another and view themselves as a minority group bound together by signed language, shared traditions, values and culture. This is also the case for non-Western Deaf communities, where there are relationships between Deaf people from the neighbouring villages (Kusters, 2010).

Cultural pride and cohesion is significantly more relevant to groups of people who have limited rights and who are in a minority than to dominant groups (Ahmad, Darr, Jones, & Nisar, 1998). Like other minority groups Deaf people have had to identify their inherited norms and values in order to ensure they can be represented within the main society in which they function (Ladd, 2003).

...therein lie the crucial distinction between majority and minority cultures – the former are under no obligation either to make explicit the beliefs which drive their actions, let alone to have to justify their actual existence. The latter, by contrast, are not only required to do so, but operate under a double yoke. There is the extent to which they lack (or are denied) the material resources to accomplish this justification, whilst majority cultural dominance ensures that is *they* who investigate and analyse the 'Other', who file the reports which collectively constitute what the West defines as 'knowledge'. (Ladd, 2003, p. 21)

Participation as a member of the Deaf community is not fixed in childhood. A Deaf person who might have been oral (relied on speech, assisted hearing and lip-reading to communicate) when young but acquired sign language in adulthood might later feel part of a Deaf community because they identify with some of the shared experiences with other members (Valentine & Skelton, 2003). Whether an individual is a member of the Deaf community or not is based on 'attitudinal deafness', rather than how much (or how little) an individual can hear (Baker-Shenk & Cokely, 1980). Although, the life experiences of culturally Deaf people vary, they tend to have shared beliefs, values, and pride in being Deaf. The term 'Deafhood' has been developed to capture the essence of being Deaf (Ladd, 2003). Deafhood is described as a process in which Deaf

people realise and act upon to enhance their Deaf identity. It is not unusual for deaf people who having been reared in a hearing environment and who then meet other Deaf people and learn BSL to “shift over time in an individual’s self-identity from deaf to Deaf” (Valentine & Skelton, 2003, p. 304). This shift would be a result of them exploring their own identity/identities because of their introduction to the Deaf community. Ladd (2003) considers that Deafhood enables Deaf people to move on from being stuck in traditions and to strive for a future in which being Deaf no longer has negative connotations.

### **3.2. d/Deaf people and their language**

Typically infants begin to acquire their native language before the age of two, and this acquisition is rapidly developed during the same two or three years in every culture (Konner, 1991). In order to enable a deaf child to acquire language, to reach their potential and to achieve the optimum outcome, they need exposure to a language-rich environment both in terms of quality and quantity of language (Calderon & Greenberg, 2000). However, it is well documented that many d/Deaf children (more so for those of hearing parents) experience language delay and in some cases language deficit (Mohay, 2000; Yoshinaga-Itano, 2003). In the case of sign language, Anderson and Reilly (2002) stated that many deaf children who do not have deaf parents are over three years of age before they learn any sign language. It has also been reported that some parents feel that they do not receive sufficient information in relation to the communication options for their deaf child (Young et al., 2006). A delay in language places other developmental skills at risk of delay also – for example it may affect cognitive and academic outcomes (Luft, 2011). Furthermore, the literacy skills in d/Deaf children tends to be delayed and/or the child fails to develop to their optimum potential (Mayer, 2007). For those children who use sign language, literacy skills might be affected by poor access to education, inadequate signing skills of some teachers and/or lack of provision in the educational setting. Marschark, Lang, and Albertini (2002) emphasise the importance of communication and state that “effective communication is an important ingredient of healthy psychological functioning” (2002, p. 61). Without effective communication, it is more challenging to achieve skills such as interaction with others, the ability to navigate through society and develop a sense of self.

BSL has no written form. Some Deaf people are bilingual i.e. they understand written and/or spoken English and sign language. The unique aspect of

bilingualism in Deaf people, (compared to most hearing bilinguals), is the difference in the modality between the two languages (visual and written formats). Furthermore, one must bear in mind that being bilingual does not necessarily mean that the level of the fluency in sign language and English are balanced, as someone may be more fluent in BSL (as it is used as a first language) than English (which is used as a second language). For some Deaf people the use of English as a second language may only be in its written form (Grosjean, 1996), as not all Deaf people have intelligible speech to the untrained ear. Whilst information and news is indeed available, in written format, in the media and on the internet those d/Deaf people with poor literacy skills may find this difficult to access. In summary, for d/Deaf people with poor literacy skills, there are significant barriers in accessing information, for example, in reading health related information which may help to maintain their mental well-being.

### ***3.2.1. Deaf people and British Sign Language***

Deaf people in the UK, who identify themselves as Deaf and are part of a Deaf community, are likely to use BSL in order to communicate. British Sign Language is a language in its own right. It is a visual-spatial language with its own grammatical structure (Sutton-Spence & Woll, 1999). Findings from the GP patient survey revealed that there are at least 100,000 Deaf BSL users in England (BSMHD, 2010). It was not until 2003 however that the UK Government accepted BSL as an official indigenous language (Smith, 2003). Despite this recognition, BSL still has no legal protection (i.e. there is no BSL Bill or BSL Act that has been adopted in law by the UK Government). As a consequence, there is currently no legal obligation for service providers to ensure that Deaf people have the right to full linguistic access to education, employment and health services in the UK. If BSL had legal protection, then one would expect that accessibility would be improved by, for example, making health related information available in BSL, an increased awareness of BSL, and a growth in the number of BSL/English interpreters. Communication barriers, whether experienced in sign language or spoken/written language, can be a frustrating experience. The ability to overcome the difficulties associated with experiencing communication barriers on a daily basis depends on an individual person's strategies of dealing with them and their outlook on life (Griggs, 1998).

In order to understand the limited legal rights of Deaf people in the UK it is essential to understand Deaf people's struggle over hundreds of years to obtain equal status and recognition and in particular the discrimination against Deaf people who use sign languages. The Milan Congress (2<sup>nd</sup> International Congress on Education of the Deaf (ICED)) held in 1880 resulted in educational policies in the UK that banned the use of sign language in the majority of educational settings for deaf children. It was claimed that d/Deaf children should be taught to speak and hear in order to 'fit in' with society and become 'normal'. This was a result of the medical model influencing the perspective of the delegates who attended the Congress. Furthermore, there was an assumption at the time that the use of sign language would restrict the development of spoken language. Although it is acknowledged that sign language has been used in some educational settings since then (dependent on the particular school or local education policy), it is only recently that there has been an acknowledgement that the ban on sign language in schools imposed by 1880 Milan Congress was unacceptable. At the 2010 21<sup>st</sup> ICED, in Vancouver, Canada, the detrimental effects of the Milan 1880 Congress were acknowledged and this resulted in the rejection of all the resolutions that had been made in relation to the exclusion of sign language in educational settings for d/Deaf people (Rogers, 2010).

Under the Equality Act 2010, which applies to England, Wales and Scotland, Deaf people are regarded as disabled, rather than a linguistic minority group. The Act states that organisations have a duty to make reasonable adjustments to meet the needs of an individual. However, the term 'reasonable adjustment' is open to interpretation. For example, one could be offered subtitles on video material, yet these may not be fully accessible for a Deaf person whose preferred language is BSL.

### **3.3. Non-signing deaf people**

As previously stated, there are some deaf people (who might have similar hearing levels to Deaf people) who do not use sign language. This may be as a result of personal choice or because of a lack of opportunity to meet Deaf people. The fact that the majority of parents of deaf children are hearing (Mitchell & Karchmer, 2004), together with the decline in the number of specialist schools for deaf children has meant some Deaf people may not be offered the opportunity to be part of the Deaf community until later in life (Ladd, 2003).

The integration of disabled children into mainstream settings emanated from the Warnock Report (1978) and was reinforced by the UNESCO Salamanca Statement (1994). Both reflect the social model of disability (Lindsay, 2003). However it can be argued that the needs of d/Deaf children are different to those with a physical disability as deaf children have specific language/communication needs, they do not face physical barriers to access. In 2005, Baroness Warnock admitted that there may have been some confusion following the Warnock Report (1978) and acknowledged that inclusion in mainstream settings was not suitable for all children (Warnock, 2005). This was further acknowledged at the Education and Skills Committee meeting who stated: "It is also important to remember that specific groups view separate schools as a more effective route to inclusion, and as a means of maintaining cultural and linguistic identity, such as within the Deaf community." (House of Commons Education and Skills Committee, 2006, p. 134).

### **3.3.1. *Type of schools and mental health outcomes***

There are mixed findings in studies of mental health outcomes of deaf children/young people dependant on the type of schools they attended (mainstream school or deaf school). Hindley (1993) reported that those d/Deaf people who attended mainstream school have poorer mental health in comparison to those who attended deaf schools. However, Van Eldik (2005), who included hard of hearing pupils as well as deaf pupils in the sample, reported that young people at deaf schools had a higher prevalence of mental health problems compared to those who attended mainstream school or hard of hearing schools. What is not clear is whether there were any d/Deaf pupils in the mainstream school that took part in the study. Without both d/Deaf and hard of hearing children in the study, it would be difficult to make comparisons. Both Van Eldik (2005) and Hindley (1993) conducted the study when deaf young people were still at school. Whilst it is acknowledged that Van Eldik (2005) modified the assessment into plain English, it could be argued that this would remain a problem for those with poor literacy skills and that this may have affected the results. Although in Hindley's study (1993) validation assessment was used, there are again some findings that should be taken with caution; for example some of the 'parents' reports were completed by house-parents at the boarding school. In a retrospective study of Bat-Chava (1994), it was found that group identification (amount of d/Deaf friends and level of involvement with the Deaf community) moderated the effect resulting

from the type of school attended on self-esteem. That means that if the Deaf person identified more strongly with their peer group, then there is less association between the type of school they attended and their self-esteem. It is therefore suggested that a key factor in the development of self-esteem is whether an individual feels that they identify with their peer group and whether they feel that they are part of the community.

### **3.4. Identities in transition**

The definition of identity has been raised in academic discussion (Kroger, 2007). There are two main types of identity; social identity (which defines the self as part of group identity) and personal identity (Hogg & Vaughan, 2002). For example, deaf people from hearing families who first encounter the Deaf community later in life, may start to explore what it means to them to be a d/Deaf person (Valentine & Skelton, 2003) and depending on the individual's situation, they might experience identity confusion. Identities do not always remain fixed however, as they sometimes change throughout one's life and can depend on the situation, this is known as situated identity (e.g. a deaf person may be experienced differently by others when with hearing families or at their place of work; they may also emphasise or de-emphasise different facets of their identity depending on situation and context).

For many years Deaf adults have advocated for Deaf children to be taught together as there is a belief that this will promote a positive sense of identity and pride (Ahmad et al., 1998). In many ways the needs of a deaf child are different to those of a physically disabled child, for example if a hearing child who is a wheelchair user is placed in a mainstream setting, the school would ensure that there is a ramp available to ensure that the child can access the building. However, for a d/Deaf child (who might be the only deaf child in a school), there are communication barriers both inside and outside the classroom and because of this they are very likely to experience a feeling of isolation (Oliva, 2004).

We know that meeting d/Deaf adults can be advantageous for both deaf children and their families in terms of the development of positive attitudes toward Deaf people (Mohay, Milton, Hindmarsh, & Ganley, 1998), resulting in parents feeling more able to parent their deaf child (Hintermair, 2000), learning more sign language (Takala, Kuusela, & Takala, 2000), and improving communication

competence (Watkins, Pitman, & Walden, 1998). However, the inclusion of d/Deaf adults as part of the professional teams working with deaf children and their families is rare in the UK (Rogers & Young, 2011).

Both family and educational experiences influence the development of a d/Deaf person's identity as they grow up (Leigh, 2009). Some people identify themselves as bicultural, i.e. having some degree of affiliation with both Deaf and hearing people (dependent on the social context) and as bilingual, i.e. using both sign language and English language (whether it is in written and/or spoken form). For some deaf children, it is not until adulthood that they meet d/Deaf adults for the first time. They may also acquire sign language at this time. A deaf child's perception of being deaf and of their identity may therefore be very different from how they perceive themselves as an adult. An adult's perception of being deaf and their sense of self may be affected by, for example, exposure to Deaf people, Deaf community and sign language.

#### **4. Inequality issues in d/Deaf populations**

It is widely known that d/Deaf people experience inequality, for example, in education, employment, and health. The main reason for such inequality is due to the communication difficulties between d/Deaf and hearing people and a lack of access to information and services. In comparison to hearing people, the median reading age of a d/Deaf school leaver is approximately 9 years old (Conrad, 1979; Traxler, 2000) and unemployment for d/Deaf people is about four times higher than the hearing population (RNID, 2003). In studies of hearing populations, it is known that there is a relationship between being unemployed and mental health difficulties (HM Government, 2011). d/Deaf people also face barriers accessing health services (Alexander, Ladd, & Powell, 2012; RNID, 2004) because of communication difficulties, lack of knowledge and feelings of isolation and stigma which can be compounded by the attitude of health professionals ("Disability: Beyond the medical model", 2009). Experiencing inequalities, in turn, may have an effect on a d/Deaf person's mental well-being (Fellinger, Holzinger, & Pollard, 2012), because for example they may experience delay in getting the right support in place and this may compound the problem and create additional stress.

## **5. d/Deaf people and mental health**

d/Deaf people of all ages experience poorer mental well-being in comparison with hearing people. As previously mentioned, it is known that d/Deaf people are more likely to experience inequity in employment, lower educational achievement, social exclusion, lower socio-economic status, difficulties in communicating, and are more likely to experience physical, emotional and/or sexual abuse (Kennedy, 2000; Kvam, 2004). All of the above factors have been found to impact on mental well-being outcomes in hearing populations. The cohort of d/Deaf children studied by Hindley (1993) provided the first available evidence of the prevalence of psychiatric disorder<sup>4</sup> within these populations. However, the d/Deaf young people in Hindley's study who were classified as likely to have a psychiatric disorder were not offered treatment at the time because no suitable services were available. It is common for mental health services not to be accessible to d/Deaf populations. At the time of the original study, there were no mental health services appropriate for d/Deaf children; the first d/Deaf children's mental health service was set up as a result of the findings from Hindley's study.

Hindley (1993) had used the term 'psychiatric disorder' to refer to specific diagnoses using DSM-III (American Psychiatric Association, 1980). The terms 'mental health problem' or 'mental health disorder' are now widely used and accepted terms within the NHS, rather than the term 'psychiatric disorder'. The disorders identified by Hindley (1993), and the term 'psychiatric disorder' itself, may have had different connotations at the time of the study by Hindley (1993), particularly as he included people with general mental health difficulties rather than only those who had a specific diagnosed 'psychiatric disorder'. In the context of mental health, service users believe that policies and practice are still dominated by the medical model (Beresford, Nettle, & Perring, 2010). The term 'mental health problem' might also be perceived to be negative but not as negative or stigmatising as the term 'psychiatric disorder'. Mental health is only one aspect of overall well-being and can be positive or negative. For the purposes of this thesis, the term mental well-being will be used unless otherwise specified.

---

<sup>4</sup> Hindley (1993) used the term psychiatric disorder to describe disturbed children whether be it an emotional, social interaction, or behavioural problem.



### **5.1. Access to mental health services**

Although improved access to mental health services has been a Government priority in recent years, this has not been extended to d/Deaf people. There are numerous reasons for this, in particular the financial implications of providing accessible services i.e. it is more expensive to provide services for d/Deaf people than to provide mainstream services (Department of Health, 2002). Inadequacies of mental health policies for d/Deaf people have come to light as a result of the *Inquiry into the Treatment of Daniel Joseph* (Mishcon, Sensky, Lindsey, & Cook, 2000). Daniel Joseph is a Deaf person with a history of mental health problems who attacked two women, one of whom died as a result of the assault. The treatment and care of Daniel Joseph was subsequently investigated and findings published. The report made recommendations on appropriate care and treatment for d/Deaf people. The Equality Act 2010 and policies such as the public sector Equality Duty, 2011, (section 149 of Equality Act 2010) should also go some way to promote improved access to health services for members of the Deaf community.

Accessing support from mental health services is difficult for many sectors of society including BME groups and older people (Department of Health, 2009; HM Government, 2011a). However, despite this, support for the hearing population in relation to mental well-being is more likely to be available than for d/Deaf populations. This can be attributed to communication barriers and a lack of knowledge about d/Deaf people by professionals (Fellinger et al., 2012). For those d/Deaf people who are also from other minority groups, or who are older, the difficulties in accessing support are likely to be further compounded. Hearing people can access support via local services, or participate in activities that promote their well-being. Care pathways to support mental well-being difficulties include primary, secondary and tertiary care services. Culturally appropriate mental health services for d/Deaf people are limited (Emery, 2008). There are particular concerns about the accessibility of primary care services. Primary care service professionals may fail to recognise the early symptoms of some d/Deaf people's mental well-being difficulties (Department of Health, 2005). Additionally, whilst there are some secondary and tertiary level services in place specifically for d/Deaf people experiencing mental well-being difficulties, there are far fewer of these in primary care. Despite the lack of access to primary care, the prevalence of the common mental health problems in d/Deaf populations is higher than that of

hearing populations (Kvam, Loeb, & Tambs, 2007) and better provision of primary level care services for d/Deaf people could assist in promoting their mental well-being.

## **6. Concept of mental well-being**

The concept of what constitutes well-being remains an on-going debate amongst academics and professionals working within the field of mental health. However, the current definition (that will be accepted for the purpose of this paper) defines well-being as how one evaluates oneself in terms of 'physical, mental, social and environmental status, with each aspect interacting with the other and each having differing levels of importance and impact according to each individual' (Kiefer, 2008, p. 244). It is often linked with the conceptualisation of 'the good life' (Carlisle & Hanlon, 2008, p. 265), although this is relative to the situation and life experiences of a person. It is of note that the concept of well-being may differ across ethnic groups (Sonnentag & Fritz, 2007), and age (children/parents) (Bullinger, Schmidt, Peterson, & Ravens-Sieberer, 2006).

Definitions of well-being have been developed within the general population; that is, the hearing population. However, between November 2010 and April 2011 there was a debate on measuring national well-being with the aim of finding out what matters to people in the UK (Evans, 2011). d/Deaf people were included in this debate, and that they raised a number of themes "Again, much of the discussions concerned the importance of family and friends, health (physical, mental and emotional), money, employment and education. However, the issue of equality was raised many times" (Evans, 2011, p. 23). An example of the quotes given included:

- "The hearing community could learn something about tolerance from the deaf community"
- "Better communication [in British Sign Language] would reduce our stress levels"

Aspects of well-being in d/Deaf populations may differ from those of the hearing population because the life experiences of d/Deaf people are likely to differ from their hearing peers. Deaf people are not only different to hearing people by virtue of using a different language, but also in their way of thinking, particularly as Deaf people are visually oriented beings (Hauser, O'Hearn, McKee, Steider, & Thew,

2010). Deaf people are more likely to face communication barriers (Parasnis, 1996), discrimination (Ladd, 2003) and difficulty in accessing health services (Wallhagen, Strawbridge, Shema, Kurata, & Kaplan, 2001) compared to their hearing counterparts. Subsequently, they have different life experiences which could influence their emotional experiences and self perceptions.

The causes and/or effects of well-being have been explored in past studies. Studies have attempted to identify predictive factors in well-being outcomes. These factors include personality characteristics (Landau & Litwin, 2001), genetics (Røysamb, Harris, Magnus, Vittersø, & Tambs, 2002), and self-complexity (McConnell, Strain, Brown, & Rydell, 2009). The relationships between well-being and various factors have also been explored in past studies; this may include social support and locus of control (Landau & Litwin, 2001), perceived discrimination (Fujishiro, 2009), and burnout (Milfont, Denny, Ameratunga, Robinson, & Merry, 2008) for example.

Various issues encountered in d/Deaf populations may affect well-being. This may include issues such as communication and access barriers; feelings of exclusion and/or lack of a sense of belonging within communities; and/or having a poor sense of one's own identity.

## **7. Conclusion**

This chapter has addressed the main issues which underpin the subsequent studies in this thesis. Consideration has been given to terminology, models of deafness in addition to issues such as exclusion and discrimination. The significance of communities, identities, culture, and language has also been discussed in order to emphasise those factors which may affect the mental well-being of a d/Deaf person. Inequalities between d/Deaf and hearing people have been highlighted, particularly in relation to access to mental health services. These discussions go some way towards portraying an understanding of the factors which have an influence on the mental well-being outcomes of a d/Deaf person and why it was felt important to give the matter further exploration. The following chapter describes the methodology used and will take account of the above factors when researching d/Deaf populations.

## **CHAPTER THREE: METHODOLOGY**

### **1. Overview**

The methods employed in each of the three studies contained within this thesis are outlined in the corresponding five publications (paper A, paper B, paper C, paper D and paper E). This chapter therefore takes a broader view by considering the justification for the research methods that were used and their combination within the overall research design. It also focuses on specific issues which have arisen and which cut across the various studies. In this respect, five key issues will be discussed: issues whilst conducting research with d/Deaf people; longitudinal cohort study; ethics; translating mental health assessments into BSL and collecting data remotely.

### **2. Aims and objectives of the study**

As previously stated, the association between mental health difficulties in childhood and well-being in adulthood amongst d/Deaf populations has been little explored. Little is also known in relation to how well the standardised mental health assessments can be used with d/Deaf populations. Therefore, the research aims and objectives were as follows:

Aims:

- i. To gain an understanding from the literature of the association between mental well-being in childhood and later adulthood outcomes in d/Deaf populations;
- ii. To establish how well the standardised mental health assessments can be used with d/Deaf populations; and
- iii. To gain an understanding of d/Deaf people's perceptions of their own mental well-being since leaving school, and their view about the risks and protective factors in the pathway from childhood to adult well-being for d/Deaf people.

Objectives:

- i. To examine the literature in order to understand the association between childhood and adulthood mental well-being outcomes in d/Deaf populations;
- ii. To translate four standardised mental well-being assessments into BSL;
- iii. To test the reliability of the CORE-OM (in BSL and English) with d/Deaf populations;

- iv. To validate the BSL mental health assessments in British Sign Language;  
and
- v. To explore Deaf people's perspectives on their mental well-being since childhood and to examine how this relates to their adulthood mental well-being outcomes.

### **2.1. Research design of this study**

Little is known about how the factors that are associated with d/Deaf people's childhood experiences may influence their mental well-being outcomes in adulthood. Despite research relating to mental health and d/Deaf people, there is, in essence, no knowledge of the pathways between childhood to adulthood in d/Deaf populations which may influence mental well-being (see Paper A for a Signall chapter which contains a review of the current state of knowledge).

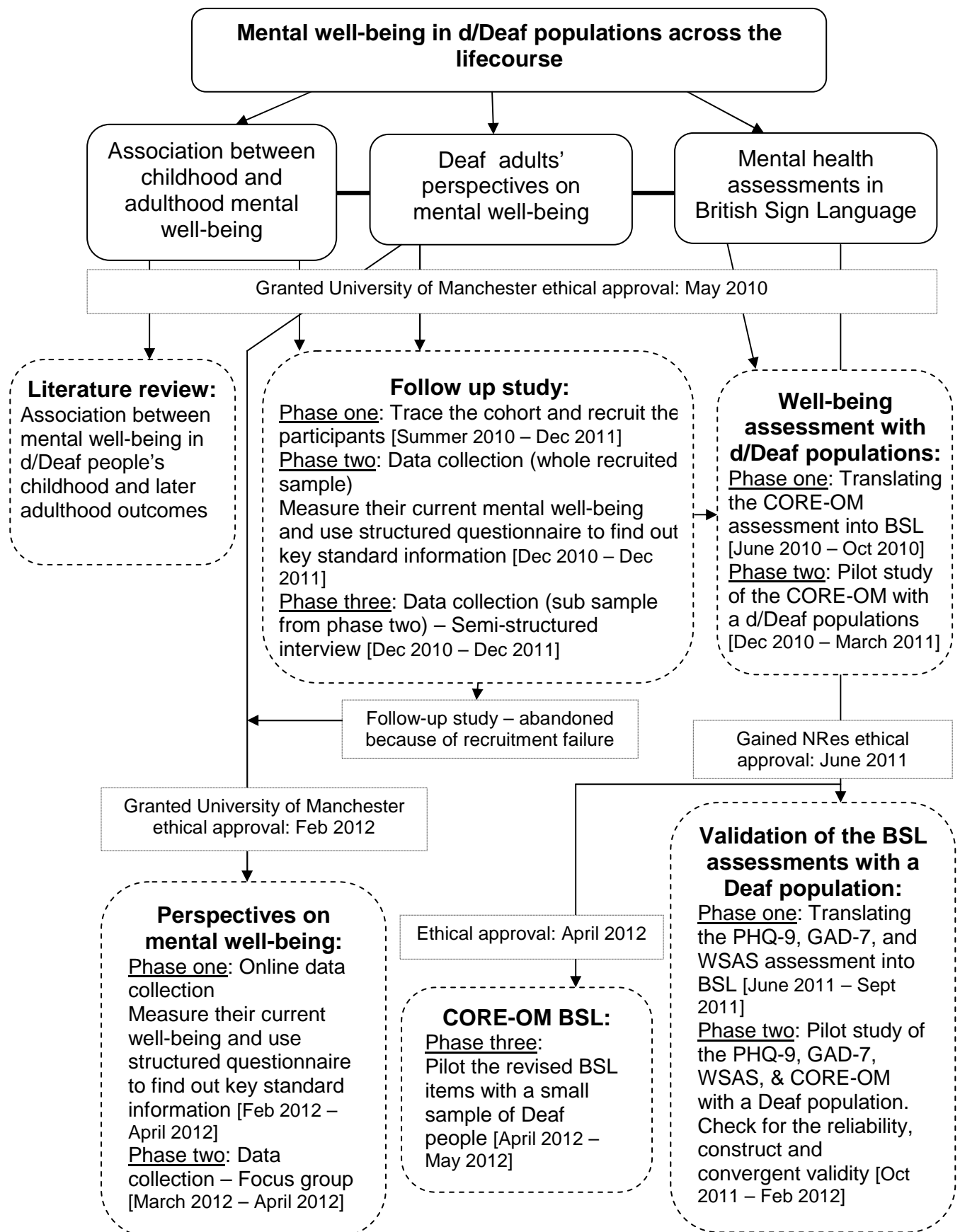


Figure 1. A diagram of the route map of the overall work

The original proposal was to conduct a long-term follow-up study of the mental well-being outcomes of a cohort of 81 d/Deaf young people who had been studied

by Hindley (1993) in 1988. At the time of Hindley's study the d/Deaf young people's ages ranged between the ages of 11 and 16 years of age. The original intention was to ascertain the original participants' current well-being and to explore their life course events.

Hindley (1993) set out to determine the prevalence of mental health difficulties in deaf young people as this had previously never been established. At the time this was the most comprehensive study that had ever been undertaken in the UK and its results remain well cited nearly 20 years later. d/Deaf young people were recruited from four different schools in a borough of London; one deaf school and three Partially Hearing Units (PHUs) (see appendix 1 for a critique of that study). In total, 81 young d/Deaf people had taken part and the study concluded that the prevalence of mental health problems among d/Deaf young people was estimated to be between 43.2% and 50.3%.

The original, unique data set held baseline records on the 81 d/Deaf children, containing an assessment of their mental health and the factors contingent to that state. The assessments that had been used by Hindley were Rutter A(2) and Rutter B(2) (Rutter, Tizard, & Whitmore, 1970), the Teacher's Checklist (TCL) and Parent's Checklist (PCL) (both developed by Hindley, 1993), the Child Assessment Schedule (CAS) (Hodges, 1987) for diagnostic interview and the Parent-Child Assessment Schedule (P-CAS) (developed by Hindley, 1993). The original data did not include names or contact details of the d/Deaf young people and/or their families because consent had not been obtained for a follow-up at the time. Although the personal details of the participants in the original study are held securely and separately by St George's Hospital Trust, London, and also at the institution of the original study, these were not accessible to the researcher because of the ethical issues involved. It seemed apparent however that identification of the original participants would be possible (with their consent) by matching the data that was available. The fact that the set of data has the date of birth of each child and also the name of the schools that they had attended would enable the researcher to link the current participants' data to that in the original study. It would therefore be logical to attempt to recruit to the study by asking people to make contact if they had attended these schools in the relevant years and then identify them by matching their profile to the data that was available.

The traced participants would then be asked to complete a well-being assessment (CORE-OM) and a questionnaire (relating to life course and life events) online, with both the British Sign Language version and the English version made available to them. At the start of the study there was no BSL version of the CORE-OM in existence and therefore one of the aspects of the study design was to produce a BSL CORE-OM and to test its reliability and validity prior to its use with the traced cohort. Those traced participants who agreed to be interviewed would be interviewed (phase three), using a semi structured approach, which would aim to guide participants to reflect on their transition from school days to adult life, significant turning points for them, major stresses and pressures, key successes and how they consider their mental well-being to have been over the past 20 years. The intention was to investigate the attributions participants make to their life events and the influences they identify, and how they construct the impact of these on their mental well-being.

In order to ascertain the current well-being of the participants it was decided to use standardised assessment and questionnaire tools including the Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM). However, before this could be achieved, the CORE-OM needed to be translated into British Sign Language (BSL) to make it accessible to the d/Deaf population. Within the research design, it was also planned to conduct a pilot study with the general d/Deaf population in order to check the reliability and validity of the translated CORE-OM. The pilot study was intended to involve participants outside of those in Hindley's original study.

It was considered that a feasible target would be to recruit 60 of the 81 original participants primarily because of the extensive networks which exist in the Deaf community, my own high profile within the Deaf community (as a Deaf person) and the fact that it is common for deaf people to maintain contact with the people that they knew at school. In practice, tracing the original cohort of deaf young people was problematic. This will be explained later in this chapter (see issues on 'longitudinal cohort study'). Despite extensive efforts only 11 people completed the survey and of those, only 2 names matched the details of participants from the original cohort. As a result the follow-up study was subsequently abandoned.



However, the translation and validation of the BSL CORE-OM was retained as a key element of the thesis because at the time there was no reliable way of assessing the well-being of Deaf people in BSL in existence. In addition, the issues surrounding psychological assessments and the well-being of d/Deaf people were expanded to form a more substantial part of the thesis than originally envisaged. This entailed working with IAPT (Improving Access to Psychological Therapies), a national Department of Health Initiative, to produce 3 of the minimum data set standard assessments in BSL namely: PHQ-9 (Spitzer, Kroenke, & Williams, 1999), GAD-7 (Spitzer, Kroenke, Williams, & Lowe, 2006) and the Work Social Adjustment Scale (Mundt, Marks, Shear, & Greist, 2002). In addition, by piloting them on large numbers of Deaf volunteers, the psychometric properties could be examined. Having reliable and validated mental well-being assessments in BSL is a major step forward in understanding the mental well-being of Deaf people.

The first pilot study involved both the BSL version of the Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM) as well as the unmodified English version (see appendix 2 for materials). Those d/Deaf people who agreed to take part were asked to choose one of the CORE-OM versions (BSL or English) (see paper C on the result of the pilot study of CORE-OM). The second pilot study of mental health assessments focused on the BSL versions of Patient Health Questionnaire (PHQ-9), Generalised Anxiety Disorder 7-items (GAD-7), and Work and Social Adjustment Scale (WSAS). A further pilot study was subsequently used to check the convergent validity of the CORE-OM BSL version through the correlation of items in PHQ-9, GAD-7, and WSAS with specific items in the CORE-OM (see paper D on the pilot study of CORE-OM as well as PHQ-9, GAD7, and WSAS) (see appendix 3 for materials). The construct validity of the BSL versions of PHQ-9, GAD-7, and WSAS were also examined. A key outcome of this thesis is the production, for the first time, of four standard mental health assessments for use with the Deaf population, whose reliability and validity have been examined and found to be good (see appendix 4 which has a CD<sup>5</sup> containing the BSL versions of CORE-OM, PHQ-9, GAD-7, and WSAS). These are now available for clinical use with the Deaf population in the UK.

---

<sup>5</sup> The video files in the DVD are labelled as beta copies because the final versions will be re-filmed to improve their quality. The quality of the versions in the beta copies is adequate for the purpose of the PhD and it is unreasonable to wait until the final versions are complete, as they are being produced with different technical requirements, for a purpose other than the PhD.

In order to address the relationship between mental ill health in childhood and adult well-being after the follow up study had been abandoned, a new element was added to the research design. It had been planned to address the question of the relationship between childhood and adulthood outcomes by comparing original data with follow up data generated by the traced cohort; both in terms of mental health assessments and in terms of individual interviews during which participants would explore the connections from a qualitative and personal perspective. However, without sufficient participants from the original cohort, it was not possible to explore the association linked to baseline data on the characteristics of adults when they were children. Nonetheless the intention to invite Deaf adults to explore, in their own terms, the significance of experiences in childhood for their adult wellbeing could be undertaken albeit with groups who were not part of the Hindley cohort.

Therefore, 27 Deaf adults were recruited to four focus groups with the aim of exploring how d/Deaf individuals make sense of their current well-being in terms of their childhood experiences (see appendix 5 for materials). They were asked what their perceptions were of risk and protective factors for mental well-being outcomes in d/Deaf populations, as well as how they relate their childhood experiences as a d/Deaf child to their later adult well-being (see paper E which reports the results of the focus groups). Each participant's well-being was measured using the BSL CORE-OM (see appendix 6 for descriptive statistics of the scores on CORE-OM and TEIQue-SF from the focus groups' participants).

This study has aimed to broaden knowledge relating to mental well-being in d/Deaf populations. This includes Deaf people's own perceptions of mental well-being and incorporates an understanding of how standardised mental health assessments are best used with d/Deaf people. In order to achieve this, three separate but inter-related studies were undertaken on d/Deaf populations' mental well-being across the lifecourse, which in turn produced five output papers [Papers A, B, C, D, and E]. Initially, this involved establishing reliable and valid mental health assessments with the Deaf population, and subsequently setting up focus groups with Deaf people to gain their perspectives on mental well-being. These two elements were not dependent on each other but were designed to yield complementary components of an investigation into d/Deaf people's mental well-being. That is to

say, whilst the study uses both quantitative and qualitative data collection strategies, it is not a mixed methods study in which one study was designed to yield results which influenced the design of the next study. A literature review exploring the pathways between d/Deaf people's childhoods and adulthoods was also carried out (see Paper A). This set the baseline for what was known specifically about the relationship between childhood and later mental well-being, rather than d/Deaf people's general mental well-being. The various parts of the research design (see Figure 1) did not test out hypotheses generated from this literature review, but addressed specific gaps in the evidence base, paying attention to the knowledge that would be needed to develop a better understanding of d/Deaf people's well-being in the future. For example, papers from the studies on mental well-being assessments with d/Deaf populations were produced, covering: the challenges of translating mental health assessments into BSL (Paper B), the reliability of the CORE-OM with d/Deaf populations (Paper C), and the reliability and validation of mental health assessments with the signing Deaf population (Paper D). The findings from the focus groups with Deaf people were produced in Paper E. They are presented in their own right to acknowledge the significance of cultural variations in understanding mental well-being, and to highlight how d/Deaf people's experiences shape that understanding. These insights contribute to the discussion of the cumulative significance of all aspects of the study design, their results and implications in Chapter 9.

### **2.1.1. Recruitment strategies employed in these studies**

The participants were recruited in different parts of the studies. Below are the details of recruitment strategies that were employed for each part of this study. For each study, the information was available in printed format (information sheet) as well as in BSL (in person and via the videos on the project website).

#### **2.1.1.1. Follow up study**

A mail shot (both in printed and in electronic form) was sent out to schools, to Deaf communities (including known ex-pupils) and Teachers of the Deaf with the aim of tracing the original cohort members. Adverts were placed in magazines (e.g. BATOD and BDA) as well as on various organisations' websites. Talks were given at various Deaf clubs, including those in London and also Deaf health forums. Individuals were invited to identify themselves to the researcher if they thought that they had taken part in the original study. It was not permitted for a secondary

person to inform the research study of the names of any individuals they believed had been participants.

#### **2.1.1.2. *Well-being assessment with d/Deaf populations (CORE-OM)***

Recruitment to this study happened through distributing information through the Deaf Community using various networks. Adverts requesting participation were placed on websites such as the British Deaf Association (BDA), Royal Association for Deaf People (RAD), etc., as well as in Deaf-related magazines and through social networking sites. Talks about this study were given at various Deaf clubs in the England, Deaf health forums, and to Deaf students in education settings. The aim was to reach as diverse a population as possible by targeting forums and locations that were likely to be used by Deaf people of differing ages and backgrounds.

#### **2.1.1.3. *Validation of the BSL assessments with a Deaf population***

The recruitment strategies for this part of study were similar to 2.1.1.2., but different Deaf clubs across England were targeted. Nine NHS trusts in England were also approved as recruitment channels under governance arrangements subsequent to ethical approval. An explanation about the study including seeking potential participants also featured in the Deaf magazine programme on the BBC 'See Hear'.

#### **2.1.1.4. *Perspectives on mental well-being***

The advertisements for seeking participation in the focus groups were created and given to various d/Deaf organisations as well as key Deaf members who agreed to assist in disseminating the information about this study to as many d/Deaf people as possible. Information about how to get involved in a focus group was also placed on this study's website.

The total number of participants who provided complete data for each part of the studies were as following: follow up study (n=2), CORE-OM study (n=47 who did the BSL version, and n=69 who did the English version), phase three of the CORE-OM study (n=37), validation of the BSL assessments study (n=113), and perspective on mental well-being study (n=27). There were a few participants who did, for example, both the CORE-OM study and the validation of the BSL assessments study, but this does not affect the overall study's results because

each component part of each study had different aims and therefore it was not necessary to prevent people taking part in more than one element of the study.

### **3. Ethical approval**

The ethics application for this study was reviewed by the ethics committee of the School of Nursing, Midwifery and Social Work at The University of Manchester and provisional approval was granted (Ethical Approval Number: 10/1040/NMSW). The pilot of mental health assessments of PHQ-9, GAD-7, WSAS and CORE-OM in BSL, was approved by National Research Ethics Service (NRES Committee Yorkshire and The Humber – Leeds West; REC number: 11/YH/0180) (see appendix 7 for the approval letters).

### **4. Justification of the research methods used**

Papers (B, C, D, and E) provide details of the research methods used in each element of the study. This section addresses (i) the justification for the choice of measure of well-being; (ii) the perspective of Deaf adults on mental well-being and their retrospective exploration of the connections between childhood and adulthood.

#### **4.1. Perspectives from d/Deaf people on mental well-being**

One way to obtain access to people's perspectives and experiences and to understand their meanings of concepts is to use qualitative approaches. The nature of reality (ontology) and the nature of knowledge (epistemological) may be perceived differently according to people's belief systems. There are various epistemological positions such as positivism, empiricism, hypothetico-deductivism, and social constructionism (see Willig, 2001, for review). Social constructionism for example is concerned with how the same experience may be perceived differently across people. This "suggests that there are 'knowledges' rather than 'knowledge'" (Willig, 2001, p. 7). Empiricism on the other hand argues that knowledge comes from facts of experience. Researchers from different epistemological positions may have different perspectives on how research should be carried out and in turn this can affect the interpretations made from the data analysis.

Harris, Holmes and Mertens (2009) for example, demonstrate how unfamiliarity with sign language and Deaf culture will result in a different understanding of what is reality when standardised tests were to be used with d/Deaf people. Stinson

argued however that: “a researcher who carefully and judiciously employs quantitative methodologies can be every bit as sensitive to the perspectives of other cultures and the knowledge yielded can be just as valuable” (1994, p. 18), be it from an ‘outsider’ perspective.

Goertz and Mahoney (2012) stated that the differences between qualitative and quantitative approaches are related to ontology and epistemology, not the methods which are employed. For example, quantitative approaches would seek an indicator-latent variable to identify what has the relationship with the latent variable because ontologically, reality is present, it merely needs identifying and measuring. Whereas qualitative studies might use a semantic approach because ontologically reality is constructed and its meaning requires exploration and definition. Coolican (2004) comments that most qualitative approaches are “embedded in a consciously selected epistemology” (Coolican, 2004, p. 559). Murphy, Dingwall, Greatbatch, Parker and Watson (1998) discussed the relationship between qualitative and quantitative approaches and stated that any ontological and/or epistemological positions are not necessarily fixed to particular qualitative research. In the context of concepts and measurements, Goertz and Mahoney (2012) state:

One can think of the two approaches in the terms of differing emphases on concepts versus measurement. Qualitative scholars focus on concepts but do not think much about measurement models or how to aggregate defining dimensions. Conversely, quantitative schools focus their attention on measurement, and devote less attention to concepts. (Goertz & Mahoney, 2012, p. 208-9).

In studies where the outcome factors are of interest, quantitative approaches alone might not be sufficient. Although a quantitative approach might show the link between a variable (A) and the outcome measure (B), it does not say how the process was achieved from (A) to (B). As Murphy et al. (1998) summarise:

Statistical analysis may conceal as well as reveal social processes. While outcome studies can establish a link between intervention and outcome, they are less able to explain the process by which the intervention was translated into that outcome. It is these dynamic aspects of health technology that qualitative research is best able to illuminate. (Murphy et al., 1998, p. 88)

Quantitative approaches alone do not provide an in depth perspective of individuals' mental well-being. In the context of mental health, d/Deaf people have often been described as having greater mental health difficulties in comparison to the hearing population because much of the understanding of d/Deaf people's mental health has emerged from quantitative studies which reduce a person's experience to a number or score. Murphy et al., (1998) state that qualitative approaches are useful when people have "questions about processes rather than outcomes or where quantitative research has thrown up puzzling results or identified deviant cases that seem to do much better or much worse than the population norm" (Murphy et al., 1998, p. 3).

Therefore, if we are to understand the mental well-being of d/Deaf people then it is necessary to take into account how they make sense of the world around them and how they perceive it relates to their mental well-being, not just to measure it. Little is known about how d/Deaf people perceive their own mental well-being and what they consider to be the important things in their life course that contribute to well-being outcomes in later life. Consequently, in order to gain Deaf people's perspective on mental well-being, focus groups were set up across England (see paper E for the details of this study) with the intention of gaining qualitative data.

There are an increasing number of research designs that involve using mixed methods of research (Kettles, Creswell & Zhang, 2011), i.e. which use both qualitative and quantitative approaches to collect and analyse data. Kettles et al. (2011) describe four main research designs: convergent parallel (this involves collecting qualitative and quantitative data on the same topic); embedded ("which one set of data affords a secondary or supporting role in a study where the other data is the primary data type" (Kettles et al., 2011, p. 538)); explanatory (this method involves two parts, for example one part involves quantitative data collection and at a follow-up qualitative data is used to gain a better understanding of the first data); and exploratory design (different approaches to the collection of data in two parts). According to Kettles et al. (2011) the issues of timing, weighting and mixing, need to be considered. Timing might relate to whether the different methods of collecting data should be used simultaneously or consecutively, and weighting considers which approach is given more emphasis or whether they are both equal. Strategies for mixing data are; to merge, embed or connect the data with each other.

Although in this part of the study a qualitative data approach (by means of focus groups) was used to ascertain Deaf people's perspective on mental well-being, a quantitative approach was also used to measure the mental well-being of the participants (see appendix 6 for descriptive statistics of the score on the mental well-being of the focus groups' participants). This is outlined in figure 1 of the research plan for the whole project and in paper E.

A focus group involves group discussion on specific topics with a small number of people as a way of collecting qualitative data (Wilkinson, 2003). For this study, the focus groups were considered to be preferable to conducting individual interviews because they allow interaction between participants and the opportunity for participants to contribute their views without feeling that the process is too intrusive - which may be the case in one-to-one interviews. Willig (2001) considers the strength of the focus group to be "its ability to mobilize participants to respond and comment on one another's contributions. In this way, statements are challenged, extended, developed, undermined or qualified in ways that generate rich data for the researcher." (Willig, 2001, p. 29). This is particularly the case for d/Deaf people who may previously have had limited opportunity to discuss this specific topic due to the communication barriers in conversations faced on a day to day basis. Focus groups are given the opportunity for d/Deaf people to collectively share ideas and experiences in a way that they may have never had chance to do before.

#### **4.2. Measuring mental well-being**

The justification for why it was deemed necessary to establish the mental well-being of a specified cohort of d/Deaf people, and the psychometric properties of the assessments of mental well-being are detailed in the pilot study of CORE-OM with d/Deaf populations and validation of the BSL versions of CORE-OM, PHQ-9, GAD-7, and WSAS. Details of the research methods used are also covered in these papers (see three papers: B, C and D).

##### **4.2.1. *Well-being assessment***

One way of identifying the difference in the quantity of the variable of interest across individuals is to measure the data in numerical terms. Whilst items in the



assessment may be in the form of descriptive statements, these can be translated “into numerical estimates of severity, and once this is done they may be combined into an overall score, termed a ‘health index’” (McDowell & Newell, 1987, p. 19). It is usual for there to be, as a form of assessment, scales in the tests which enable an individual score on the variable to be assessed (Robson, 2002).

A questionnaire format is one way of getting participants to self-report. However, there are disadvantages to using questionnaires as a means of assessment, namely that participants might not answer truthfully and may provide what they perceive to be socially desirable answers. Some questionnaires force people to choose from the available answers (forced-choice technique) (Anastasi & Urbina, 1997) and this may not necessarily fit with their view. It was considered that in this particular study, it would be advantageous to use questionnaires as then the internal consistency of the assessment items could be checked to see how well they correlate with each other. Additionally, self-report of rating of health is essential, as Bullinger et al. (2006) state, “since the quality of life is a subjective perception, it should also be assessed in self report and through the patients’ perspective.” (Bullinger et al., 2006, p. 353). It is always important to ensure that assessments are consistently revised as they are highly sensitive to bias from cultural, class and other social factors, and therefore need to be standardised for reliability and validity. Comparing an individual’s score with scores from the same population that have been standardised is known as ‘norm referenced’.

Self-report assessments are commonly used within the health service, for example, in IAPT services, to routinely record outcome measures (Department of Health, 2011). The rationale for selecting a self-report assessment rather than a clinician rated measure within this study was that this would enable participants to evaluate themselves and their feelings; additionally, it can allow them to remain anonymous when the data is used for research purposes. Diener (1994) reported that the self-reported measures of well-being appeared to be satisfactory in terms of reliability and validity.

#### ***4.2.2. Deciding which assessment to use to measure mental well-being***

There are a number of issues to consider when deciding which assessment to use. Firstly, it is important to consider the reliability and the validity of an assessment, and whether it measures all or only particular aspects of well-being;

for example, self-esteem. Reliability of the test refers to the “consistency of the measure at different points in time or across different circumstances” (Howitt & Cramer, 2005, p. 219) whereas validity refers to how well the test measures what it sets out to measure.

However, before choosing which assessment to use, a number of issues need to be considered:

- The concept of well-being;
- The psychometric properties of the well-being assessment;
- Is there a validated version of the assessment in the language of the particular population that the researcher is interested in? If not, can it be translated into another language in a reliable way?
- Is it culturally appropriate?

#### **4.2.3. *Measuring well-being***

It has been argued that psychological health is more difficult to measure than other areas of health because of the problems in establishing limits and boundaries as to what constitutes wellness (McDowell & Newell, 1996). Ryff (1995) stated “knowledge of psychological well-being persistently lags behind knowledge of psychological dysfunction” (1995, p. 99).

Ryff (1995) felt that many assessments of well-being lack a conceptual framework. It had been suggested that the most effective way of measuring psychological well-being is to screen for psychological distress however, Uher and Goodman (2010) considered distress as the opposite of well-being. McDowell and Newell (1996) suggest that there are limitations in measuring distress and hence stated that measuring global well-being is necessary in order to examine a more comprehensive measure of distress. They also point out that there are difficulties in the interpretation of assessments and in showing specific boundaries and definitions when using the scales which measure well-being (McDowell & Newell, 1996). Furthermore, assessments of well-being may indicate a negative response but not necessarily the exact nature of the potential difficulty. Some assessments include more than one dimension with the aim of measuring global well-being. Ryff (1995) listed six core elements of well-being as: self-acceptance; purpose in life; environmental mastery; positive relations with other people; autonomy and personal growth. Given this, including measures of both the positive and negative

dimensions of well-being are more likely to provide a better picture of a person's well-being, rather than focusing on the negative aspects alone (Diener, 1994).

Other approaches to measuring well-being are via life-satisfaction questionnaires or by measuring responses to life experiences – however, both of these methods are limited. Using only a quantitative approach to the collection of data on well-being outcomes is not sufficient. Quantitative approaches do not allow for a participant's interpretation, understanding or thoughts on the statement or questions to be explored. When using the Short-Form 36 Health Status Questionnaire, Mallinson (2002) identified a number of problems including the use of double-barrelled questions, use of questions which lead to normative assumptions, making comparisons (for example, to others or to how one used to be before making judgements about oneself) and making assessments of health based on certain characteristics, e.g. age (conceptualising health).

In this study, both quantitative and qualitative methods were used. Focus groups with d/Deaf people were conducted to gain their perspective on their well-being in addition to the data collected from well-being assessments. This allowed the collection of qualitative data in addition to the quantitative data obtained from the assessments tools.

#### **4.2.4. *Well-being assessments***

Initially, a search in the PsycInfo database was undertaken to identify well-being assessments. Combined keywords 'well-being', 'measur\$', 'self-report', and 'valid\$' were inputted and the search was limited to journals written in the English language. Of the 92 hits which were found, there were potentially 6 which related to well-being assessments. These included the Subjective Well-Being Inventory (Sell and Nagpal, 1992), Personal Wellbeing Index (International Wellbeing Group, 2005), World Health Organisation Quality of Life (Skevington, Lotfy, & O'Connell, 2004), General Health Questionnaire (Goldberg, 1972), Psychological Well-Being Scales (Ryff, 1989), and the Clinical Outcomes in Routine Evaluation Outcome Measure (CORE-OM) (Barkham et al., 1998). The mental well-being assessments listed below are all self-report questionnaires (see Table 1 for list of assessments with information) and are described particularly in relation to their suitability for use with d/Deaf participants.

#### **4.2.4.1. Subjective Well-Being Inventory**

Sell and Nagpal (1992) created the Subjective Well-Being Inventory (SUBI), which contains 40 items with 11 domains of well-being from the Indian population: general well-being – positive effects; expectation-achievement congruence; confidence in coping; transcendence; family group support; social support; primary group concern; inadequate mental mastery; perceived ill-health; deficiency in social contacts; general well-being – negative effects. SUBI is one of the main World Health Organisation assessments of quality of life for both national and cross-cultural research. However, a Japanese study identified that when SUBI was translated into Japanese from a factor analysis, only 7 out of the possible 11 domains were identified (Tonan, Sonoda, & Ono, 1995). This may indicate that translating the items into Japanese did not capture four of the domains (expectation-achievement congruence, transcendence, primary group concern and inadequate mental mastery) that had originally been identified in Sell and Nagpal's study (1992). This may be as a result of the different cultural perspectives on the concept of well-being; for example, looking specifically at the expectation-achievement congruence domain, the way in which a person defines success may differ across cultures. There may also be cultural differences in how a person prioritises success in relation to well-being.

#### **4.2.4.2. Personal Wellbeing Index**

The Personal Wellbeing Index was developed in Australia and asks for a measure of satisfaction in 8 aspects of life: standard of living, personal health, achieving in life, personal relationships, personal safety, community-connectedness, future security, and spirituality-religion (International Wellbeing Group, 2005). The Personal Wellbeing Index has been used with different cultural populations, for example, in Algeria (Tiliouine, 2009). However, concerns about cultural differences in perception of the concepts of well-being satisfaction and happiness in Australia and Hong Kong have arisen in a study by Lau, Cummins, and McPherson (2005).

There are two domains in the Personal Wellbeing Index assessment that may not be valid with d/Deaf populations namely: community connectedness and achieving in life. Asking d/Deaf people how much they are satisfied with 'feeling part of your community' is dependent on the social context in which they are living (hearing or Deaf community). This could result in invalidated data if used with d/Deaf populations.

#### **4.2.4.3. General Health Questionnaire**

The General Health Questionnaire (GHQ) (Goldberg, 1972) was designed as a screening tool that could be used to detect minor psychiatric disorders. Studies have also used GHQ to measure the well-being of participants.

GHQ requires respondents to think about their health in the past few weeks, and whether it has differed from their past well-being, therefore GHQ should not be used to establish long-standing attributes of people's health. The GHQ has been used in some longitudinal study research to measure the well-being outcomes of participants (for example; Whittington & Huppert, 1998). However, the GHQ only covers the distress aspect of well-being.

The GHQ has been translated into several different languages. The Iranian version of GHQ-28 was checked for reliability and validity and was found to be sound, and the factor analysis identified the same four domains as Goldberg's version of GHQ-28 (Malakouti, Fatollahi, Mirabzadeh, & Zandi, 2007).

The GHQ has been used with d/Deaf populations both in other countries and in the UK. However, the BSL version is not available, as it has not been checked for its reliability and validity. Researchers in the UK who previously used the GHQ did so by carrying out interviews in person using either BSL or spoken English (Griggs, 1998; Ridgeway, 1998). Fellingner et al. (2005a) also used the shorter version of the GHQ (GHQ-12) as one of the tools to measure quality of life within d/Deaf populations. This was translated into Austrian Sign Language; it was found that the reliability of the translated version was at an acceptable level, but was lower than that of the written version. Interestingly, the scores from those who found the questionnaire difficult to complete had much lower reliability than the scores from those who found it easier (0.49 vs. 0.72). This indicates that for an assessment to be reliable, it is important that participants understand the questions that are asked.

#### **4.2.4.4. Clinical Outcomes in Routine Evaluation Outcome Measure (CORE-OM)**

CORE-OM (Barkham et al., 1998) is a self-report assessment, which aims to audit, evaluate and measure outcomes for mental health services in the UK (Barkham et

al., 1998). It measures global distress and has four subscales of assessment; well-being, commonly experienced problems or symptoms, life/social functioning, and risk to self and others. Some of the items in the CORE-OM have reverse scores. The purpose of the CORE-OM is to compare global levels of distress before and after therapy, but it can also be used for research purposes.

The CORE-OM has been checked for convergent validity and it correlated well with assessments of depression such as the Beck Depression Inventory (Barkham, Mullin, Leach, Stiles, & Lucock, 2007; Cahill et al., 2006) and the Clinical Interview Schedule which assesses for psychiatric illness (Connell et al., 2007). Although CORE-OM was designed for a clinical population, it can also be used with the general population. Connell et al. (2007) recommended a cut-off score of 10 between the general population and the clinical population, with the score range of 0-40 - the lowest score indicating more positive well-being. However, some researchers have used the original scoring which involved the item score averages from a range of 0 to 4 (Evans et al., 2002) (See Paper C on CORE-OM study with d/Deaf people for more details).

#### **4.2.4.5. *Psychological Well-Being Scales***

The Psychological Well-Being Scale assessment was developed by Ryff (1989). Ryff (1989) aimed to include positive aspects of psychological functioning in the assessment, namely self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life, and personal growth. The internal consistency of each subscale ranges from .86 to .93. Kafka and Kozma (2004) subsequently developed this further by identifying 15 factors from their initial factor analysis (rather than six) when examining the construct validity of the Psychological Well-Being Scales.

#### **4.2.4.6. *World Health Organization Quality of Life Questionnaire - BREF***

The World Health Organization Quality of Life Questionnaire - Bref (WHOQOL-BREF) (Skevington et al., 2004) contains 26 items covering four domains; namely physical health, psychological health, social relationships, and environment. The assessment is available in eight languages. Fellingner et al. (2005a), who translated the assessment into Austrian Sign Language, found that the reliability of this was lower in comparison to the hearing population's normative data.

Table 1

Table of assessments with information

Assessment	Author/date	Validity and reliability	Translated into other written	Translated into signed language(s)	British Sign Language version?	Comments
Subjective Well-Being Inventory	Sell and Nagpal (1992)		Yes. E.g. Japanese (Tonan et al., 1995) – only identified 7 of 11 domains.	None available	None available	One of the main WHO assessments
Personal Wellbeing Index	International Wellbeing Group			None available	None available	
General Health Questionnaire (GHQ)	Goldberg (1972)	Version GHQ-30 is the most validated version.	Yes. E.g. Portuguese (Laranjeira, 2008)	Austrian Sign Language (ÖGS) Fellingner et al (2005a)	Been used with d/Deaf populations in UK but BSL version has not been produced.	Screening to identify psychiatric disorder.
Clinical Outcomes in Routine Evaluation Outcome Measure (CORE-OM)	Barkham et al. (1998)	Reliability: Internal consistency of .94 (Barkham et al., 2001).	Yes. E.g. Italian (Palmieri et al., 2009) and Swedish (Elfstrom et al., 2012).		Draft BSL version by Baker et al. (2008) – reliability and validity have not been checked.	Aims to measure global distress including subjective well-being.
Psychological Well-Being Scales	Ryff (1989)	Reliability: Internal consistency of subscales range from .86 to .93. Validity: convergent and discriminant validity with other assessments (Ryff, 1989) Construct Validity: Factor analysis failed to produce six factors as theorised by Ryff (Kafka & Kozma, 2004)		None available.	None available.	
World Health Organization Quality of Life Questionnaire – BREF	Skevington et al. (2004)		8 different written language versions are available.	Austrian Sign Language (ÖGS) Fellingner et al (2005a)	None available.	

#### **4.2.5. Rationale for the selection of well-being assessment for this study**

Following a review of the well-being assessments outlined above, it was decided that CORE-OM was most appropriate for this study as this was the most effective tool for capturing global well-being. Many of the other assessments only capture certain aspects of well-being; for example, the Social Readjustment Rating Scale (Holmes & Rahe, 1967) focuses only on the stresses that people have experienced. Furthermore, the psychometric properties of the translated versions of some assessments have not captured all of the well-being domains in the original versions (e.g. Tonan et al., 1995). The psychometric properties of CORE-OM were found to be good, as they correlated with other assessments of depression and psychiatric illness. The CORE-OM can also detect differences in mental health outcomes between the clinical population and the general population. As a result the CORE-OM was selected as the assessment tool that would be translated for the purpose of this study as a first step towards having a mental well-being assessment that is accessible for d/Deaf people. In the longer term it was recognised that a completely new assessment which is culturally and linguistically appropriate may need to be devised.

##### **4.2.5.1. Using the CORE-OM in this study**

At the initial stage of the study, there were no mental well-being assessments that were available in British Sign Language so the psychometric properties were unknown. This included the d/Deaf populations' well-being norm. Work had previously been undertaken to try to adapt the English version of the CORE-OM into language that is suitable for d/Deaf populations; into plain English (Connolly, 2004) and into British Sign Language (Baker et al., 2008). However, the latter only completed the first stage of translation. Furthermore a back-translation protocol of translating the assessment back into English to check for equivalence in both versions was not utilised. The reliability and validity of this version had also not been checked. It was therefore deemed imperative for this study to carry out a forward and back translation of the CORE-OM and to pilot it within the general d/Deaf populations. The permission and co-operation of the originator, Evans, was secured to carry out this process.



The cut-off score for the CORE-OM in the general population is 10 (Connell et al., 2007). However, because the CORE-OM had not previously been standardised with d/Deaf populations, it was not known what the cut off score would be. In order to determine this for d/Deaf populations, it was essential to ensure the reliability and validity of the British Sign Language version of the CORE-OM, to find out what the norm score is for d/Deaf populations (both clinical and non-clinical), and then compare it with the clinical population and the general population in the study by Connell et al. (2007).

In addition it was also deemed important to establish whether the CORE-OM, in its current form, had any missing domains that are of primary relevance for d/Deaf people. Brooks and Davis's (2007) study had attempted to find out whether domains of the CORE-OM assessment were missing for people with learning difficulties by interviewing a group of such people. They identified that the experience of stigma and discrimination was a missing domain. Consequently interviews (conducted with a sub-sample of the current study) were designed to develop a greater understanding of d/Deaf people's perspectives on well-being and to identify missing domains in relation to well-being.

#### **4.2.5.2. Procedure**

Firstly, the British Sign Language version of the CORE-OM would be checked for convergent validity with another assessment that had been translated into British Sign Language, the TEIQue (Trait emotional intelligence questionnaire). An examination of the convergent validity indicates how well a test correlates with other tests that measure a similar concept. The TEIQue is a self-report assessment which aims to measure 'emotional self-efficacy' which is linked to a "constellation of emotion-related self perceptions and dispositions" (Petrides & Furnham, 2003, p. 40). The TEIQue was chosen because there had been a previous pilot study of a British Sign Language version of the TEIQue (Gascon-Ramos, Young, Petrides, Stone, & Woolfe, 2010). It had been found that there is a relationship between TEIQue and mental health outcomes such as depression (Petrides, Perez-Gonzalez, & Furnham, 2007). It was originally intention for the BSL TEIQue to be included in the follow-up study with Hindley (1993) cohort as a means of establishing convergent validity with the CORE-OM. However, this was not possible because insufficient numbers were recruited to the follow-up study. Instead, convergent validity was checked with other BSL mental health

assessments (PHQ-9, GAD-7, and WSAS) that had been produced during the duration of this study. As the reliability of the CORE-OM British Sign Language version was found to be good (see paper C), the check on its convergent validity with the PHQ-9, GAD-7, and WSAS British Sign Language versions had been made (see paper D).

In conclusion, the content of any given assessments should be developed with a particular population in mind in order to ensure that the assessment covers all aspects that the researcher is interested in, for example, whether they are interested in global self-esteem, or in particular aspects of self-esteem such as self-image. Using an assessment with people from outside the population for which it was developed may not be relevant or appropriate. This may be because of the different life experiences and specific characteristics that are unique to a cultural group which may not have been taken into account during the original development of the assessment tool. If an assessment is to be used with a specific cultural and linguistic minority group, e.g. the d/Deaf populations, a pilot study should be conducted first in addition to collecting qualitative data. This then ensures that all aspects that are relevant to d/Deaf populations are being measured.

## **5. Specific issues arisen**

There is little published on issues concerning methodology and method in studies which have involved d/Deaf people. Beyond the details of methods that are published in papers B, C, D and E and in addition to the details of design covered in section 2.3 in this chapter, other issues of methodological interest have arisen during the course of this study. This section aims to discuss some of these as they have spanned the thesis as a whole and make a contribution to the literature in their own right. They are: researching with d/Deaf people; longitudinal cohort studies in the context of d/Deaf people(s); ethical issues; translating mental health assessments into BSL and collecting data remotely.

### **5.1. Researching with d/Deaf people**

As this study involved d/Deaf people as participants in research, specific issues have arisen. Whilst it is acknowledged that researching d/Deaf people is not new, historically this has been carried out by academics who are not themselves deaf.

This raises issues of power. Importantly, many researchers have been heavily influenced by the medical model of deafness, thus the “dissenting Deaf voice has been pushed aside” (Ladd, 2003, p. 268). Some have tended to conduct research ‘on’ rather than ‘with’ d/Deaf people, and often sought to make comparisons with hearing peers. It has only been relatively recently that there has been a growth in research with d/Deaf people, and in particular involving Deaf people as researchers. The knowledge and the relationship of the researcher with d/Deaf people and their epistemological position are of relevance in this regard. De Clerck (2010) emphasised this: “epistemological theorizing must pay attention to the dynamic historical and sociological context and the linguistic conceptual frameworks that influence the production of science and knowledge” (2010, p. 437). The fact that I am a Deaf researcher carries a number of advantages which will be discussed later in this chapter.

In this section, issues including the aim of the research, who will benefit from it, data collection, the fact that I am a Deaf researcher and how the findings represent what participants have said, will be discussed.

#### **5.1.1. *Benefits and ethics of research with d/Deaf people***

If a researcher wishes to carry out research with a minority culture group, they should firstly consider the aim of the research, its relevance and the benefits that the particular community that is being researched will gain. This thesis is focussed on d/Deaf people’s mental well-being. This is particularly relevant to d/Deaf people because of the higher prevalence of mental health difficulties in d/Deaf populations in comparison with people who are not deaf. It is therefore considered that a greater knowledge of the topic would benefit both d/Deaf populations and wider society as knowledge gleaned from research with a minority cultural group should also contribute to the greater knowledge of diversity within the general population and human development. However, whilst there may be benefits in increased knowledge for wider society, the researcher also needs to consider whether this could be potentially harmful for a particular minority cultural group. An example of this would be genetic engineering research. Pollard (1992) argues that it can be unethical if the research agenda does not offer direct benefits to the particular community that it is researching. However, the definition of what constitutes “doing the right thing” is a matter of perspective (Leigh & Marschark, 2005). Ladd (2003) argued that researching with Deaf people should be “constructed around a culture-

linguistic model” (2003, p. 268). Some past research involving d/Deaf people would be considered today as “ethically abusive” (Harris et al., 2009, p. 106). Researchers must always take into account that what is considered to be the benefit of the research will ultimately depend on the model of deafness from which it is derived. Research from a medical model viewpoint for example, with the focus on the auditory, would consider that the purpose and benefit of their research would be to enable d/Deaf people to fit into hearing society. This in turn might be seen as for the greater good for the greater number of people - known as utilitarianism. Critics of teleological ethics would argue that sometimes acts are not in the interests of the person and that, in fact if costs and benefits are considered this may not be worthwhile. In essence, a researcher may find it hard to be impartial because they have preconceived notions of what the benefits will be. Nonetheless, researchers do have an ethical responsibility to work in the best interest of the target group that they are researching. However, of concern as Harris et al (2009) highlighted, there is a lack of the “voice” of Deaf communities in relation to the ethics of research with d/Deaf people.

The ideology of a researcher who is outside of the culture is also of importance, as it could influence how the d/Deaf people are being represented. As stated earlier, research with d/Deaf people sometimes involves making comparisons between d/Deaf and hearing people. Studies which employ comparative designs often conclude that d/Deaf people have less positive outcomes in comparison with their hearing counterparts, for example in education and emotional well-being. Deaf epistemology arises as “deaf individuals live their lives in a visual reality, which leads to the acquisition of a knowledge base that is different from that of hearing individuals” (Hauser et al., 2010, p. 487). Marschark , Rhoten, and Fabich (2007) stated that “ignoring differences between deaf and hearing children is less ethical, less respectful and far less academically helpful than identifying them” (2007, p. 52). Where differences are identified, researchers should question if this is the result of the research design used, and seek to understand why there are differences. Furthermore, different perspectives might produce different and/or build upon or add to existing knowledge, for example, “deaf epistemologies have looked at old problems from a different angle and contributed to a more appropriate science” (De Clerck, 2010, p. 442).

### **5.1.2. Data collection**

Whilst collecting data from d/Deaf people, it is necessary to obtain demographic information including language usage. This is because of the heterogeneous nature of d/Deaf populations (Young & Hunt, 2011). The authors argued d/Deaf individuals are heterogeneous not only in term of language use but also age of onset of deafness, identity and whether they are members of the Deaf community or not. Those researching d/Deaf individuals should consider the demographics of the participants that are being recruited and whether they are representative of the particular d/Deaf populations they are interested in or not.

Young and Hunt (2011) commented that if a researcher wishes to carry out research with Deaf people whose language is BSL, they would need to think about the accessibility of the research for Deaf participants. Researching this population raises a number of specific issues including how they give informed consent and the anonymity of the data, not only to ensure that the data collection is meaningful but also in relation to ethical issues. It would be unethical to ask participants to take part if they do not fully understand the purpose of the project for example. As Deaf people are visually oriented beings (Hauser et al., 2010), it is essential that the researcher considers how the data should be collected and how the data is interpreted to allow the d/Deaf participants to contribute to the research.

### **5.1.3. Researcher as an insider/outsider of the Deaf community**

There are both advantages and potential disadvantages to engaging a researcher who is Deaf. Young and Hunt (2011) stated that whether the researcher is inside or outside of the d/Deaf populations is relevant to the interpretation of the data (Young & Hunt, 2011). An outsider from the Deaf community may interpret that d/Deaf people lack something which is valued in hearing culture and in doing so they are not taking into account the value of something which is meaningful within that culture (Ladd, 2003).

As a Deaf researcher, being Deaf is helpful to be able to understand what is said, but also to understand the concept of what is being said. Young and Ackerman (2001) gave an example of how Deaf and hearing people might have different concepts of being 'involved'. For Deaf people, the term 'involved' is associated with language and communication. d/Deaf people have experienced a history of oppression from a hearing dominated society and the way in which d/Deaf people

have been devalued in society has resulted in a lack of trust in research among Deaf people. The fact that I am Deaf can mitigate against this to a large degree.

The concern in relation to not taking the cultural and social life of d/Deaf people into consideration when carrying out research has been raised by Deaf researchers (De Clerck, 2010). Researchers outside of the d/Deaf community may not capture what is of value to Deaf people, issues which in turn could contribute to the understanding of the Deaf Gain<sup>6</sup> (Sutherland & Rogers, 2013). With a d/Deaf researcher however participants can feel more confident and build trust with someone who is similar to them (Jones, 2004). However, it is important to take into account that there may also be some disadvantages to using researchers who are d/Deaf for example; the respondents might assume that the researcher who already knows the information and this may result in some things not being said to the researcher. Temple and Young (2004) discussed the potential challenges of the methodological and epistemological issues in the translation of research and argued that this concept can be applied to any researcher regardless of their own identity, their relationship within the Deaf community and whether they know signed language or not. In the context of qualitative research, Emery emphasised that it is “not so much in presenting facts as in presenting an interpretation of the data that can be held up as valid epistemology” (2011, p. 52).

#### ***5.1.4. Issues in relation to ensuring that the findings represent what participants have said***

It is often assumed that where the researcher does not share the same language and culture as the participants, then the use of interpreters solves any language/communication barriers. However, using an interpreter in research has many difficulties (Edwards, 1998). Edwards acknowledged models of research processes where the role of the interpreter is seen as being value free and un-reflexive, ignoring the fact that the presence of an interpreter can change power dynamics. Furthermore, signed languages are visual languages and have no written format. In the academic world, findings of research are usually reported in text format. The issue of how to ensure that the findings in text are representative of what was said in signed languages needs to be given full consideration. For example, a quote from a Deaf signer in written text involves translating from

---

<sup>6</sup> Deaf Gain is a concept which focuses on the positive aspects and to enhance the advantages of being Deaf. For a review of this please refer to Bauman, H-D. L., & Murray, J. M. (2009). Reframing: From Hearing Loss to Deaf Gain. *Deaf Studies Digital Journal*, 1, 1-10.

signed language into English. The researcher working with Deaf people who has knowledge of sign language and Deaf culture can be drawn into taking on a dual role of researcher and translator or if they do not know or are not fluent in sign language they may need to work with a translator. Temple and Young (2004) stated that “the relationships between languages and researchers, translators and the people they seek to represent are as crucial as issues of which word is best in a sentence in a language” (2004, p. 164).

## **5.2. Longitudinal cohort study**

It was initially proposed that the original follow-up study (that was abandoned) would involve a mixture of prospective and retrospective data collection - the prospective aspect being the data from the cohort in the original study, in association with their mental well-being outcomes in adulthood. A planned nested qualitative study was to be conducted by asking a subsample of the cohort about the key events in their lives such as their employment history, education, family life and social life - this would constitute the retrospective data.

As I was not involved in the original research work of Hindley’s study (1993), this in itself raised some difficulties. Kluwin and Morris (2006) describe the difficulties of analysing data carried out by different researchers, such as the differences between operational definitions of particular variables used by the original researcher and the follow-up researcher. As stated earlier, there were also difficulties encountered in tracing Hindley’s (1993) original cohort of participants and as a result it was necessary to rely on recorded information of the original cohort with no names or contact details. As explained in the book chapter for *Signall* (paper A), longitudinal studies involving d/Deaf people have been carried out previously (e.g. Griggs, 1998; Gregory, Bishop, & Sheldon, 1995). The difference between this study and previous studies was that they had information such as the names and the contact details of the original cohorts, whereas this study did not. Furthermore, in 1988 at the time of the original study, it was not planned to do a follow-up study with the original cohort. The identification of the cohort involved matching the date of birth and the name of the school they had attended and as Hill (2004) stated, if the respondents are not aware that they would be tracked, they “may be surprised, suspicious and upset by the tracking efforts” (2004, p. 495). Given the sensitive nature of the topic in Hindley’s (1993)

study, original participants may have been reluctant to acknowledge their previous involvement.

#### **5.2.1. *Tracing plan for the original cohort***

Although it was recognised at the start of the study that tracing the cohort would be challenging, there was good reason to believe it was possible given the closeness of the Deaf community and my own personal links within it. The recruitment strategies used included advertisements and making contact with the schools who had been involved in the original study in order to distribute information about the follow-up study to ex-pupils from the relevant year groups. The information about the study was also made available online in BSL and in hard copy (flyer and information sheet). I visited Deaf clubs in the London area where it was known that some of the pupils from the particular school may attend. Finally contact was made with the people who were involved in the original study such as Hindley (the original researcher) and the teachers of the deaf who had been employed at the time.

#### **5.2.2. *Difficulties of tracing the original d/Deaf cohort***

It was initially hoped to trace and recruit at least 60 people from Hindley's original study. However, this proved to be difficult for a number of reasons. Firstly the identification of most of those people who completed the follow-up study online could not be matched to the original data, with the exception of two cases. The original data from Hindley's study (1993) had already been retrieved from decaying paper copies by Young and Hindley (2004) and had been transferred to a machine-readable format. However this held the date of birth in a different numerical order and some data was missing. Additionally, the majority of the d/Deaf young people in Hindley's original cohort were reported by teachers to have some communication difficulties, therefore they may not have been aware that they were taking part in the research study at the time. At the outset of the original study in 1988 the consent of deaf young people was obtained from parents on behalf of the child and therefore some participants in the original cohort might not have been aware that they were involved in Hindley's study. This may in turn mean that they did not come forward to take part in the follow-up. Some Deaf people were identified who had been born in the year range of 1971 and 1977 and had attended one of the four schools. However when they were approached, none



could recall taking part in the original study and therefore did not feel that it involved them.

Barriers to successfully tracing the original cohort had been somewhat anticipated as a result of the fact that so many of the original cohort potentially had poor mental well-being. As Dunn and Goodyer (2006) note, in their experience, tracing original participants who were not mentally ill at the time of a study was easier than tracing those who were clinically mentally ill (Dunn & Goodyer, 2006). One of the factors contributing to this is people's loss of contact with family and friends. Another study found differences in mental well-being status between those who took part in follow-up studies and those who did not (Fichter, Kohlboeck, Quadflieg, Wyschkon, & Esser, 2009). However, one study reported differences between the childhood mental health of those who were followed up and those who were not was not found (Goldstein, Olfson, Martens, & Wolk, 2006). Fichter et al. (2009) found differences between respondents' and non-respondents' childhood mental health and it is possible that the same situation could occur in this follow-up study of Hindley's cohort of d/Deaf young people. In summary, those who did not take part may have been unreachable because they were possibly receiving psychiatric help at the time or may not have wanted to be contacted.

### **5.3. Ethics**

A code of ethics needs to be adhered to when conducting any research. This section addresses the ethical issues that needed to be considered in general terms throughout the course of this study as well as discussing the particular ethical issues that arose whilst conducting research with a Deaf population. Harris et al. (2009) argued that although most codes of ethics address cultural issues in broad terms, issues arising from undertaking research involving Deaf people have not been specifically addressed. Although Pollard (2002) has raised the issues of anonymity, informed consent and collaborate relationship whilst conducting research with the deaf community, the ethical guidelines available for research with Deaf people in general is sparse.

#### **5.3.1. *Ethics issues to consider***

The potential ethical issues, including the steps proposed to address them, are detailed for each study; i.e. the follow-up study and measuring mental well-being.

### **5.3.2. Follow-up study**

#### **5.3.2.1. Consent issues**

Knowing the names of the children who participated in the original study of Hindley (1993) would be a significant breach of privacy in a milieu where it would be not uncommon to meet some of the original participants in everyday life, due to the close-knit nature of the Deaf community. Additionally, the original consent obtained for the Hindley study took place when these children were minors, thus consent was given by their parents and they may not have been aware that they were involved in the research. Research involving young people nowadays would need to obtain consent from both young people themselves and their parents. Furthermore, no consent was obtained for a potential follow-up study at the time. This was made clear in the information sheet which explained the purpose of the study, as well as ensuring that consent was clearly given for the data linkage and for a possible further follow-up study in the future. The information was made available in both English and British Sign Language.

#### **5.3.2.2. *Participants might not have been aware that they were involved in Hindley's study***

Participants were between the ages of 11-16 years old when the Hindley study was carried out. It is not unusual for there to be communication difficulties between d/Deaf young people and their parents; therefore it is possible that the young people themselves were not aware that they had been involved in the original study. Furthermore, they may not remember that they were involved as they were young at the time.

#### **5.3.2.3. *Participants' access to their data from 1988***

Participants might wish to know whether they had previously screened positive or negative for the likelihood of having a psychiatric disorder, and if so, what sort of disorder (such as depression, a conduct disorder or dysthymic disorder) they may have. Hindley has since said that he only told parents their child's diagnosis if it was severe, therefore not all parents knew the results of their children's interviews and questionnaires. Parents and teachers had not given their permission for the child to have access to the information that had been given at the time therefore it was felt that there was no obligation to provide participants with any information about them. After much consideration, it was thought that knowing the results of the original study would do participants more harm than not telling them.

As I am a member of the Deaf community, I may be put in an ethically compromised position if I were to be able to link the original data with current data in such a way as to be able to know the identity of current participants in relation to their original data. Participants were given a coded identifier by my supervisors (not by myself) to ensure that there was no way of knowing which of the original data belonged to the current participants; only my supervisors would be able to make the data linkages based on participants' dates of birth.

### **5.3.3. *Measuring mental well-being with d/Deaf populations***

#### **5.3.3.1. *Concerns arising from the data collection***

Data collection for mental well-being outcomes were completed by online questionnaires. In the event that an individual was distressed as a result of the question/s being asked in the survey, they would be taken directly to a support page on the website with signposts to appropriate mental health services for Deaf people. Participants who took part in the BSL IAPT translation project were made aware that, should there be concerns about their mental health and other people's safety after they have completed the assessments, their GP would be contacted. If responses to specific items related to risk to self and/or to other(s) in PHQ-9 (No. 1) and/or CORE-OM (Nos. 16, 24, and 34) raised any particular concerns, their GP would be contacted by the research team to let them know that their client had taken part in the study and that this had raised concerns about their mental well-being. The GP was provided with written information of mental health services for d/Deaf people (SignHealth counselling service and BSL Healthy Minds).

### **5.4. Translating assessments into British Sign Language**

Issues related to using the standardised mental health assessments, including its translation with d/Deaf populations have been covered in papers B, C, and D. The details of the translation procedure are also in the published papers (paper B, C, and D). Paper B in particular gives insight into the issues of translating from English to BSL, for examples, on the shift of modality from a written format to a signed version. Steinberg, Lipton, Eckhardt, Goldstein, and Sullivan (1998) gave examples of the issues to consider regarding the use of standardised assessments with d/Deaf populations following work on translation of the diagnostic interview into American Sign Language. They found that issues such as translating the concept of time-within-time and time duration, English idioms, and

hearing-specific questions had raised some difficulties. This had been done on computer and this may have raised its own specific issues. Within focus groups, d/Deaf people reported not feeling comfortable being asked questions but felt that talking about mental health issues in their own language helped (Steinberg et al., 1998, p. 1604). Researchers need to think about cultural and linguistic appropriateness when considering translating assessments into signed language in order to determine whether can they be used effectively with d/Deaf populations or not.

### **5.5. Collecting data remotely**

Data to measure mental well-being and the demographic information of the participants in this study was carried out remotely through the internet. Use of the internet for data collection purposes has grown in recent years (Coolican, 2004). Traditionally, collecting data often involved using paper-based questionnaires. The benefit of research being carried out via computer is that it allows for questions to be available in sign language on videos (Gerich & Legner, 2006). Further advantages of collecting the data online are that it is easy to access for diverse populations, quicker, a greater number of participations can take part, it is cheaper and participants are self-selected (Reips, 2002). The literature findings on the demographics of the participants who take part in internet research compared to paper-and-pen approaches have found that people who participate via the internet are more diverse (Gosling, Vazire, Srivastava, & John, 2004). The disadvantages are that it is dependent on the effectiveness of the technology such as the computer itself and the speed of the broadband connection. Reips (2002) emphasised that to carry out data collection online involves careful planning, careful methodology and ethical considerations. Over 10 years ago, in 2002 Reips (2002) commented "We are in the midst of an internet revolution in experimental research" (2002, p. 243), and this has clearly developed further since then. However, there are additional ethical issues to consider when carrying out research online, for example how to obtain informed consent, how to ensure that a participant is aware that they can stop at anytime, and their confidentiality is maintained (Hewson, 2003).

Surveys in SelectSurvey were developed for this study and data from the respondents consent and the main survey (questionnaires) were stored separately. This was to ensure security and anonymity of the raw data in the main

survey. Unique code numbers were allocated to enable the linkage between the two data stores in order to be able to identify each participant. The data is kept highly secure and it is only possible for it to be accessed by the researcher who developed the survey. The data transfer and storage met security guidelines of both the University of Manchester and the NHS. In the event that the participants experienced distress, at the end of the questionnaire, they were re-directed to the support page on the website that had been developed for this project rather than having to contact the researcher. This ensures confidentiality.

d/Deaf populations are geographically dispersed, so the internet is advantageous as it enables d/Deaf people across England to take part if they wish. Furthermore, many d/Deaf people are internet users (Valentine & Skelton, 2009), and the 'visual' accessibility of the language (BSL) in this study meant that d/Deaf people could take part if they wished.

As sign language is a visual language and some Deaf people have poor literacy skills, it was also considered important to consider the feasibility of collecting data from Deaf people via face-to-face interviews. However, as Gerich and Lehner (2006) have pointed out, there are some problems with interviewing Deaf people face-to-face for the purposes of completing a questionnaire. For example there is a risk of biased answers to sensitive questions, inconsistency in how questions are given (which is not the case for a video set of questions), and more administrative work than if the questions are asked in video format.

Information about the Deaf well-being project was made available on a website that was developed for this study. This was made available in both BSL and English, and the data collection was accessed by following the link to the web survey on the website (see figure 2).

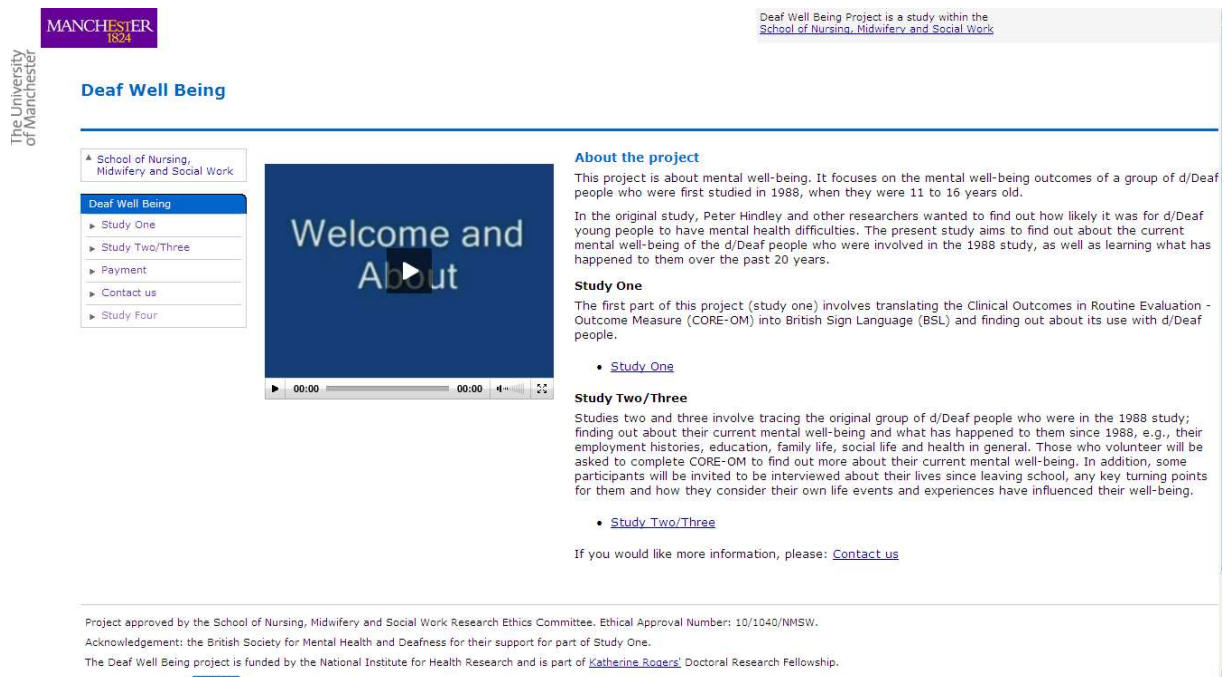


Figure 2. An image of the website developed for this study.

Following the completion of the online survey, the participant was taken directly back to the research project website. This was considered to be important in the event that the participants wished to contact the researcher and/or to seek information of an appropriate service for d/Deaf people.

## 6. Summary

This chapter has given consideration to the research design and the methods used for this study. Justifications for the methods used were addressed and further consideration was given to issues of particular methodological interest that arose in the course of the study. The next chapter will consider the five publications related to this PhD study.

## CHAPTER FOUR: PAPER A

Is there an association between deaf children's mental health difficulties and their adult well-being? The state of the evidence

Rogers, K. D., & Young, A.

In: L. Leeson and M. Vermeerbergen (Eds.), "Working with the Deaf community: Education, Mental Health & Interpreting". Dublin, Ireland: Intersources Group (Ireland) Limited.

(In press)

# **Is there an association between deaf children's mental health difficulties and their adult well-being?**

The state of the evidence

Katherine D. Rogers

Alys Young

Social Research with Deaf People Group, University of Manchester

## **1. Introduction**

Literature in the field of mental health and d/Deaf<sup>1</sup> people has established that, in general, deaf children and d/Deaf adults have poorer mental health compared to the hearing population (Hindley, Hill, McGuigan, and Kitson, 1994; van Eldik, 2005). Positive mental well-being is important to individuals, as it determines how one views oneself and relates to one's world. Huppert (2008) described well-being as:

*The concept of feeling good incorporates not only the positive emotions of happiness and contentment, but also such emotions as interest, engagement, confidence and affection. The concept of functioning effectively (in a psychological sense) involves the development of one's potential, having some control over one's life, having a sense of purpose (e.g. working towards valued goals), and experiencing positive relationships. (Huppert, 2008:2)*

Working towards and achieving goals, which are valued in society, is important for well-being, therefore, having a fair opportunity to do so is also fundamental. One concept of wellness and justice has emerged which argues that the advancement of true well-being for an individual is linked with those conditions that support social justice (Prilleitensky, Doeckei, Frieden, and Ota Wang, 2007). It is argued, for example, that without opportunities to access 'rights' and equality a person would be unable to fulfil their well-being potential.



As well as affecting individuals, mental health difficulties have an impact on the wider social context. For example, in England, a report carried out by Her Majesty's Government (2011) estimated that costs to the economy resulting from mental health problems, such as working hours lost, are in excess of £105 billion a year. HM Government (2009) declared that 44% of people who are on incapacity benefit either have mental health or behavioural difficulties. The link between socio-economic deprivation and mental ill health is well established, prompting interest in tackling such issues as social exclusion with the aim of improving mental well-being (Social Exclusion Unit, 2004). Therefore, investigating early intervention for mental well-being support is not only beneficial to the individual in the short term, it is also potentially cost effective in the long term by influencing better outcomes in terms of health, education and employment for individuals.

The focus on promoting mental well-being in UK Government policies aims to prevent mental health difficulties increasing, as exemplified in the *No health without mental health* report (HM Government, 2011). This report also outlined the importance of supporting the mental health of children, with a focus on promoting well-being at an early stage. Deaf children are not directly mentioned in the report, being more generally categorised as disabled children; a group that the consultation report acknowledged to be at greater risk of developing mental health problems. Disabled children, in general, are at risk of social exclusion (Morris, 2001). Results from the General Household Survey in 1994 stated that families with disabled children are more likely to have lower socio-economic status than families with non-disabled children (Beresford, 1995) and disabled children face difficulties in continuing education after leaving secondary school and/or gaining employment (Ofsted, 2010). Like disabled children, deaf children are also at greater risk of having poor socio-economic outcomes which in turn can affect mental well-being. Contributing factors include language delays (Mayberry, 2002), poorer literacy skills (Mayer, 2007), poorer cognitive development (Peterson and Siegal, 1999) and challenges in gaining employment as adults (Dye and Kyle, 2000). Furthermore, deaf children are more vulnerable than hearing children to abuse, including sexual abuse, as they may have difficulties in communicating their disclosure of such abuse (Obinna, 2005; Sullivan et al., 2000).

Young, Green and Rogers (2008) explained that being d/Deaf itself is not a risk factor, but rather "deafness in a range of familial, social and institutional contexts

may interact with variables and processes that render its disadvantaging effects more likely” (Young *et al.*, 2008: 43). One of the key Government actions in the UK for the transition from child to adult services is to “include information about vulnerable groups” (HM Government, 2009:41). Such groups specifically include children with special education needs, those who are in the care of the local authority or who are categorised as being disabled. However, such means of categorisation does not capture all those children who are deaf. For example, in the UK children with special educational needs have a ‘statement’ which clearly outlines what their needs are and how they are to be met. A survey undertaken by the National Deaf Children’s Society in 2008 found that 31% of deaf children did not have such a statement (NDCS, 2008).

Evaluation reports on mental health services for deaf children and their families have been carried out in England to determine whether mental health specialist services are necessary. The findings have indicated the importance of providing specialist services that have expertise in working with deaf children and their families, something which the generic Child and Adolescent Mental Health Services (CAMHS) cannot provide (Beresford, Greco, Clarke, and Sutherland, 2008). The research showed professionals were referring deaf children and parents of deaf children, as they believed that the generic CAMHS service could not meet their needs, because of their lack of expertise in this field. This report led to a limited number of specialist deaf CAMHS services being established in England.

## **2. The need for longitudinal studies of mental health outcomes**

Doing research to collect data at a single point in time does not provide a full picture, but serves merely as a snapshot; nor does it answer the question of whether factors in childhood predict outcomes in later life or not. Longitudinal studies involve following participants over a period of time. Van der Kamp and Bijleveld (1998) identified three possible aims in longitudinal studies; descriptive, explanatory and forecast. Descriptive aims involve the description of levels and patterns of changes over time; explanatory aims involve explaining changes in terms of stable or unstable characteristics, and the third aim is to forecast participants’ scores on particular variables. Although longitudinal methodologies are not necessarily a way of determining the causes of any given outcome, they

do provide insight into the causal processes that might have contributed to the factors of interest.

In a mental health context, it is vital to understand which factors influence mental health outcomes over time, so that potential risk and protective factors, which contribute to the mental well-being of individuals, families or communities, can be identified. However, the identification of a risk or preventative factor is not the same as the identification of the processes by which they might exert influence. For example it might be possible to identify common factors in childhood associated with positive outcomes for deaf children, but this alone does not tell us how these factors operate to produce those positive outcomes. Nor is the identification of risk factors enough to prevent poorer mental health outcomes in adulthood (Rutter, 2000). However, the identification and awareness of key variables in childhood is the first step in promoting good mental health outcomes later on because they can act as a guide to early intervention for children and young people who might be at risk of less than optimal outcomes, whether in mental health, quality of life, education or employment.

### **3. Comprehensive literature search**

For this review, online databases were systematically searched for literature relating to longitudinal studies in mental health contexts. The combined keywords of 'mental health' OR 'well-being' AND 'longitudinal stud\$<sup>2</sup>' OR 'follow-up stud\$' were used, with the limits of 'published in English language only' in each of the following databases up to June 2011: PsycInfo, ISI Web of Knowledge, CINAHL Plus and ASSIA. This resulted in 1,550 hits for PsycInfo, 21,872 hits for ISI Web of Knowledge, 1,917 hits for CINAHL Plus and 26 hits for the ASSIA database. For the literature search in relation to d/Deaf people, the keywords 'deaf\$' and 'hearing impair\$' were used to find possible relevant literature linked to mental health and longitudinal studies. When the keywords 'deaf\$' and 'hearing impair\$' were combined with the keywords above, despite a systematic search, only 4 partly relevant articles were found.

The authors of this chapter know of a few other publications that are somewhat related to the longitudinal study of mental well-being in d/Deaf populations that the database searches failed to identify. These include a book in relation to an 18 year follow-up study on deaf children and their families (Gregory, Bishop, and Sheldon,

1995), and an unpublished PhD thesis involving a follow-up study of mental health outcomes in the Conrad cohort<sup>3</sup> (Griggs, 1998). These will also be included in the following review.

#### **4. Mental health outcomes in adulthood – in the hearing population**

The few studies which have examined the relationship between childhood and adult mental health outcomes in the general (hearing) population have focussed on whether mental health difficulties in childhood predict mental health outcomes in adulthood. Other literature has examined whether there are characteristic factors in childhood (e.g. familial, social and educational) that predict certain kinds of mental health outcomes in adulthood. Additional literature has focused on the link between mental health in childhood and characteristic factor outcomes in adulthood, as well as the links between adverse factors in childhood and later outcomes. The duration of the studies, between first contact and later follow-ups, varies from a few years to four decades; the age of the child's first contact also varies. Tracing an original cohort with a view to involving them in a study to find out their mental health outcomes can be challenging. One study found that those who had mental health difficulties when first contacted were more difficult to trace than those who did not (Dunn and Goodyer, 2006). The definition of terms can itself be an issue, as definitions can sometimes be too wide. For example, a definition of poor mental well-being is too global and thus might mean different things to different people (Kluwin and Morris, 2006). This section of the chapter will briefly review the literature in relation to the hearing population and longitudinal mental health studies before addressing the state of evidence relating to similar questions with regard to d/Deaf populations.

##### ***4.1 Mental health difficulties in childhood as a predictive factor for later mental health outcomes***

The literature shows mixed results. Some studies showed a more general link between childhood mental health difficulties and adult mental health, finding that those who had mental health difficulties in childhood are more likely to experience recurrent mental health difficulties in adulthood than those who did not (Steinhausen, Meier and Angst, 1998; Dunn and Goodyer, 2006; Fergusson and Woodward, 2002; Trzesniewski, Donnellan, Moffitt, Robins, Poulton, and Caspi, 2006). Dekker, Ferdinand, van Lang, Bongers, van der Ende and Verhulst (2007), who carried out a large multiple-cohort study (n=2,076), found that those with an

earlier age of onset of mental health difficulties were at greater risk of having later mental health difficulties in adulthood.

Other studies found difficulties in adult mental health were dependent on specific mental health difficulties in childhood. In 2009, Fichter, Kohlboeck, Quadflieg, Wyschkon and Esser (2009) successfully followed up 82% of 345 participants, 18 years after the original study was carried out. They were interested in finding the predictive significance of specific psychiatric symptoms in childhood for adult outcomes. This longitudinal study (n=269) found that the likelihood of having problems in mental health outcomes in adulthood depended on specific symptoms in childhood, such as depressive symptoms. Similarly, Dekker et al. (2007) and Fichter et al. (2009) found that gender was associated with depression outcomes in adulthood; females were more likely to develop depression in adulthood than males, if they had depressive symptoms when they were children. The significant predictive outcome of anxiety in adulthood resulting from having phobias in childhood was another finding from Fichter et al.'s (2009) study. This study also found that for substance abusers, depressive symptoms in childhood were the only significant predictive factor (Fichter et al., 2009).

However, not all factors in childhood necessarily predict poor mental health outcomes in adulthood. Fichter et al. (2009) found that the prevalence of psychiatric symptoms such as 'lack of concentration', 'anxiety and worry', 'anxious/tense', and 'intellectual impairment' was lower in adulthood than childhood.

#### ***4.2 Social, familial and environmental factors in childhood relating to mental health difficulties outcomes in adulthood***

The transition from childhood to adulthood is not always an easy one. During this period a young person begins to seek independence and begins to find their place in the world. Some studies have attempted to find out how certain social/familial factors in childhood impact mental health outcomes in later life. Some retrospective studies have looked back to participants' childhood to find out which factors may have played a role in their adult mental health outcomes (e.g. some of the literature in the study by Pajer, 1998), whereas other studies have used a prospective approach to trace a cohort over time, from childhood to adulthood (e.g. Fergusson, Woodward, and Horwood, 2000; Power, Stansfeld, Matthews,

Manor, and Hope, 2002). Examples of the factors in childhood that have been explored include familial environment (Fergusson and Woodward, 1999), socioeconomic status (Melchior, Moffitt, Milne, Poulton, and Caspi, 2007), adverse experiences (Coates, 2010), specific personality characteristics (Tuulio-Henriksson, Poikolainen, Aalto-Setälä, and Lonnqvist, 1997), conduct/behaviour of the individual (Buchanan, Flouri, and Ten Brinke, 2002).

Characteristics of parents can be one of the key factors in the mental health outcomes of children, as the following studies have found. Information from the large longitudinal National Child Development Study of children born in 1958 in England, Scotland and Wales has been examined (n = 6,441) to identify any association between emotional and behavioural difficulties in childhood and outcomes of psychological distress in adulthood (Buchanan et al., 2002). Buchanan et al. (2002) found that children who grew up with a single parent were more likely to have psychological distress than those who grew up with their parents. Those in the National Child Development Study cohort who had a disability were excluded from Buchanan et al's (2002) study; it is not known how many of them were deaf. In the study of mental health outcomes of the birth cohort of 1025 New Zealand children, one of the key findings is that the age of mothers when they had their child were found to be significantly related to the mental health difficulties of their children. Children with teenage mothers were at greater risk of developing mental health problems; child-rearing practices and the family environment were one of the factors which influenced the relationship between maternal age and the outcomes of the child (Fergusson and Woodward, 1999). Huurre, Junkkari and Aro (2006) investigated how the divorce of parents of adolescents under the age of 16 impacted on their outcomes in adulthood and found that female children of divorced parents had more mental health difficulties than those from non-divorced families.

Personality characteristics of individuals have been examined to find out the extent to which they might be predictive of later mental health outcomes. For example, one study (n = 516) found that immature defense styles, such as passive aggression, acting out and dissociation, predict mental health difficulties one year later (Tuulio-Henriksson et al., 1997). Pajer (1998) reviewed the literature on conduct problems when females were young and their mental health difficulties in adulthood and found that those who had conduct problems in adolescence were

more likely to have psychiatric problems in adult life compared to those who did not. Pajer (1998) discussed the psychological deficit and/or difficulties in coping with adulthood as a possible explanation for those outcomes. Huppert (2008) emphasises that personality characteristics are not only associated with how one feels about oneself, but also to how well an individual might function psychologically. For example, Huppert cited studies which showed the association between a positive emotional style and sociability and an association between a negative emotional style and neuroticism.

The risk factors for suicidal behaviour in young people have been identified in a study by Fergusson et al. (2000) (n = 1,265); socioeconomic status, dysfunction in the family (e.g. number of parental changes and attachment difficulties), sexual abuse, and conduct problems in childhood. Adverse factors such as sexual abuse when young were found to be related to later mental health outcomes (Fergusson and Woodward, 2002). Interestingly, one study from the National Child Development Study in England, Scotland and Wales found that it is the grouping of protective factors (i.e. the presence of more than one) which are predictive of later and lower psychological distress outcomes. However no similar relationship existed between the grouping of risk factors in childhood and the prediction of outcomes (Buchanan et al., 2002). Buchanan *et al.* (2002) found that externalising problems (e.g. being fidgety, destroying things and fighting) in childhood, as reported by parents, predicts distress outcomes whereas internalising factors (e.g. sleep problems, being solitary and having headaches) in childhood do not. Such findings indicate the necessity of the identification of risk and protective factors in childhood to prevent later mental health outcomes and have interesting implications for deaf children in familial environments where easy communication between parent and child cannot be taken for granted. We discuss this further in later parts of this chapter.

#### ***4.3. Mental health difficulties in childhood and the outcomes in adulthood (other than mental health)***

Research on mental health difficulties in childhood has not just focussed on later mental health outcomes, but also on other outcomes, including offending behaviour, educational outcomes and employment. For example, those who had poor self-esteem when they were younger were more likely to have higher criminal convictions, lower economic prospects (Trzseniewski *et al.*, 2006), and conduct

problems. In the Christchurch Health and Development Study, a longitudinal study of a birth cohort of children in New Zealand ( $n = 964$ ), children who were depressed in middle adolescence were found to be at risk of later problems, including mental health difficulties, substance dependence, educational underachievement, unemployment and early parenthood (Fergusson and Woodward, 2002; Goodwin, Fergusson and Horwood, 2004). However, Steinhausen et al. (1998) found that the type of child and adolescent mental health difficulties did not generally predict maladjustment in adulthood. Rather, they found poor environmental factors, parents' mental health difficulties and broken homes were associated with negative outcomes in adulthood.

A few studies have found a relationship between unemployment and mental health (Hoare and Machin, 2010; HM Government, 2011). The direction of causality for mental health and unemployment is unclear; it is not known if the inability to work influences mental health, or whether having mental health difficulties results in not being able to work. Trzesniewski et al. (2006) found that, after controls for the effect of variables such as socioeconomic status and IQ, having lower self-esteem when young does not directly predict the long term unemployment in adulthood. Pernice (1996), who used both quantitative and qualitative methods of data analysis, found that those who wanted to work and those who were unable to work experienced higher distress than those who had alternatives to employment and those who were interested in training.

These findings have shown that it is not only the negative outcomes from childhood and adolescence that have an impact on mental health outcomes later in life. Other outcomes, such as employment and educational attainment, are also affected by and have an impact on mental health.

#### ***4.4. The importance of services for young people with mental health difficulties***

The studies discussed in this section relate to the hearing population. They show that interventions, which support children and young people who are experiencing mental health difficulties, are important as they might positively impact on their later mental health. Rao, Weissman, Martin and Hammond (1993) considered people who were diagnosed as depressed when young, people who had anxiety disorders when young, and those who did not experience mental health difficulties



when young. They also compared the number of suicides in a follow-up study across three groups over ten years after they were originally studied and found that all of the deaths as a result of suicide were in the depressed group (Rao et al., 1993).

The involvement of parents and teachers to identify children/young people's possible mental health difficulties is an important component of timely early intervention and support. For example, in their 2002 study (n = 1,268), Kumpulainen and Rasanen considered children who had been referred regarding a psychiatric problem by the age of 12. They found that these children had been assessed by teachers and parents as having difficulties when they were 8 years old. They also noted that those who had high scores rated by teachers when they were 8 years old were 5.2 times more likely to be referred at the age of 12. However, this result does not imply determinism – e.g. if a child has mental health difficulties at 8 years old, this will predict their mental health at 12 years old. Many mediating factors such as family support and interventions for the child can alter this outcome. The important issue is the timely recognition of difficulties at an early stage. As we will discuss later, such timely recognition is very often lacking for deaf children and their families.

Some people who experience mental health difficulties do not get the support they need from mental health services. Goldstein, Olsson, Martens and Wolk (2006) found that 37% of participants (77 out of 208) in their study responded “Yes” to the question, “Have there been times when you felt you needed treatment for emotional, family, alcohol, or drug problems, but didn't get help?” They also found that females were more likely to say “Yes” to that question. Lifetime substance dependence and lifetime mood disorders were also factors relating to the perception of not having needs met by services. It is recognised that some areas of mental health services need to be improved, with regard to meeting the needs of children and young people in general; particularly for vulnerable children and young people, including those who are deaf (Department for Children, Schools and Families and Department of Health, 2010). Examples include having clear structures for delivering early intervention, better information and more accessible services, and a co-ordinated and integrated way of working across services.

#### **4.5. Conclusions of the findings from hearing populations**

A close consideration of the research literature relating to hearing populations has led to the following conclusions which we will go on to consider in respect of d/Deaf populations.

Although it is not automatic that children who experience mental health difficulties will have such problems when they are adults, links have indeed been found between poor mental health in childhood and in adulthood. For example, depression in childhood has been associated with mental health difficulties in later life. However, poor mental well-being in childhood is not only connected with clinically identifiable mental health difficulties in adulthood, but also to a range of poor social outcomes including low educational attainment, unemployment, offending behaviour, socioeconomic status and family dysfunction.

Identifying risk factors alone is, however, insufficient. It is possible, and important, to identify protective factors in childhood which might well contribute to positive mental well-being outcomes. For example, specific personality characteristics such as defense styles have been studied for their impact on adverse mental health outcomes in adulthood. Timely recognition of mental health difficulties in childhood makes a significant contribution to the prevention of adverse effects in adulthood. Early intervention has been shown to make a difference to longer term outcomes, although how and why is not always apparent.

#### **5. Longitudinal studies with d/Deaf populations**

There are not many longitudinal studies involving d/Deaf people. Those which have been undertaken include studies of literacy (Kyle and Harris, 2010), speech/language development (Klatter-Folmer, van Hout, Kolen, and Verhoeven, 2006), cochlear implants (Preisler, Tvingstedt, and Ahlstrom, 2002; Belzner and Seal, 2009), career attainments (Schroedel and Geyer, 2000) and maternal responsiveness to deaf infants (Spencer and Meadow-Orlans, 1996). Some longitudinal studies are not relevant to our concerns in this paper, such as the longitudinal study of the outcomes of those who have had otitis media (i.e. glue ear) when young (e.g. Silva, Chalmers, and Stewart, 1986). Other studies are indeed of relevance, such as those referred to later in this section.

A handful of relevant follow-up studies have focussed on the same cohort of d/Deaf people, although not specifically focussed on mental well-being outcomes. For example, Gregory et al. (1995) traced a cohort of young deaf people aged 18-24 years old (n= 71) whose families were first studied when they were of preschool age (there were 122 families in the original study). One of their key findings concerned the quality of communication within families as children were growing up and the young people's current language outcomes. The study found that in many cases there was evidence of deaf young people experiencing childhood-long difficulties in communicating with their families, especially when in group situations. As we have remarked earlier, the possibility of being able to express oneself, be understood and learn through close social and familiar relationships is positively connected with good mental health. Instead, in many of these families, there had been a lack of consistent, elaborated and meaningful communication throughout childhood. At follow-up, when the children were 18 years old, many parents admitted they still could not communicate fluently with them. In 17% of cases the young people, now on the verge of adulthood, had little or no spoken or signed language.

However, as previously stated, when searching for papers using 'mental health' and 'longitudinal studies' with 'deaf\$' and 'hearing impair\$' keywords, only 4 studies were identified. The studies were varied: the well-being aspects of having a Hearing Dog for d/Deaf people (Guest, Collis and McNicholas, 2006); changing communication mode (Wallis, Musselman and MacKay, 2004); treatment for d/Deaf people with mental well-being difficulties (Cook, Graham and Razzano, 1993), and outcomes for deaf people who were considered to be gifted (Vernon and LaFalace-Landers, 1993).

## **6. Mental health outcomes in d/Deaf populations**

Our knowledge of mental health in d/Deaf populations has mainly emerged from non-longitudinal studies, i.e. those which have studied mental health outcomes at one point, whether during childhood or adulthood. Some have been cohort studies, others cross-sectional studies. The findings from these have indicated that there is a higher incidence of d/Deaf people, including children, experiencing mental health difficulties as compared to the hearing population (Hindley, Hill, McGuigan, and Kitson, 1994; van Eldik, 2005; Kvam, Loeb & Tambs, 2007). Various factors have been examined to identify associations with the mental health difficulties

experienced by d/Deaf people. Significant factors have been found to be related to the mental health difficulties of deaf children, including, for example, language competence (Fellinger, Holzinger, Beitel, Laucht, and Goldberg, 2009), parents' stress experience (Hintermair, 2006), and type of school (specialist deaf school and mainstream school) (Hindley *et al.*, 1994).

The early years in deaf children's lives are important for their development of the concept of self as well as language development. However, many deaf children are from hearing families who might have little or no knowledge of d/Deaf people and sign language (Young, 2003). In d/Deaf populations, the issues of communication have often been raised. Fellinger and Holzinger (2011) found that deaf children who have difficulties in communicating with their families are four times more likely to have mental health difficulties in childhood. Social experiences, in relation to social contexts, are important with regard to how d/Deaf people identify with others and their deafness (Bat-Chava, 1994; Nikolarazi & Hadjikakou, 2006). In a meta-analysis study of the self-esteem of d/Deaf people from non-longitudinal studies (Bat-Chava, 1993), the three main predictors of good self-esteem were; parents who have a positive attitude towards deafness, the availability of clear and accessible communication within the home, and whether the deaf child identifies with others within the Deaf community.

However, questions have been asked about whether the measures of mental health that have been used in d/Deaf populations are reliable and valid (Hindley, Hill, and Bond, 1993; Cromwell, 2005). With rare exceptions, the measures used have been standardised on a hearing population and often the translation processes into sign language has not been rigorous (Cromwell, 2005). Opportunities for d/Deaf people to define well-being from their own perspectives have hardly been considered. One exception is a study by Griggs (1998), who chose to explore 'Wellness' amongst d/Deaf people via interview. She identified three key issues that from a d/Deaf perspective were associated with positive mental wellness: emotional acceptance of deafness, individual styles of coping with the everyday hassles associated with being d/Deaf, and the dynamic nature of wellness as referenced by individuals themselves; for example, the use of sign language and an increased sense of control.

When Griggs (1998) attempted to make comparisons between the findings from the interviews and the scores from the assessments (including the General Health Questionnaire) which she had carried out, it was concluded that those assessments did not give a whole picture of mental well-being in d/Deaf populations. For example, half of the group who had a cut off score of above 5, which demonstrated mental health difficulties in an assessment of the General Health Questionnaire (GHQ-30), “reported wellness behaviour, characterised by positive coping” (Griggs, 1998:135). This work was important because it demonstrated that standardised assessment, when used with d/Deaf populations, might not be fully accurate, not just because of issues of translation and administration, but also because they could not capture cultural concepts of coping, positive psychology and alternative definitions of being well rooted in cultural adaptations to life in a hearing world. Indeed, this may well go some way to explain why there are more reported d/Deaf people with mental health problems than hearing people.

With those important caveats, we review below, from the longitudinal studies with d/Deaf populations, evidence of:

- mental health difficulties in childhood as a predictive factor for later mental health outcomes in d/Deaf populations;
- factors in deaf childhood that affect mental health outcomes in adulthood, and also;
- effects of mental health difficulties in deaf childhood for later outcomes not directly associated with mental health.

### ***6.1. Mental health difficulties in childhood as a predictive factor for later mental health outcomes in d/Deaf populations***

We have not found any literature that has examined a follow-up of the mental health outcomes of d/Deaf adults from childhood or adolescence. A few longitudinal studies have included mental health status outcomes of d/Deaf adults but these do not specify if the adults involved had mental health difficulties in childhood. There is no comprehensive evidence regarding the association between mental health difficulties in deaf childhood and the mental health outcomes of d/Deaf adults. Consequently, we do not know the predictive validity of childhood mental health status and adult well being.

## **6.2. Social, familial and environmental factors in childhood relating to mental health difficulties in adulthood in d/Deaf populations**

There are hardly any longitudinal studies that have examined the mental health outcomes of deaf children. A finding from the Early Developmental Stages of Psychopathology study in Germany, a longitudinal study by van der Werf, Thewissen, Dominguez, Lieb, Wittchen, and van Os (2011), showed that being deaf ( $n = 151$ ) increases the risk of having psychosis when young. Despite their acknowledgment that in some cases the possible cause of the deafness may be related to the psychosis outcome rather than deafness per se, it is not clear what they mean by 'exposure of hearing impairment'. Nor did they report at what age deafness commenced in the participants in their study. Although a retrospective study rather than a longitudinal one, Hindley et al. (1994) found that rubella was linked to a psychiatric disorder, as 5 out of the 8 children in his study who were deaf as a result of rubella had psychiatric disorders. The findings from van der Werf et al. (2011) did not examine some of the factors that have been highlighted in previous studies, such as the language competence and educational environment of the deaf child. Without looking beyond the hearing function, it does not tell us anything about the childhood development of deaf children and their mental health outcomes in adulthood.

Beyond simply being d/Deaf, factors of ongoing communication (Wallis et al., 2004) and being gifted (Vernon and LaFalce-Landers, 1993) have been examined in longitudinal studies, with a view to find their association with mental health outcomes in d/Deaf young people/adults. The longitudinal study of Wallis *et al.* (2004) ( $n = 57$ ) found that children who did not commence signing at an early stage in their development and/or whose mothers did not sign, had greater difficulties in mental health in adolescence compared to those whose methods of communicating (both signing and oral) with their mothers had not changed.

The factor of being bright d/Deaf young people has also been explored, in the follow-up study of 'gifted d/Deaf students' (whose IQs were greater than 130) ( $n = 57$ ) (Vernon and LaFalce-Landers, 1993). The authors found that 9% required inpatient hospitalisation for mental health difficulties, 30% received outpatient psychotherapy, and 18% had fair to poor adjustment. They found that males outnumbered females in the pathological and borderline categories. It is possible that subjects may have felt frustrated if they were not recognised for their abilities,

as d/Deaf people are often seen as less competent than their hearing counterparts. However, questions about the validity of using IQ tests with d/Deaf people have been raised in previous studies, and whether test performance is dependent on language ability rather than intelligence (Marschark, 1993; Maller & French, 2004).

Griggs (1998) examined d/Deaf people who were receiving or had received support from specialist psychiatric services for d/Deaf people, by linking referrals to such services to data from an earlier study by Conrad (1979) (n=573). The study by Conrad (1979) had focused on the outcomes of d/Deaf school leavers, such as educational attainment, speech reading ability and literacy. Conrad identified that their median reading age was 9 years old. Griggs (1998) found that the overall rate of referral was much higher in the Conrad cohort than in the general hearing population, although the real figure could be even higher because, as Griggs reported, Conrad excluded those with emotional or behavioural difficulties from his original study. Additionally it should be noted that the referral rate for those d/Deaf people referred to mainstream psychiatric services was not examined in the Griggs (1998) study, so it is possible that the figures could be higher still.

Within-cohort comparisons were made between those who were referred to specialist psychiatric services and those who had never been referred (Griggs, 1998). Significant differences were identified between the two groups, including differences in reading age and intelligence scores. There was no difference in the ability to produce intelligible speech between those two groups. Issues of communication, aggression and violent behaviour, as well as their family's attitude to deafness, were mentioned in most of the d/Deaf patients' notes in the referred group (Griggs, 1998). However, it is not known which types of school (deaf or mainstream) the people in those two groups attended, and if this made a difference.

From the follow-up studies with d/Deaf populations, factors of reading age (Griggs, 1998), being bright (Vernon and LaFalce-Landers, 1993) and consistent communication (Wallis et al., 2004) have been explored in relation to mental health outcomes. These factors were, however, examined individually and the records of the characteristics in childhood were not considered in the same studies

in order to establish what, if any, were the protective and risk factors associated with mental health outcomes in adulthood, or indeed, whether they differed to findings relating to the hearing population.

### ***6.3. Mental health in childhood and the later outcomes (other than mental health) in d/Deaf populations***

No evidence was located from studies of d/Deaf adults' socio-economic or familial outcomes which had related these to their childhood mental health status on an individual or a population level.

### ***6.4. Conclusions of the findings from d/Deaf populations***

The paucity of prospective or retrospective longitudinal of deaf children's mental well-being makes comparison with studies from hearing populations very difficult. It is also difficult to draw strong conclusions from studies of d/Deaf populations in their own right about potential trajectories from poor mental health in childhood to outcomes in adulthood.

## **7. Current gaps in literatures on mental well-being outcomes for d/Deaf populations**

When literature searches were carried out to find longitudinal studies in general involving d/Deaf people, we found several that related to the medical aspect of the ear, such as cochlear implants, but there were few longitudinal studies regarding mental health and deaf children. Yet surely mental well-being outcomes should be a priority when considering the development of deaf children and therefore a focus for research? The range of literature to date is insufficient to enable a full picture of the trajectories for d/Deaf people from childhood to mental well-being in adulthood to be formed. We know far less about protective and risk factors that contribute to d/Deaf people's well-being in comparison with the evidence from hearing populations. We have very little knowledge about how d/Deaf people themselves perceive their well-being as they grow up. How do deaf young people have the opportunity to develop their concept of self and acquire the skills and understanding to navigate through society and establish what is necessary for positive well-being?



## 8. Future work

One of the authors of this chapter, Rogers is currently doing a follow-up study of an original cohort of d/Deaf young people whose mental health was first studied in 1988 when they were aged between 11 and 16 years old (Hindley et al., 1994). This follow-up study explores their significant positive and negative life events and their perspectives on their own mental well-being over the last 20 years. All participants will undergo assessments to measure their well-being. The aim of the follow-up study is to attempt to explain the course of the participants' mental well-being over time; stable/unstable characteristics such as family and environmental factors are also being considered. Comparisons with the original data will help us to understand how factors, such as communication approaches, linguistic competence and home environment in childhood have influenced the well-being of d/Deaf participants twenty years on. As Skovgaard *et al.* (2005) emphasised, longitudinal study of mental health difficulties from an early age will contribute to “the knowledge of the risk factors and the course of psychopathology and thus add to the scientific knowledge base for treatment and prevention in early childhood” (Skovgaard *et al.*, 2005: 202).

### *Acknowledgements*

This article presents independent research commissioned by the National Institute for Health Research (NIHR). The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

Special thanks to Professor Karina Lovell for her feedback on a previous draft of this chapter.

### **Endnotes**

1. ‘Deaf’ with a capital ‘D’ is used when referring to a person whose first language is a sign language such as British Sign Language (BSL) and who is culturally Deaf. ‘d/Deaf’ is used to indicate that those referred to are deaf without specific differentiation. In the case of children and young people, we use the term ‘deaf’, as it might not yet be clear what their preferred identity is.

2. The symbol '\$' indicates the use of the truncation of the word. For example, 'stud\$' might retrieve 'study', 'studying', and 'studies'.
3. Conrad cohort refers to a study carried out by Conrad (1979) on a group of deaf school leavers in the UK. One of the findings was that the median reading age for that group was 9 years.

## References

Bat-Chava, Y. (1993). Antecedents of Self-Esteem in Deaf People: A Meta-Analytic Review. *Rehabilitation Psychology*, 38(4), 221-234.

Bat-Chava, Y. (1994). Group Identification and Self-Esteem of Deaf Adults. *Personality and Social Psychology Bulletin*, 20, 494-502.

Belzner, K. A., & Seal, B. C. (2009). Children with Cochlear Implants: A Review of Demographics and Communication Outcomes. *American Annals of the Deaf*, 154(3), 311-333.

Beresford, B. (1995). *Expert Opinions: A national survey of parents caring for a severely disabled child*. Bristol, UK: Community care into practice series, Policy Press.

Beresford, B., Greco, V., Clarke, S. & Sutherland, H. (2008). *An Evaluation of Specialist Mental Health Services for Deaf Children and Young People*. York, UK: Social Policy Research Unit, University of York.

Buchanan, A. Flouri, E. & Ten Brinke, J. (2002). Emotional and behavioural problems in childhood and distress in adult life: Risk and protective factors. *Australian and New Zealand Journal of Psychiatry*, 36, 521-527.

Coates, D. (2010). Impact of Childhood Abuse: Biopsychosocial Pathways Through Which Adult Mental Health is Compromised. *Australian Social Work*, 63(4), 391-403.

Conrad, R. (1979). *The Deaf Schoolchild: Language and Cognitive Function*. London: Harper and Row.

Cook, J. A., Graham, K. K., & Razzano, L., (1993). Psychosocial Rehabilitation of Deaf Persons with Severe Mental Illness: A Multivariate Model of Residential Outcomes. *Rehabilitation Psychology*, 38(4), 261-274.

Cromwell, J. (2005). Deafness and the art of psychometric testing. *The psychologist*, 18(12), 738-740.

Dekker, M. C., Ferdinand, R. F., van Lang, N. D. J., Bongers, I. L., van der Ende, J., & Verhulst, F. C. (2007). Development trajectories of depressive symptoms from early childhood to late adolescence: gender differences and adult outcome. *Journal of Child Psychology and Psychiatry*, 48(7), 657-666.

Department for Children, Schools and Families and Department of Health (2010). Keeping Children and Young People in Mind: The Government's full response to the independent review of CAMHS. London, DH. Retrieved June 27, 2011, from [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@ps/documents/digitalasset/dh\\_110930.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_110930.pdf)

Dunn, V., & Goodyer, I. M. (2006). Longitudinal investigation into childhood- and adolescence-onset depression: psychiatric outcome in early adulthood. *British Journal of Psychiatry*, 188, 216-222.

Dye, M., & Kyle, J. (2000). *Deaf People in the Community: Demographics of the Deaf Community in the UK*. Bristol, UK: Deaf Studies Trust.

Fellinger, J., & Holzinger, D. (2011). Enhancing Resilience to Mental Health Disorders in Deaf School Children. In: D.H. Zand & K.J. Pierce (Eds.), *Resilience in Deaf Children: Adaptation Through Emerging Adulthood* (pp. 169-206). New York: Springer.

Fellinger, J., Holzinger, D., Beitel, C., Laucht, M., & Goldberg, D. P. (2009). The impact of language skills on mental health in teenagers with hearing impairments. *Acta Psychiatrica Scandinavica*, 120, 153-159.

Fergusson, D. M., & Woodward, L. J. (1999). Maternal Age and Educational and Psychosocial Outcomes in Early Adulthood. *Journal of Child Psychology and Psychiatry*, 43(3), 479-489.

Fergusson, D. M., Woodward, L. J., & Horwood, L. J. (2000). Risk factors and life processes associated with the onset of suicidal behaviour during adolescence and early adulthood. *Psychological Medicine*, 30, 23-39.

Fergusson, D. M., & Woodward, L. J. (2002). Mental Health, Educational, and Social Role Outcomes of Adolescents With Depression. *Archives of General Psychiatry*, 59(3), 225-231.

Fichter, M. M., Kohlboeck, G., Quadflieg, N., Wyschkon, A., & Esser, G. (2009). From childhood to adult age: 18-year longitudinal results and prediction of the course of mental disorders in the community. *Social Psychiatry and Psychiatric Epidemiology*, 44(9), 792-803.

Goldstein, R. B., Olfson, M., Martens, E. G. & Wolk, S. I. (2006). Subjective Unmet Need for Mental Health Services in Depressed Children Grown Up. *Administration and Policy in Mental Health and Mental Health Services Research*, 33(6), 666-673.

Goodwin, R. D., Fergusson, D. M., & Horwood, L. J. (2004). Association between anxiety disorders and substance use disorders among young persons: Results of a 21-year longitudinal study. *Journal of Psychiatric Research*, 38, 295-304.

Gregory, S., Bishop, J., & Sheldon, L. (1995). *Deaf Young People and their Families: Developing Understanding*. Cambridge: Cambridge University Press.

Griggs, M. (1998). *Deafness and mental health: perceptions of health within the Deaf community*. Unpublished doctoral dissertation, University of Bristol – Bristol, UK.

Guest, C. M., Collis, G. M., & McNicholas, J. (2006). Hearing Dogs: A Longitudinal Study of Social and Psychological Effects on Deaf and Hard-of-Hearing Recipients. *Journal of Deaf Studies and Deaf Education*, 11(2), 252-261.

Hindley, P., Hill, P., & Bond, D. (1993). Interviewing the Deaf Children, the Interviewer Effect: a Research Note. *Journal of Child Psychology and Psychiatry*, 34(8), 1461-1467.

- Hindley, P., Hill, P. D., McGuigan, S., & Kitson, N. (1994). Psychiatric Disorder in Deaf and Hearing Impaired Children and Young People: A Prevalence Study. *Journal of Child Psychology and Psychiatry*, 35(5), 917-934.
- Hintermair, M. (2006). Parental Resources, Parental Stress, and Socioemotional Development of Deaf and Hard of Hearing Children. *Journal of Deaf Studies and Deaf Education*, 11(4), 493-513.
- HM Government. (2009). *New Horizons: A shared vision for mental health*. London: HM Government.
- HM Government. (2011). *No health without mental health: A cross-government mental health outcomes strategy for people of all ages*. London: HM Government.
- Hoare, P. N., and Machin, M. A. (2010). The impact of reemployment on access to the latent and manifest benefits of employment and mental health. *Journal of Occupational and Organizational Psychology*, 83(3), 759-770.
- Huppert, F. A. (2008). *Mental Capital and Wellbeing: Making the most of ourselves in the 21<sup>st</sup> century. State-of-science review. Psychological wellbeing: evidence regarding its causes and consequences*. SR-X2. London: Government Office for Science Foresight project.
- Huurre, T., Junkkari, H., & Aro, H. (2006). Long-term Psychosocial effects of parents divorce: A follow-up study from adolescence to adulthood. *European Archives of Psychiatry and Clinical Neuroscience*, 256(4), 256-263.
- Klatter-Folmer, J., van Hout, R., Kolen, E., & Verhoeven, L. (2006). Language Development in Deaf Children's Interactions With Deaf and Hearing Adults: A Dutch Longitudinal Study. *Journal of Deaf Studies and Deaf Education*, 11(2), 238-251.
- Kluwin, T. N., & Morris, C. S. (2006). Lost in a Giant Database: The Potentials and Pitfalls of Secondary Analysis for Deaf Education. *American Annals of the Deaf*, 151(2), 121-128.

Kumpulainen, K., & Rasanen, E. (2002). Symptoms and Deviant Behavior Among Eight-Year-Olds as Predictors of Referral for Psychiatric Evaluation by Age 12. *Psychiatric Services*, 53(2), 201-206.

Kvam, M. H., Loeb, M., & Tambs, K. (2007). Mental Health in Deaf Adults: Symptoms of Anxiety and Depression Among Hearing and Deaf Individuals. *Journal of Deaf Studies and Deaf Education*, 12(1), 1-7.

Kyle, F. E., & Harris, M. (2010). Predictors of reading development in deaf children: a 3-year longitudinal study. *Journal of Experimental Child Psychology*, 107(3), 229-243.

Maller, S. J., & French, B. F. (2004). Universal Nonverbal Intelligence Test Factor Invariance across Deaf and Standardization Samples. *Educational and psychological Measurement*, 64(4), 647-660.

Marschark, M. (1993). *Psychological Development of Deaf Children*. New York: Oxford University Press.

Mayberry, R. I. (2002). Cognitive development in deaf children: the interface of language and perception in neuropsychology. In: S.J. Segalowitz and I. Rapin. (Eds.) *Handbook of Neuropsychology*, 2nd Edition, Volume 8, Part II (pp. 71-107). 2nd Edition. Amsterdam: Elsevier.

Mayer, C. (2007). What Really Matters in the Early Literacy Development of Deaf Children. *Journal of Deaf Studies and Deaf Education*, 12(4), 411-431.

Melchior, M., Moffitt, T. E., Milne, B. J., Poulton, R., & Caspi, A. (2007). Why do children from socioeconomically disadvantaged families suffer from poor health when they reach adulthood? A lifecourse study. *American Journal of Epidemiology*, 166, 966-974.

Morris, J. (2001) *That Kind of Life? Social Exclusion and Young Disabled People with High Levels of Support Needs*. London, Scope.

NDCS. (2008). *Results from NDCS survey on educational attainment of deaf children* (May 2008). London: National Deaf Children Society.

Nikolarazi, M., & Hadjikakou, K. (2006). The role of educational experiences in the development of deaf identity. *Journal of Deaf Studies and Deaf Education*, 11(4), 477–492.

Obinna, J. (2005). *Understanding Sexual Violence in the Deaf Community: A Preliminary Report on the Service Provider Perspective*. Minneapolis, MN: Council on Crime and Justice.

Ofsted (2010). *The Special Educational Needs and Disability Review: a statement is not enough*. Manchester, UK: Ofsted.

Pajer, K. A. (1998). What happens to "bad" girls? A review of the adult outcomes of antisocial adolescent girls. *American Journal of Psychiatry*, 155, 862-870.

Pernice, R. (1996). Methodological issues in unemployment research: Quantitative and/or qualitative approaches? *Journal of Occupational and Organizational Psychology*, 69(4), 339-349.

Peterson, C. C., & Siegal, M. (1999). "Representing inner worlds: Theory of mind in autistic, deaf, and normal hearing children." *Psychological Science*, 10, 126-129

Power, C., Stansfeld, S.A., Matthews, S., Manor, O., & Hope, S. (2002). Childhood and adulthood risk factors for socio-economic differentials in psychological distress: evidence from the 1958 British birth cohort. *Social Science and Medicine*, 55, 1989-2004.

Preisler, G., Tvingstedt, A. L., & Ahlstrom, M. (2002). A psychosocial follow-up study of deaf preschool children using cochlear implants. *Child: Care, Health and Development*, 28(5), 403-418.

Prilleltensky, I., Dokecki, P., Frieden, G., & Ota Wang, V. (2007). Counseling for Wellness and Justice: Foundations and Ethical Dilemmas. In E. Aldarondo (Ed.),



*Advancing social justice through clinical practice* (pp.19–42). Mahwah, NJ: Lawrence Erlbaum.

Rao, U., Weissman, M. M., Martin, J. A., & Hammond, R. W. (1993). Childhood Depression and Risk of Suicide: A Preliminary Report of a Longitudinal Study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 32(1), 21-27.

Rutter, M. (2000). Resilience reconsidered: Conceptual consideration, empirical findings, and policy implications. In J.P. Shonkoff (Ed.), *Handbook of early intervention* (pp. 651-682). Cambridge: Cambridge University Press.

Schroedel, J. G., & Geyer, P. D. (2000). Long-term career attainments of deaf and hard of hearing college graduates: results from a 15-year follow-up survey. *American Annals of the Deaf*, 145(4), 303-314.

Skovgaard, A. M., Olsen, E. M., Houmann, T., Christiansen, E., Samberg, V., Lichtenberg, A., & Jorgensen, T. (2005). The Copenhagen County child cohort: Design of a longitudinal study of child mental health. *Scandinavian Journal of Public Health*, 33, 197-202.

Silva, P. A., Chalmers, D. & Stewart, I. (1986). Some audiological, education and behavioural characteristics of children with bilateral otitis media with effusion—a longitudinal study. *Journal of Learning Disabilities*, 19, 165-169.

Social Exclusion Unit. (2004). Mental Health and Social Exclusion: Social Exclusion Unit Report Summary. London: Social Exclusion Unit.

Spencer, P. E., & Meadow-Orlans, K. P. (1996). Play, language, and maternal responsiveness: A longitudinal study of deaf and hearing impaired infants. *Child Development*, 67(6), 3176-3191.

Steinhausen, H. C., Meier, M., & Angst, J. (1998). The Zurich long-term outcome study of child and adolescent psychiatric disorders in males. *Psychological Medicine*, 28, 375-383.

Sullivan, P., Brookhouser, P., & Scanlan, M. (2000). Maltreatment of deaf and hard of hearing children. In: P. Hindley & N. Kitson (Eds.), *Mental Health and Deafness* (pp.148-184). London: Whurr.

Trzesniewski, K. H., Donnellan, M. B., Moffitt, T.E, Robins, R. W., Poulton, R., & Caspi, A . (2006). Low self-esteem during adolescence predicts poor health, criminal behavior, and limited economic prospects during adulthood. *Developmental Psychology*, 42, 381-390.

Tuulio-Henriksson, A., Poikolainen, K., Aalto-Setälä, T., & Lonnqvist, J. (1997). Psychological defense styles in late adolescence and young adulthood: a follow-up study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 36(8), 1148-1153.

Van der Kamp, L. J. Th., & Bijleveld, C. C. J. H. (1998). In: C.C.J.H. Bijleveld, L.J.Th. van der Kamp, A. Mooijaart, W.A. van der Kloot, R. van der Leeden, and E. van Der Burg, *Longitudinal data analysis: Designs, models, and methods*. Thousand Oaks, CA: Sage Publications.

van der Werf, M., Thewissen, V., Dominguez, M. D., Lieb, R., Wittchen, H., & van Os, J. (2011). Adolescent development of psychosis as an outcome of hearing impairment: a 10-year longitudinal study. *Psychological Medicine*, 41, 477-485.

Van Eldik, T. (2005). Mental Health Problems of Dutch Youth with Hearing Loss as Shown on the Youth Self Report. *American Annals of the Deaf*, 150(1), 11-16.

Vernon, M., & LaFalce-Landers, E. (1993). A Longitudinal Study of Intellectually Gifted Deaf and Hard of Hearing People: Educational, Psychological, and Career Outcomes. *American Annals of the Deaf*, 138(5), 427-434.

Wallis, D., Musselman, C., & MacKay, S. (2004). Hearing Mothers and Their Deaf Children: The Relationship between Early, Ongoing Mode Match and Subsequent Mental Health Functioning in Adolescence. *Journal of Deaf Studies and Deaf Education*, 9(1), 2-14.

Young, A. (2003). *Parenting and Deaf Children: A Psycho-Social Literature Based Framework*. London: NDCS.

Young, A., Green, L., & Rogers, K. (2008). Resilience and deaf children: a literature review. *Deafness and Educational International*, 10(1), 40-55.

## **CHAPTER FIVE: PAPER B**

The challenges of translating the Clinical Outcomes in Routine Evaluation -  
Outcome Measure (CORE-OM) into British Sign Language

Rogers, K. D., Young, A., Lovell, K., & Evans, C.

Journal of Deaf Studies and Deaf Education (2013) Advance online publication.

## **The challenges of translating the Clinical Outcomes in Routine Evaluation - Outcome Measure (CORE-OM) into British Sign Language**

Katherine D. Rogers, Alys Young, Karina Lovell, Chris Evans

### **1. Abstract**

This article discusses translation issues arising during the production of a British Sign Language (BSL) version of the psychological outcome measure “Clinical Outcomes in Routine Evaluation – Outcome Measure” (CORE-OM). The process included forward translation, meeting with a team of translators, producing a second draft of the BSL version and back translating into English. Further modifications were made to the BSL version before piloting it with d/Deaf populations. Details of the translation process are addressed, including (i) the implications of translating between modalities (written text to visual language); (ii) clarity of frequency anchors: analogical versus digital encoding; (iii) pronouns and the direction of signing; and (iv) the influence of the on-screen format. The discussion of item-specific issues encountered when producing a BSL version of the CORE-OM includes the expression of precise emotional states in a language which uses visual modifiers; problems associated with iconic signs; and the influence of Deaf world knowledge when interpreting specific statements. Finally, it addresses the extent to which lessons learned through this translation process are generalisable to other signed languages and spoken language translations of standardised instruments. Despite the challenges, a BSL version of the CORE-OM has been produced and found to be reliable.

## **2. Purpose of the study**

This paper focuses on the challenges that arose in the translation and standardisation of the Clinical Outcomes in Routine Evaluation - Outcome Measure (CORE-OM) into British Sign Language (BSL) for use with Deaf<sup>1</sup> people. The CORE-OM (Evans et al., 2000, 2002) is a widely used outcome measure that measures changes in mental health (Barkham et al., 1998). It is routinely used as an initial outcome measure of well-being and to measure treatment outcomes for individual patients as well as to audit and evaluate outcomes of mental health services in the UK (Barkham et al., 1998). Shortened forms, e.g., the CORE-10, are available (Barkham et al., 2012). Prior to this study, although the CORE-OM was being used with Deaf people in mental health services, there was no single translation into BSL which was common across services, nor was there any translation in use whose reliability had been tested with a population of Deaf BSL users. The results of the pilot testing of the BSL CORE-OM, its reliability and validation are reported elsewhere (Rogers, Evans, Campbell, Young, & Lovell, 2013a). The focus of this article is the translation methodology used, the challenges identified in working from a written language (English) into a signed language (BSL), additional issues which arise from the highly structured nature of self-report measures, and the lexical domain of the instrument which includes precise distinctions in the expression of emotion, mental states and self-awareness.

## **3. Rationale of the study**

Outcome measures are widely used in clinical practice and research (Jackson & Furnham, 2000), and can be norm-referenced so that an individual's score can be compared with scores from others in the same population (Aiken & Groth-Marnat, 2006). Norm-referencing relies on establishing how a given population performs on a measure in order to establish the normal distribution of scores, with

means and standard deviations, within that population (Coaley, 2009). However these cannot be established unless one can be sure that the instrument used is linguistically and culturally matched to the population who will be measured by it. Although it is perfectly possible to create bespoke instruments for given language and cultures, it is far more common to translate instruments whose properties are already established and then test the reliability of the translated version. Despite the substantial challenges in translating measures from one language to another, having an outcome measure translated rather than developing a new one can be beneficial: it is cheaper and quicker, allows for comparison between populations, and enables people to do the outcome measure in their preferred language (Hambleton & Patsula, 1998).

The translation of a standard instrument needs to be understood *and* be meaningful to the target population in terms of the concepts it uses and how they are expressed (Todd & Bradley, 1994). Cultural norms are associated with language use but not defined by them. Simply translating into another language does not ensure cultural equivalence (Lim & Firkola, 2000). Language used to describe the same concept can vary by culture (Nolan, 2005). For example, El-Rufaie and Absood (1987) translated from English into Arabic the Hospital Anxiety and Depression Scale (HADS: Zigmond & Snaith, 1983). However, it became clear on empirical testing of the translation that there is no phrase indicating anxiety corresponding to the English “butterflies in the stomach.” Although linguistically accurate, the translation resulted in a nonsense item. El-Rufaie and Absood (1987) also note that there are no words in Arabic strictly corresponding to the English words “anxiety” and “depression.” Vocabulary alone does not show how one perceives or makes sense of an actual word and effort is required to find ways of getting a particular concept across when translating a measure, even if

there is no word corresponding to that used in the source instrument in the target culture (Nolan, 2005).

The translated version of an instrument also requires standardisation within the target population; Aiken and Groth-Marnat (2006) state that the main purpose of standardisation is establishing the norm so that individual scores can be compared to it. This usually entails piloting the translated version with a sample from the target population and examining the psychometric properties of the translated instrument based on their scores. However, these tests of a translated measure are separate from, and can only come after good translation.

There are basic guidelines for translating a *standard instrument* (Brislin, 1970; Hambleton, 1994; Wild et al., 2005; Muniz, & Bartram, 2007; International Test Commission, 2010). Process is important because problems with process could contribute to translation errors (Solano-Flores, Backhoff & Contreras-Nino, 2009). A basic approach involves initially translating from language A into language B, then a different person using the translated version carries out a back translation from language B into language A (version A1). Finally, the equivalence of the meanings of versions A and A1 are compared. If the process fails to achieve equivalent meanings between the original version (source language) and the back-translated version, then the translation is considered inadequate. Brislin (1970) emphasises that familiarity with the subject area of the instrument will lead to more accurate translation, known as content effect, but translation by too specialist a team can lead to a wording in the target language that is not understood by significant numbers of lay people. Effective translation requires cultural knowledge, not just linguistic or subject-specific knowledge (Forsyth, Kudela, Levin, Lawrence & Willis, 2007).

Worldwide, there is a dearth of valid and reliable outcome measures that have been effectively translated into signed languages and normed with Deaf



populations (Samady et al., 2008). Although there has been an increasing interest in signing standard outcome measures for use with Deaf people via an interpreter (e.g., Wilson & Wells, 2009), this is different from producing a translated version with reliability and validity checked within the population where it will be used. Mental health outcome measures in signed languages for Deaf populations are important because of the high prevalence of mental health difficulties in Deaf populations (Hindley, Hill, McGuigan, & Kitson, 1994; Fellingner, Holzinger, & Pollard, 2012). Prior to the start of this study, the only available reliable BSL mental health measure was the BSL version of the Trait Emotional Intelligence Questionnaire (Gascon-Ramos, Young, Petrides, Stone & Woolfe, 2010). Since this study has been carried out, other BSL mental health outcome measures have been produced including the Patient Health Questionnaire (PHQ-9), the Generalized Anxiety Disorder (GAD-7), and the Work and Social Adjustment Scale (WSAS) (Rogers et al., 2013b). Other mental health measures have been translated into other sign languages, such as the Rosenberg Self-Esteem Scale in ASL (Crowe, 2002), the Multidimensional Health Locus of Control into ASL (Samady et al., 2008), and the 12-item General Health Questionnaire into Austrian Sign Language (Fellinger et al., 2005).

In what follows, we discuss the process of translation we used. We highlight eleven translation issues which arise specifically in respect of translating from a written into a signed language and seeking a cultural equivalence, within the constraints of a standardised outcome measure. We consider their generalisability to other translation tasks involving Deaf people. The psychometric properties of the BSL CORE-OM are reported elsewhere (Rogers et al., 2013a).

## **4. Methods**

### **4.1. Clinical Outcomes in Routine Evaluation – Outcome Measure**

The CORE-OM measure of global distress contains 34 items covering four domains: well-being, commonly experienced problems or symptoms, life/social functioning, and risk (to self and others). There are five response options for each item, which in the English version are: 'Not at all', 'Only occasionally', 'Sometimes', 'Often', and 'Most or all the time' (See figure 1 for the example of the CORE-OM English version). It has been validated with the general population as well as with users of primary and secondary mental health services (Evans et al., 2002). It has been translated into over 20 other written languages, including Italian (Palmieri et al., 2009), Slovak (Gampe, Biešcad, Balúnová–Labanicová, Timulák, & Evans, 2007), Portuguese (Sales, Moleiro, Evans & Alves, 2012) and Swedish (Elfström et al., 2012).

**IMPORTANT - PLEASE READ THIS FIRST**

This form has 34 statements about how you have been OVER THE LAST WEEK.  
 Please read each statement and think how often you felt that way last week.  
 Then tick the box which is closest to this.  
*Please use a dark pen (not pencil) and tick clearly within the boxes.*

Over the last week		Not at all	Only Occasionally	Sometimes	Often	Most or all the time	OFFICE USE ONLY
1	I have felt terribly alone and isolated	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> F
2	I have felt tense, anxious or nervous	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> P
3	I have felt I have someone to turn to for support when needed	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> F
4	I have felt O.K. about myself	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> W
5	I have felt totally lacking in energy and enthusiasm	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> P
6	I have been physically violent to others	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> R
7	I have felt able to cope when things go wrong	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> F
8	I have been troubled by aches, pains or other physical problems	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> P
9	I have thought of hurting myself	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> R

Figure 1. Example of the Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM) English version.

## **4.2. Translation procedure used for this study**

The translation of the English version of the CORE-OM into BSL followed the same procedure as the one outlined by Evans (2008) for translation between written languages, with additional consideration given to issues arising from the modality (signed not written) and grammatical properties of a visual, gestural, spatial language.

**First stage.** Five Deaf people bilingual in written English and BSL, from different professional backgrounds, each carried out a forward translation from English into BSL (first draft). They received information explaining the purpose of the study. The rationale for selecting people with a variety of professional backgrounds for the forward translation was to incorporate their potentially differing perspectives on the meaning of the statements in the CORE-OM. The five consisted of three women and two men: one Deaf qualified BSL/English interpreter, one Deaf clinical psychologist, one Deaf mental health support worker, and two lay Deaf people. Each did a forward translation of the CORE-OM into BSL, which they filmed individually, their translations being stored on video.

**Second stage.** During the second stage, first author [K. D. Rogers] and one of the people involved in the creation of the original outcome measure tool Chris Evans met with the group of forward translators. The group examined each of the five BSL versions created by the Deaf translators in the first stage. Together, they reviewed the differences between BSL versions, item by item. Discussions included clarifying the meaning of specific items in English and using this as a reference point for the identification of the preferred BSL version. Contemporaneous notes were taken of the discussion points, which were also filmed, for later reference. Where useful, Chris Evans was asked why items were phrased they were in the English and options in BSL explained to him to see if

decisions that had led to the version in written English would help choose the best option in BSL.

**Third stage.** This process resulted in the production of an agreed BSL version of the CORE-OM by one of the team of forward translators (second draft).

**Fourth stage.** The agreed second draft of the BSL version was translated back into English by two Deaf individuals independent to the study. They had not seen the original written English version or the first draft of the BSL version. In parallel, five BSL users were asked to complete the CORE-OM BSL, to check whether they had any difficulties with it. Any points raised, including requests for clarification, comments on the style of signing, or choice of specific signs, were noted.

**Fifth stage.** Feedback from the back translation team and the five people completing the BSL CORE-OM was considered in detail, comparing the back translators' comments and checking the original English version, as well as looking back to the BSL version. Further modifications were made to some of the BSL items. These steps led to the production of the final version of the CORE-OM in BSL, ready to be piloted. All major changes through stages three to five were explained to Chris Evans to provide quality assurance on the translation process for CORE System Trust<sup>2</sup>.

#### **4.3. Data collection using the final draft of the BSL CORE-OM**

The BSL CORE-OM was piloted using an online version whereby participants watched each item in BSL and clicked a response (See figure 2 for an example of the BSL version of the CORE-OM in the survey tool). The survey tool on the computer showed the BSL version of each CORE-OM item individually per screen page. A detailed description of the web hosting the BSL CORE-OM can be found in Rogers et al. (2013a). Data were encrypted and uploaded to secure storage. For full details of the piloting process see Rogers et al. (2013a). Previous studies have used similar techniques (Montoya et al., 2004; Fellingner et al., 2005; Graybill

et al., 2010). Subtitles were not included in order to establish the reliability of the BSL version without the influence of written English.



CORE-OM BSL 2.

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Mostly/Always

Back

Next

Cancel

*Figure 2.* Example of the British Sign Language (BSL) version of the CORE-OM in the survey tool (shown in SelectSurvey.NET software implementation).

## 5. Translation challenges

The following discussion on specific translation challenges and how they were resolved is based on an analysis of notes produced from the forward translators' initial meeting; observations of the difficulties in equivalence identified when the forward and back translations were compared; and from the discussions between translators, the originator of the standard instrument and first author [K. D. Rogers].

## 5.1. General Issues

**5.1.1. Implications of modality.** The BSL CORE-OM involved translating between languages and between modalities. The original is in a written form, whilst the BSL version, accessed online, is in a visual form. This shift in modality had implications for some very basic issues about the administration of the instrument; for example, the initial instructions. The instructions in the English CORE-OM use the word 'statement' when referring to each of the items. This would not make sense in BSL because participants would not read a statement, but instead would be watching a signer for each item. 'Statement' as a word can easily be translated into BSL, but to do so would be confusing because it would not match the physical realities of how the instrument would be accessed (on screen and through video). Consequently, instead of using 'statement', the BSL instruction was; "You will see that there are several video screens - 34 of them - which will be signed. What is signed on the screen relates to this week. You need to think about to what extent you have felt like that during this last week. There are five options that you can click; never, rarely, sometimes, often or mostly/always." Although the text of the items was not subtitled, the words or phrase for each of the rating anchors were provided as subtitles on the screen in the BSL instruction video when each of those anchors is signed.

**5.1.2. Clarity of the frequency anchors: analogical versus digital encoding.** The decision to subtitle the frequency anchors, but not the items themselves, arises from the need for the anchors to be reliable punctuation of a continuous scale of frequency. However, features of BSL led us to simplify some of the English words in the rating anchors; for example, 'not at all' was changed to 'never', 'only occasionally' was changed to 'rarely', and 'most or all the time' was changed to 'mostly/always'. 'Sometimes' and 'often' were unchanged. These changes were made primarily for reasons of clarity. For example, one of the BSL

signs used for 'often' and 'all the time' can involve using the same handshape, but the frequency of occurrence is differentiated by the speed of signing and facial expression; the more often something happens, the faster the sign and the more severe the facial expression but the actual handshape used remains the same: a good example of the use of more analogical encoding in BSL compared with written English.

In face to face conversations that happen in real time, any potential confusion can easily be clarified between signers. However, the rating scale would be accessed autonomously and without live interaction. Therefore, to avoid any possible confusion, it was decided that the sign for each rating on the scale would be made visually distinct in its form, not just its movement: digitally not analogically distinguished. Whilst this makes sense for defining anchor points, it has to be recognised that it is a deviation from normal interactive signed BSL and results from the asynchronous form of delivery. Written language communication has many centuries of cultural evolution to cope with this absence of interaction, something that is relatively culturally new in signed languages and has only really become available and necessary with the creation of filmed signing in the last half century. This aspect of "taped" signed language will no doubt evolve and develop over the years within signing communities.

**5.1.3. Pronouns and the direction of the signing.** In the English version, statements usually start with 'I', so, the reader will know that the statement is about them. For example, the English CORE-OM states: "I have felt despairing or hopeless." However, it is different when a signer uses 'I' in BSL. Imagine a participant watching the screen, seeing the signer on it produce a translated version of a statement that begins with 'I'. There is the risk that the participant might think that the statement refers to what *the signer* might be feeling, rather than asking what *they*, the participant, feel. To minimise possible confusion, it was

agreed to change the pronoun from 'I' to 'You', resulting in a change in the direction of the signed item. 'I have felt despairing or hopeless' in English becomes 'This week, you (with the signer in the video signing towards the camera and respondent) have felt helpless and hopeless' in BSL. In this way it is clear that whoever is watching the video will know that it is asking them to what extent *they* have felt a certain way in the last week.

**5.1.4. Format of the BSL CORE-OM shown on screen.** The CORE-OM requires a participant to consider their feelings 'over the last week', rather than more generally. The English version is printed on a double-sided piece of paper, so one can easily glance back and see 'Over the last week' clearly written at the top of both pages. However, in the BSL version, each item requires its own page in the web interface to accommodate the necessary separate video screen containing the BSL version of that specific item. There was concern that some people might forget that the statements are about how one has felt in the last week, rather than 'in the moment', or even in the last year, because the reminder of the time frame was missing. It was therefore agreed that each BSL statement on video would start with 'In the last week'.

## **5.2. Specific concepts within CORE-OM items**

**5.2.1. Emotional state in BSL.** Some items in the CORE-OM include words related to one's emotional state, such as 'anxious' or 'nervous'. In English, 'anxiety' is one word, but it can have a range of meanings such as physical feelings of anxiety (sweatiness and heart pounding) and cognitive/emotional connotations (worrying thoughts). In BSL, there is more than one sign for anxiety depending on context and the nuance of the meaning that is sought. Therefore, covering the *range* of meanings in one sign for 'anxiety' was challenging. One solution was to use a sign that involved the signer tapping on their heart. This was non-specific and could potentially include a range of meanings; being anxious or



nervous. However the same sign, in terms of its shape (index finger curved), location (placed on the heart) and its movement (tapping several times), was used for both 'anxious' and 'nervous'. The differentiation in meaning is subtle and produced by the use of slightly different facial expressions whilst signing. Once again, the issue of remote access to the signing, rather than real-time, live interaction, raised concerns about potential confusion between the two signs. It was decided to use the sign for 'anxiety' incorporating two bent fingers placed on the side of the head, shaking the hand. The sign involving tapping the heart would be used for 'nervous'. In this way each sign was distinct when viewed via video, but broad enough to encompass a range of potential meanings.

**5.2.2. The intensity of facial expression in sign language.** The intensity of facial expression in BSL is important and can modify a sign made with the hands to cover a spectrum of intensity that in English might be communicated with a succession of different words indicating intensity: "uneasy," "anxious," "worried," "terrified" with qualifying adjectives used to add gradation "anxious," "very anxious," "extremely anxious." In BSL, the intensity of feeling throughout such a continuum can be indicated using the same sign but with progressively more intense facial expressions.

Some items were discussed in order to clarify the meaning of the statement. For example, "I have felt OK about myself" looks straightforward in English, but some of the translators were not sure which sign to use: a thumbs up (as in "I am fine") or a moving open hand (as in "I am not too bad"). The 'thumbs up' sign, with its positive connotations, might indicate that feeling OK is positive, as opposed to neutral. Additionally, because the statement is about how one feels about *oneself*, it was initially agreed to include a sign in which one's hands 'open up' the chest so that the signer can 'look inside oneself' (indicating insight), so that viewers would be clear that the item was asking about *oneself*. However, the two back translators

interpreted the second draft of the BSL version differently: “This week, you have felt OK in yourself” and “This week you have explored your feelings and feel good.” To avoid confusion about this item, it was agreed, in the final draft, to use only head movement to indicate the reference to oneself.

**5.2.3. Use of visually motivated signs without giving examples.** As BSL is a visual language, some signs can be iconic and visually motivated, although others are arbitrary, whereas words in English are completely arbitrary (Sutton-Spence & Woll, 1999). An example of this might be the term ‘suicidal’; in English, the written word and the sound of the word itself do not represent the meaning of the term ‘suicide’. However, in BSL the signs commonly used for suicide/suicidal may, to a greater or lesser extent, visually represent the action of killing oneself in a variety of different ways such as by hanging. This issue was resolved by translating the statement to refer to ‘ending one’s life’, rather than to ‘suicide’ but again this is a deviation from typical conversational BSL.

Statements such as “I have been physically violent to others” also proved difficult to translate into BSL without potentially giving visual examples which can be suggestive. “Physically violent” could mean anything including hitting, slapping, pushing, banging, or throwing things. Using certain signs for these examples could lead to the respondent thinking of these specifics and possibly omitting other aspects of physically violent behaviour. In order to resolve this problem the signer did not give specific examples but made it clear that the aim was to harm another person.

**5.2.4. Using the appropriate sign for the specific context.** Specific words in certain items could create difficulties. For example, ‘wrong’ in the statement: “I have felt able to cope when things go wrong.” In English, it is not relevant who was at fault. However, if the sign for wrong (a fist with the little finger extended) were to be used, it could lead to viewers thinking that ‘wrong’ in this instance meant ‘fault’.

This is because this sign for wrong can sometimes be used in the context of 'fault'. In BSL, this sign is usually associated with 'bad'. It was agreed not to use the BSL sign for wrong, instead replacing it with the sign for 'messed up', which was appropriate for this context.

For a different item, the English statement, "I have thought of hurting myself," it was agreed to use the lip-pattern for the word 'harm' instead of 'hurt' when signing. One translator felt that for Deaf BSL users, the sign used with the lip-pattern 'hurt' was more related to emotions; e.g., 'I feel hurt!' whereas 'harm' was more physical and clearer for this item.

**5.2.5. Confirmation of the statement.** Sometimes in BSL, confirmation or negation is indicated by a sign at the end or near the end of a sentence. For example, when translating the statement "Tension and anxiety have prevented me doing important things," the sign for 'cannot' is added at the end to reinforce the concept that negative feelings (tension and anxiety) are what is stopping one from doing important things. 'Cannot' in BSL is equivalent to 'prevent' in this context. This is one example of how sign languages do not follow a "Subject, Verb, Object" construction. Instead, they use multiple and *simultaneous* channels for language construction such as location, movement, handshape and orientation (Sutton-Spence & Woll, 1999; Vermeerbergen & Leeson, 2011).

**5.2.6. Words in a Deaf social context.** Some items might be perceived differently by hearing people and Deaf people, for example: "Talking to people has felt too much for me." 'Talking' in this context could be misinterpreted as meaning communicating in spoken language only. If a Deaf person struggles to make themselves understood when talking, they may strongly agree with this statement, and yet feel perfectly able to communicate with others in ways they may have not taken this statement to incorporate. Hearing people might simply consider the word 'talking' to mean speaking with other people and not think of it as including

various other ways of communicating. It was therefore agreed to use a BSL sign indicating 'discussing', instead of 'talking'.

**5.2.7. Challenges of translating English words into BSL.** Not all English words can be directly translated into BSL; these problem words are sometimes known as 'false friends'. For example, 'warmth' in English can mean affection, heat, and friendliness. When talking about affectionate warmth, the sign 'warmth' in BSL would not make sense as it is usually associated only with heat.

Furthermore, some of the statements in the CORE-OM are in the passive case, or abstract English; information as to the 'who' or 'what' is not mentioned. However, in BSL, passive abstract information, such as 'it' in the statement "I have thought it would be better if I were dead" needs to be made more explicit – to this end, several signs are required to elaborate on what 'it' might be ('I', 'family', 'they', etc.). In order to maintain the abstract nature of the original, it was agreed that 'it' would be removed in translation, leaving it vague regarding who would benefit if one were dead.

## **6. Discussion**

The example we have used in this study relates to one sign language, British Sign Language, and one translation context - a standardised outcome measure tool used within mental health services. The question therefore arises, whether the translation challenges we have highlighted are generalisable to other signed languages and other translation contexts. The multi-dimensional nature of signed languages in comparison with written languages is the same regardless of the specific languages involved. Samady et al. (2008) describe this as the difference between working in three rather than two dimensions and describe translations into ASL as: "composed of dynamic three-dimensional pictures created with the hands, body, and facial expressions" (Samady et al., 2008, p. 481). However, Stokoe (1979) regards signed languages as consisting of four dimensions:

“Speech has only one dimension...; writing has two dimensions; models have three; but only signed languages have at their disposal four dimensions – the three spatial dimensions accessible to a signer’s body, as well as the dimension of time” (Stokoe, 1979, as cited in Sacks, 1989, p. 89-90). Slobin (2008, p. 15) describes this dimension in terms of “*gradient* phenomena that are available to signers – rate and intensity and expansiveness of movement.” These phenomena can radically change the nuance of meaning associated with the same signed expression. Although as we have demonstrated in this study, the finely grained nuances of movement which create exact distinctions in meaning when used in conjunction with the same handshape or location of sign may not be the best choice in all circumstances. They leave open possibilities of ambiguity of meaning, particularly when signed expressions are viewed from a distance (on screen) rather than interacted with as a result of live exchanges.

However, standardised outcome measures commonly require responses indicating self-assessed degrees of intensity such as ‘rarely’, ‘often’, ‘frequently’ etc. Therefore the kinds of gradient phenomena afforded by the fourth dimension of sign languages can also be highly advantageous. It allows for the easy expression of degrees of feeling through the rate and intensity of a signed expression, usually in conjunction with other features of facial expression. In this sense it is akin to the grading of volume in spoken languages and repetition of words to convey intensity (‘no’ said quietly is quite different from ‘no’ said loudly and/or repeated). This kind of grading of intensity, whether in signed or spoken languages is usually referred to as ‘analogical’ in that the medium allows the possibility of conveying different degrees of intensity on a continuous scale. By contrast written texts cannot do this in the same way and are regarded as digital; they have singular points of expression which in and of themselves indicate differentiations in intensity usually through the choice of vocabulary (e.g., ‘only

occasionally' versus 'often') or by attributing meanings to numbers (e.g., 1 versus 3). The two dimensional written text comes closest to analogical encoding of a continuous gradient when using two dimensional visual means, e.g., no **no NO**.

In common with broad translation literature as well as that specific to sign languages (Graybill et al., 2010), we knew that cultural equivalence of key concepts was critical. The linguistic correctness of a translated item was of less importance than the capacity of the translated item to be meaningful within the cultural context of those who would be completing the outcome measures. Like Graybill et al. (2010) we found that some concepts expressed by a single word could not be expressed by a single sign, and like Montoya et al. (2004), that some phrases in spoken language had no equivalent in a signed language. But we also demonstrated that even when a culturally equivalent expression or term is found, it still may not be meaningful, because the root concept is not one that is common in the lives of those completing the outcome measure, or may be differently understood. We note the example from our study of 'feeling that you can talk to people'. In the context of other translation works on CORE-OM, Chris Evans noted an often cited example of difficulty in translations between spoken language cultures were the "risk to other" items as different cultures vary in the amount of shame involved in discussing anger and violence to the extent that it can be a seriously taboo topic in some cultures. Similarly, embedded cultural and religious links between suicide and guilt or shame significantly influence the meaning attributed to the concept of 'risk' in ways not considered in societies where risk may behave a more functional or personally emotional meaning only.

The online format in our study also raises new issues for consideration. Generally, there has been a growth in research being carried out by means of computer and issues pertaining to the use of using paper-and-pen versus computer administrated outcome measures has been debated (Epstein,

Klinkenberg, Wiley, & McKinley, 2001; Buchanan, 2002). Buchanan (2002), for example, questions whether online delivery of outcome measures might skew norms and argues that these should be established for the online versions and compared with the paper-and-pen versions. Other studies have reported the equivalence of psychometric properties in both types of the administration of the outcome measure (e.g., Kleinman, Leidy, Crawley, Bonomi, & Schoenfeld, 2001). One of the benefits of using online outcome measure over the paper-and-pen is identified as the potential to reach a large number of people, including those who may be at risk (Buchanan, 2002). In our study, the key advantage to online delivery was reaching a large number of a highly dispersed population in a format best suited the properties of the language used *and* which ensured a fixed translation whose properties could be formally explored (Rogers et al., 2013a).

Into the future, a key line of enquiry will be the investigation of the influence of the onscreen format on participants' responses. This study suggested implications for the signed modality and online format which should be investigated. For example, the necessity of repositioning self-referential words ('I' and 'My' to 'You' and 'Your'), identified also by Montoya et al., (2004) has been clearly justified but goes against translation practice in the mainstream. What is its impact on the psychological self-reflection processes required to respond if a declarative 'you' or 'your' prompts that process rather a personalised 'I' or 'my'? Another issue relating to signed translations is that the instruction and the statements are delivered by a particular individual signing, whereas written translations are undesignated coming from a completely unknown, abstract other. This raises the question of whether the presence of an identifiable individual signer might influence the way in which respondents answer. Sign Language communities, even on a national scale, are small communities; it is perfectly possible that the signer is known to a proportion of those who take the outcome measure. Their

personal characteristics, family life, social status, professional expertise and role in the Deaf community might also be known. In our study we did not use an interpreter to sign the final versions of the BSL CORE-OM but deliberately used a native Deaf signer with an academic linguistic background. We did not investigate the implications of this choice in comparison with using a hearing interpreter who might be regarded as both an insider and an outsider. Yet the interpreter's identity outside of this role would also have had an influence and s/he would have likely been known by some participants. The broader issue of whether it matters who delivers a seen signed translation and its effects requires investigation as online delivery of signed outcome measures is likely to grow.

Although the BSL version of the CORE-OM has now been produced, it does not necessarily mean that it is suitable for all signing Deaf communities in the United Kingdom. Issues that need to be considered include the regional variations of BSL across Deaf communities and the range of BSL competencies that exists within those communities. For example, the English version of the CORE-OM has been modified and simplified people with learning disabilities. Having established the BSL-CORE-OM it will now be possible to create a simpler version for those Deaf people with learning disabilities or who have low levels of BSL.

## **7. Conclusion**

Despite considerable challenges, we were able to use the best practice translation processes formalised and required by the originators of the CORE-OM outcome measure to produce a reliable and valid version of this standardised outcome measure. In so doing we have identified translation challenges and issues specific to signed languages which are of generalisable significance. Robust, reliable outcome measures are vital to ensuring that the mental well-being of a Deaf person can be thoroughly assessed and appropriate services provided as has been the case for their hearing counterparts for some considerable time.



## **Notes**

<sup>1</sup> 'Deaf' with a capital 'D' is used when referring to a person who is culturally Deaf and whose first or preferred language is British Sign Language. 'd/Deaf' is used to indicate those who are deaf without a specific differentiation. In the case of children and young people we use the term 'deaf', as it might not yet be clear what their preferred cultural identity is.

<sup>2</sup> CORE System Trust is made up of some of the authors of the original instrument and one of the main sponsors of the work that developed its many applications. It is a not for profit company that holds and protects the copyright so the measure remains free to reproduce on paper and it maintains the quality standards for translation. Contact Chris Evans if seeking more information on the CORE-OM, other CORE measures and the CORE system more generally.

## **Funding**

Katherine D. Rogers's doctoral research fellowship by the National Institute for Health Research (Award reference number: DRF-2009-02-118).

## **Acknowledgements**

This article presents independent research commissioned by the National Institute for Health Research (NIHR). The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

## References

- Aiken, L. R., & Groth-Marnat, G. (2006). *Psychological Testing and Assessment* (12th Ed.). Boston, MA: Pearson Education Group, Inc.
- Barkham, M., Evans, C., Margison, F., McGrath, G. Mellor-Clark, J., Milne, D., & Connell, J. (1998). The rationale for developing and implementing core outcome batteries for routine use in service settings and psychotherapy outcome research. *Journal of Mental Health*, 7(1), 35-47. doi:10.1080/09638239818328
- Barkham, M., Bewick, B., Mullin, T., Gilbody, S., Connell, J., Cahill, J., ... Evans, C. (2012). The CORE-10: A short measure of psychological distress for routine use in the psychological therapies. *Counselling and Psychotherapy Research: Linking research with practice*. Advance online publication. doi:10.1080/14733145.2012.729069.
- Brislin, R. W. (1970). Back-translation for cross-cultural research. *Journal of Cross-Cultural Psychology*, 1(3), 185-216. doi:10.1177/135910457000100301
- Buchanan, T. (2002). Online Assessment: Desirable or Dangerous? *Professional Psychology: Research and Practice*, 33(2), 148-154. doi:10.1037//0735-7028.33.2.148
- Coaley, K. (2009). *An Introduction to Psychological Assessment and Psychometrics*. London, England: Sage.
- Crowe, T. V. (2002). Translation of the Rosenberg Self-Esteem Scale into American Sign Language: A Principal Components Analysis. *Social Work Research*, 26(1), 57-63. doi:10.1093/swr/26.1.57
- El-Rufaie, O. E. F. A., & Absood, G. (1987). Validity study of the Hospital Anxiety and Depression Scale among a group of Saudi patients. *British Journal of Psychiatry*, 151(5), 687-688. doi:10.1192/bjp.151.5.687

- Elfström, M. L., Evans, C., Lundgren, J., Johansson, B., Hakeberg, M., & Carlsson, S. G. (2012). Validation of the Swedish version of the Clinical Outcomes in Routine Evaluation Outcome Measure (CORE-OM). *Clinical Psychology & Psychotherapy*. Advance online publication. doi:10.1002/cpp.1788
- Epstein, J., Klinkenberg, W. D., Wiley, D., & McKinley, L. (2001). Insuring sample equivalence across internet and paper-and-pencil assessments. *Computers in Human Behavior*, 17(3), 339-346. doi:10.1016/S0747-5632(01)00002-4
- Evans, C. (2008). *Translating and "normalising" CORE system: CORE System Trust (CST) position statement*. Retrieved from [http://www.psychtc.org/CORE-OM/Translating\\_CORE-OM\\_CST\\_position\\_statement.pdf](http://www.psychtc.org/CORE-OM/Translating_CORE-OM_CST_position_statement.pdf)
- Evans, C., Mellor-Clark, J., Margison, F., Barkham, M., Audin, K., Connell, J., & McGrath, G. (2000). CORE: Clinical Outcomes in Routine Evaluation. *Journal of Mental Health*, 9(3), 247-255. doi:10.1080/jmh.9.3.247.255
- Evans, C., Connell, J., Barkham, M., Margison, F., McGrath, G., Mellor-Clark, J., & Audin, K. (2002). Towards a standardised brief outcome measure: psychometric properties and utility of the CORE-OM. *British Journal of Psychiatry*, 180(1), 51-60. doi:10.1192/bjp.180.1.51
- Fellinger, J., Holzinger, D., Dobner, U., Gerich, J., Lehner, R., Lenz, G., & Goldberg, D. (2005). An innovative and reliable way of measuring health-related quality of life and mental distress in the deaf community. *Social Psychiatry and Psychiatric Epidemiology*, 40(3), 245-250. doi:10.1007/s00127-005-0862-9
- Fellinger, J., Holzinger, D., & Pollard, R. (2012). Mental health of deaf people. *The Lancet*, 379(9820), 1037-1044. doi:10.1016/S0140-6736(11)61143-4
- Forsyth, B. H., Kudela, M. S., Levin, K., Lawrence, D., & Willis, G. B. (2007). Methods for Translating an English-Language Survey Questionnaire on

- Tobacco Use into Mandarin, Cantonese, Korean, and Vietnamese. *Field Methods*, 19(3), 264-283. doi:10.1177/1525822X07302105
- Gampe, K., Biešcad, M., Balúnová–Labanicová, L., Timulák, L., & Evans, C. (2007). Slovenská adaptácia metódy CORE-OM (Clinical Outcomes in Routine Evaluation – Outcome Measure). [A Slovak adaptation of CORE-OM (Clinical Outcome in Routine Evaluation – Outcome Measure)]. *Ceská a slovenská psychiatrie. [Czech and Slovak Psychiatry]*, 103(1), 4–13. Retrieved from <http://www.cspsychiatr.cz/detail.php?stat=312>
- Gascon-Ramos, M., Young, A. M., Petrides, K. V. Stone, C., & Woolfe, T. (2010). *TEIQue British Sign Language Version - a pilot project (Final report to the Nuffield Foundation, February 2010)*. Manchester, United Kingdom: Authors.
- Graybill, P., Aggas, J., Dean, R. K., Demers, S., Finigan, E. G., & Pollard, R. Q. (2010). A Community-Participatory Approach to Adapting Survey Items for Deaf Individuals and American Sign Language. *Field Methods*, 22(4), 429-448. doi:10.1177/1525822X10379201
- Hambleton, R. K. (1994). Guidelines for adapting educational and psychological tests: A progress report. *European Journal of Psychological Assessment*, 10(3), 229-244.
- Hambleton, R. K., & Patsula, L. (1998). Adapting tests for use in multiple languages and cultures. *Social Indicators Research*, 45(1-3), 153-171. doi:10.1023/A:1006941729637
- Hindley, P., Hill, P. D., McGuigan, S., & Kitson, N. (1994). Psychiatric Disorder in Deaf and Hearing Impaired Children and Young People: A Prevalence Study. *Journal of Child Psychology and Psychiatry*, 35(5), 917-934. doi:10.1111/j.1469-7610.1994.tb02302.x
- International Test Commission. (2010). International Test Commission Guidelines for Translating and Adapting Tests. Retrieved from <http://www.intestcom.org>

- Jackson, C. J., & Furnham, A. (2000). *Designing and Analysing Questionnaires and Surveys: A Manual for Health Professionals and Administrators*. London, UK: Whurr Publishers Ltd.
- Kleinman, L., Leidy, N. K., Crawley, J., Bonomi, A., & Schoenfeld, P. (2001). A Comparative Trail of Paper-and-Pen Versus Computer Administration of the Quality of Life in Reflux and Dyspepsia (QOLRAD) Questionnaire. *Medical Care*, 39(2), 181-189. Retrieved from <http://www.jstor.org/stable/3768040>
- Lim, L., & Firkola, P. (2000). Methodological issues in cross-cultural management research: Problems, solutions, and proposals. *Asia Pacific Journal of Management*, 17(1), 133-154. doi:10.1023/A:1015493005484
- Montoya, L. A., Egnatovitch, R., Eckhardt, E., Goldstein, M., Goldstein, R. A., & Steinberg, A. G. (2004). Translation Challenges and Strategies: The ASL Translation of a Computer-Based, Psychiatric Diagnostic Interview. *Sign Language Studies*, 4(4), 314-344. doi:10.1353/sls.2004.0019
- Muniz, J. & Bartram, D. (2007). Improving International Tests and Testing. *European Psychologist*, 12(3), 206-219. doi:10.1027/1016-9040.12.3.206
- Nolan, J. (2005). *Interpretation: Techniques and Exercises*. Clevedon, England: Multilingual Matters Ltd.
- Palmieri, G., Evans, C., Hansen, V., Brancaloni, G., Ferrari, S., Porcelli, P., ... Rigatelli, M. (2009). Validation of the Italian version of the Clinical Outcomes in Routine Evaluation Outcome Measure (CORE-OM). *Clinical Psychology and Psychotherapy*, 16(5), 444-449. doi:10.1002/cpp.646
- Rogers, K. D., Young, A., Lovell, K., & Evans, C. (2013a). The reliability of British Sign Language and English versions of the CORE-OM with d/Deaf populations in the UK: a pilot study. *Journal of Deaf Studies and Deaf Education*.
- Rogers, K. D., Young, A., Lovell, K., Campbell, M., Scott, P. R., & Kendal, S. (2013b). The British Sign Language Versions of the Patient Health

- Questionnaire, the Generalized Anxiety Disorder 7-Item Scale, and the Work and Social Adjustment Scale. *Journal of Deaf Studies and Deaf Education*, 18, 110-122. doi:10.1093/deafed/ens040
- Sacks, O. (1989). *Seeing Voices*. London, England: Picador.
- Sales, C., Moleiro, C., Evans, C., & Alves, P. (2012). Versão Portuguesa do CORE-OM: Tradução, adaptação e estudo preliminar das suas propriedades psicométricas (The Portuguese version of CORE-OM: Translation, adaptation and preliminary data on its psychometric properties). *Interface*, 39(2), 54–59. Retrieved from <http://www.scielo.br/pdf/rpc/v39n2/03/pdf>
- Samady, W., Sadler, G. R., Nakaji, M., Malcarne, V. L., Trybus, R., & Athale, N. (2008). Translation of the Multidimensional Health Locus of Control Scales for Users of American Sign Language. *Public Health Nursing*, 25(5), 480-489. doi:10.1111/j.1525-1446.2008.00732.x
- Solano-Flores, G., Backhoff, E., & Contreras-Nino, L. A. (2009). Theory of Test Translation Error. *International Journal of Testing*, 9(2), 78-91. doi:10.1080/15305050902880835
- Slobin, D. I. (2008). Breaking the Molds: Signed Languages and the Nature of Human Language. *Sign Language Studies*, 8(2), 114-130. doi:10.1353/sls.2008.0004
- Sutton-Spence, R. & Woll, B. (1999). *The linguistics of British Sign Language: an introduction*. Cambridge, UK: Cambridge University Press.
- Todd, C, & Bradley, C. (1994). Evaluating the design and development of psychological scales. In C. Bradley (Ed.) *Handbook of psychology and diabetes: A guide to psychological measurement in diabetes research and practice* (pp. 15-42). Chur, Switzerland: Harwood Academic.
- Vermeerbergen, M., & Leeson, L. (2011) European signed languages – towards a typological snapshot. In B. Kortmann, J. Van der Auwera (Eds.). *The*

*languages and linguistics of Europe: A comprehensive guide* (pp. 269-290).

Berlin, Germany: Mouton de Gruyter.

Wild, D., Grove, A., Martin, M., Eremenco, S., McElroy, S., Verjee-Lorenz, A., & Erikson, P. (2005). Principles of good practice for the translation and cultural adaptation process for Patient-Reported Outcomes (PRO) measures: report of the ISPOR task force for translation and cultural adaptation. *Value in Health*, 8(2), 94–104. doi:10.1111/j.1524-4733.2005.04054.x

Wilson, J. A. B., & Wells, M. G. (2009). Telehealth and the Deaf: A Comparison Study. *Journal of Deaf Studies and Deaf Education*, 14(3), 386-402. doi:10.1093/deafed/enp008

Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, 67(6), 361–370. doi:10.1111/j.1600-0447.1983.tb09716.x

## **CHAPTER SIX: PAPER C**

The reliability of British Sign Language and English versions of the Clinical Outcomes in Routine Evaluation – Outcome Measure with d/Deaf populations in the UK: a pilot study

Rogers, K. D., Evans, C., Campbell, M., Young, A., & Lovell, K.

Submitted for publication



## 1. Abstract

Previous research has established that the mental well-being of d/Deaf people is poorer than that of the hearing populations. However, there is a paucity of valid and reliable mental health instruments in sign language that have been normed with d/Deaf populations. The aim of this study was to find out the reliability of the Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM) with d/Deaf populations. A BSL (British Sign Language) version was produced using a team approach to forward translation and a back-translation check. The CORE-OM was incorporated into an online survey, to be completed in either BSL or English. In December 2010 to March 2011, data were collected from 136 d/Deaf people. Cronbach's alpha was used to measure the internal consistency of the items in the CORE-OM. Comparisons were made between each version, including comparisons with the non-clinical hearing populations in a previous study. The reliability for the overall score, as well as the non-risk items in both BSL and English versions, was found to be satisfactory. The internal reliability of each domain in the BSL version was found to be good and comparable to the English version in hearing populations. Two domains of the CORE-OM in the English version completed by d/Deaf people were questionable. This is the first time the CORE-OM has been translated into BSL, and it was shown to be reliable. The English version of CORE-OM raised the question whether it is possible to use a mental health assessment with d/Deaf populations that has been standardised with hearing populations. Furthermore, this study has shown that it is possible to collect data from d/Deaf populations in the UK via the web (both in BSL and English).

**Keywords:** d/Deaf people, mental health assessment, sign language, reliability

**What is already known about this topic**

- There are few mental health assessments available in British Sign Language (BSL).
- There is little research comparing the reliability of using English and BSL versions of mental health assessments with d/Deaf populations.

**What this paper adds**

- The reliability of the CORE-OM BSL version was found to be good but two domains of risk and functioning in the English version had lower reliability in the d/Deaf population.
- There may be problems using an assessment with d/Deaf populations that has been standardised with hearing populations.
- It is feasible to collect questionnaire data from d/Deaf populations via the web.

## 2. Introduction

In the UK, around one in a thousand children are born deaf (Bamford *et al.*, 2004). In developed countries, approximately 95% deaf children have hearing parents (Michell and Karchmer, 2004). The impact of deafness is highly variable, dependent on complex interactions such factors as the degree of hearing loss, age of onset and age of recognition, family resources (emotional and environmental), whether parents are hearing or d/Deaf, type and quality of child and family support and co-occurrence with disability and illness. Capital 'D' is used when referring to a person whose first language is British Sign Language (BSL) and who is culturally Deaf (following Woodward, 1972). Lower case 'd' is used to refer to people with a hearing loss who use spoken language and do not identify themselves as culturally Deaf. Therefore d/D is used inclusively to mark both populations without any specific differentiation. However, despite this heterogeneity, some issues remain constant: d/Deaf children are at risk of poor exposure to sufficient quantity and quality of language to achieve optimal language acquisition whether in signed or spoken language (Marschark, 2007); the majority experience significant difficulties in achieving age appropriate literacy (Mayer, 2007); d/Deaf children are between 2 and 4 times more likely to be victims of abuse than their hearing counterparts (Sullivan and Knutson, 2000) and over 40% of d/Deaf children experience mental health problems, in comparison with 25% of the hearing populations (Department of Health, 2005).

A visual language, British Sign Language (BSL) is the primary language of the British Deaf populations. It was recognised as an official language by the British Government in 2003. In the UK, there are at least 100,000 Deaf people who use BSL as their preferred language (British Society for Mental Health and Deafness, 2010). However, access to health and social care services for d/Deaf people has historically been poor in comparison to hearing populations, it is more expensive to

ensure that there are accessible services for d/Deaf people (Department of Health, 2002). The Department of Health (2005) has recognised that professionals at primary care service level failed to identify the early symptoms of possible mental health difficulties in some d/Deaf people.

There is a paucity of well-being assessment instruments/measures that have been translated into signed languages that have been piloted with d/Deaf populations to establish the reliability of the assessment. This paper will focus on d/Deaf people who took part in a pilot study of the Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM) to find out the reliability of the CORE-OM with d/Deaf populations. Although d/Deaf people share one common feature, nevertheless, they are heterogeneous populations, rather than homogeneous (Roberts and Hindley, 1999) as some consider themselves part of the Deaf community and Deaf culture, whereas some do not.

### **2.1. Rationale for the study**

Our aim was to determine the reliability of the BSL and English versions of the CORE-OM with d/Deaf populations. The first stage involved translating the CORE-OM into British Sign Language (BSL) and conducting a pilot study. This paper focuses on the method of translating the well-being assessment into BSL (phase one), as well as the reliability of the results from the pilot study with d/Deaf populations (phase two) using both the BSL and English versions, and the exploratory analysis of the BSL item(s) in the CORE-OM that were considered as to not to have correlated well with other items were revised in order to improve reliability and then piloted with a small number of Deaf people (phase three).

The rationale for translating the CORE-OM into BSL was that BSL is the *preferred* language used amongst the Deaf populations in Britain. It is erroneous to assume that written English is accessible to many d/Deaf people as levels of literacy are significantly lower than in hearing populations (Mayer, 2007). BSL has

no written form and is an entirely visual language that uses space, location, handshapes and movement to convey meaning (Sutton-Spence and Woll, 1999). Few well-being assessments are available in BSL, or indeed any other signed languages, and even fewer have determined reliability and validity (Samady *et al.*, 2008). Moreover, there is little knowledge of how successful translated signed language assessments are both linguistically and conceptually, with d/Deaf populations. In addition there is a paucity of literature on how well unmodified English versions of measures can be used with d/Deaf populations bearing in mind the issues of poor literacy and cultural differences discussed earlier. There are few studies that have attempted to test two language versions (BSL and English) of the same assessment with d/Deaf populations. It is important to evaluate how useful each of the versions of the CORE-OM might be, as this will tell us whether or not using a particular language version with d/Deaf populations in the community matters. Having reliable, validated assessments for d/Deaf populations is important to the health of d/Deaf people. It will assist services such as mental health teams working with d/Deaf people in being able to identify difficulties in the first instance and to record differences in d/Deaf individuals' scores as a result of treatment.

### **3. Methods**

This study was given ethical approval by the School of Nursing, Midwifery and Social Work Research Ethics Committee at the University of Manchester. There were two phases: phase one involved translating the CORE-OM into BSL and phase two consisted of the pilot study.

#### **3.1. Psychometric properties of the CORE-OM**

The Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM), a self-report measure, (Barkham *et al.*, 1998), measures global distress and has 34 items with four domain scores of measurement: well-being, commonly

experienced problems or symptoms, life/social functioning, and risk to self and others. The CORE-OM has been checked for convergent validity and it correlates well with measurements of depression such as the Beck Depression Inventory (Barkham *et al.*, 2007; Cahill *et al.*, 2006) and the Clinical Interview Schedule (Connell *et al.*, 2007). There are four bands above the cut off score; mild, moderate, moderately severe, and severe (CORE Partnership, 2007). There are two ways of scoring the CORE-OM. The original scoring (Evans *et al.*, 2002) used item score averages, giving a range of 0 to 4, with the cut-off score differing for gender (1.17 for males and 1.27 for females). More recently Connell *et al.* (2007) recommended multiplying the average item score by 10, giving a range of between 0-40 and suggested recommended a cut-off score of 10 between the general populations and the clinical populations regardless of gender. In both methods lower scores indicate more positive well-being. This study uses the earlier scoring to facilitate comparison with the hearing populations data in Evans *et al.* (2002). The clinical cut-off score for d/Deaf populations is not known and it is not appropriate to transfer the norm to d/Deaf populations. The CORE-OM has been translated into over 20 languages including Slovak (Gampe *et al.*, 2007), Italian (Palmieri *et al.*, 2009) and Swedish (Elfström *et al.*, 2012) validated for a range of cultural groups. For further information on translation contact Chris Evans. The CORE-OM has also been translated into British Sign Language (BSL) for Deaf people (Rogers, Young, Lovell & Evans, 2013).

### **3.2. Phase One: Translating the CORE-OM into BSL**

The translation was carried using the following procedure outlined by a member of the CORE System Trust team (Evans, 2008), although there were slight modifications to the procedure to meet the needs of piloting in a visual language; see Figure 1.

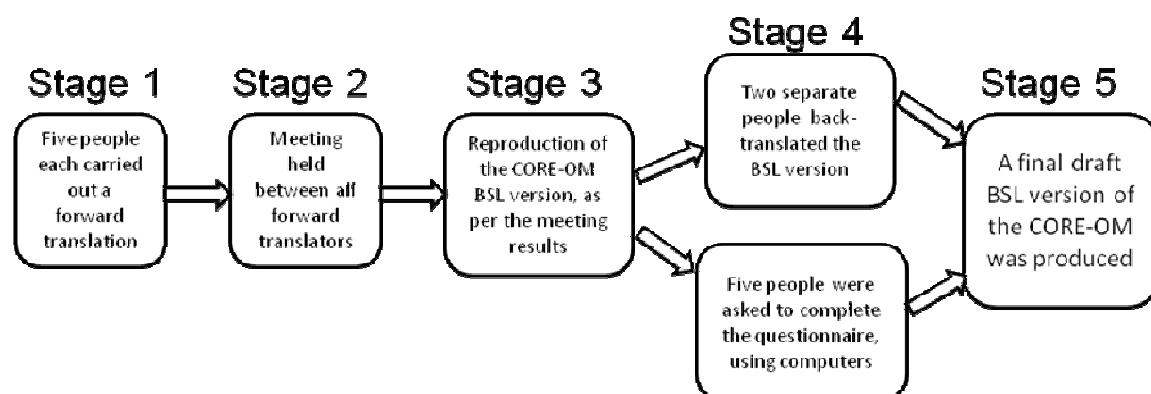


Figure 1. Translation procedure for translating the CORE-OM into BSL

During the first stage, five Deaf people from differing professional backgrounds who were bilingual in English and BSL, each carried out a forward translation from English into BSL (first draft). The forward translation team consisted of three women and two men and included one Deaf qualified BSL/English interpreter, one Deaf clinical psychologist, one Deaf mental health support worker, and two lay Deaf people. It is common translational practice for forward translators' first or main language to be the same as the target language (Wild *et al.*, 2005). Each forward translation was filmed individually, and their translations were stored on video. The rationale for selecting people with a variety of professional backgrounds to complete the forward translation was to gain different perspectives on the meaning of the statements in the CORE-OM.

In the second stage, the first author (Rogers), who is bilingual in BSL and English, and Chris Evans, the creator of the original assessment tool, met with the forward translators as a group. Two BSL/English interpreters were present at the meeting to aid the discussion between them. The group examined each of the five BSL versions in video format that were created by the Deaf translators in the first stage. They reviewed the differences between the BSL versions and scrutinised each individual item of the CORE-OM. This involved clarifying the meaning of the

English version and using this as a reference point for the identification of the preferred BSL version for each item.

In the third stage, the group had now an agreed BSL version of the CORE-OM by one of the team of forward translators (second draft).

In the fourth stage, two tasks occurred simultaneously: a back-translation of the BSL version, to test equivalence to the original English written version, and a pre-pilot of the BSL version, to check if any difficulties occurred. The back-translating task involved the agreed second draft of the BSL version, being translated back into English by two Deaf individuals (not previously involved in the study). They had not seen the original written English version nor the first draft of the BSL version. The pre-pilot was carried out with five BSL users (also not previously involved in the study), both professional and non-professional. They were asked to complete the CORE-OM BSL questionnaire which had been uploaded to an online version using the SelectSurvey tool. At this point, they were asked to comment on the delivery method of the CORE-OM through a web interface and raise any points they wished concerning the style of signing or the use of specific signs, as well as any technical difficulties they might have encountered.

In the fifth stage, feedback from the five people who completed the CORE-OM BSL version, from the back translation team, and from a discussion with Chris Evans about the back-translated English versions, was considered in detail. This involved comparing the comments across the original and back-translated English items and looking back at the BSL items. Further modifications were made to some of the items and all of the items were re-filmed for the new BSL version. These steps led to the production of the final draft BSL version of the CORE-OM, ready to be piloted.



### **3.3. Web hosting of the assessment**

It was necessary to have the CORE-OM BSL version hosted online because BSL is a visual language. The items had to be watched, not read which is the case with traditional self-report questionnaires. In other words, not only is the BSL version of the CORE-OM in a different language but it also expressed in a different modality. The final draft of the BSL version of the CORE-OM was incorporated into SelectSurvey. SelectSurvey is an online survey tool, where the question can be asked in text and/or in video and the respondents can respond in a variety of ways such as on a rating scale, choosing from multiple answers, or via a comments box. Two separate SelectSurvey versions of the CORE-OM were developed, BSL and English, both of which were then mounted on the Deaf Well-Being website developed for this study. The Deaf Well-Being website included information about the whole project as well as an explanation about the purpose of this pilot study. All of the information, including the consent form, was produced in BSL and English. The website is available to the public; however, data collected through SelectSurvey is highly secure. They encrypted the web presentation and strongly encrypted storage of the data on the server. The data transfer and data storage met security guidelines for all confidential data passing into and within a University. The database behind SelectSurvey was only accessible by the researcher (Rogers) and a member of the IT team. Two data files were stored for each respondent, and both were confidential. One file contained the respondent's personal information, name, and what they had consented to; and other data file, stored separately, contained the answers that the participants gave to both the demographic questionnaire and the CORE-OM. The linkage between the two data stores to identify each participant was achieved by allocating unique code numbers.

For the BSL version, SelectSurvey showed the BSL translation of each item individually, with one item per screen page. Respondents were asked to select one of the option buttons for the rating scale before moving on to the next page, which showed a BSL video clip of the next item (see Figure 2 for an example of the BSL version of the CORE-OM). The BSL version only showed BSL videos without English subtitles. The rationale for not having subtitles was to determine the reliability of the BSL version without English subtitles influencing the results. The SelectSurvey structure was different for the English version. All 34 CORE-OM items can be seen on one SelectSurvey screen page (see Figure 3). This meant that comparing the BSL with the English versions, the BSL version had a total of 46 SelectSurvey pages (including consent pages and a demographic questionnaire) whereas the English version had only four.



*Figure 2.* Example of the BSL version of the CORE-OM in the SelectSurvey tool

IMPORTANT - PLEASE READ THIS FIRST

This form has 34 statements about how you have been OVER THE LAST WEEK.  
Please read each statement and think how often you felt that way last week.  
Then click the box which is closest to this.

1. I have felt terribly alone and isolated  
☐ Not at all ☐ Only occasionally ☐ Sometimes ☐ Often ☐ Most or all the time
2. I have felt tense, anxious or nervous  
☐ Not at all ☐ Only occasionally ☐ Sometimes ☐ Often ☐ Most or all the time
3. I have felt I have someone to turn to for support when needed  
☐ Not at all ☐ Only occasionally ☐ Sometimes ☐ Often ☐ Most or all the time
4. I have felt O.K. about myself  
☐ Not at all ☐ Only occasionally ☐ Sometimes ☐ Often ☐ Most or all the time
5. I have felt totally lacking in energy and enthusiasm  
☐ Not at all ☐ Only occasionally ☐ Sometimes ☐ Often ☐ Most or all the time

*Figure 3.* Example of the English version of the CORE-OM in the SelectSurvey tool

### 3.4. Phase Two: Pilot study of the CORE-OM with d/Deaf populations

The primary purpose of the pilot study was to determine the reliability of both the BSL and English versions with d/Deaf populations. The secondary purpose was to make a comparison between the reliability of the two versions completed by d/Deaf respondents, and the reliability of data from the English version completed by hearing respondents.

A between-subjects design was used. A sample size of 50 for each version was deemed to be sufficiently large enough to be reasonably confident that an observed Cronbach's alpha of 0.75 corresponds to a population value of 0.70 (Hertzog, 2008).

Inclusion criteria for the pilot study were d/Deaf adults aged 18 or above. Exclusion was any d/Deaf adults who had been part of a cohort in the study conducted in 1988 by Peter Hindley (Hindley, 1993). This was because the final version of the CORE-OM was to be used in the future in a separate study which would recruit from this cohort. Participants were identified using a range of recruitment strategies, including sending emails and text messages to members of

the Deaf community, placing adverts in d/Deaf related media, and delivering presentations about the study at various Deaf clubs and special interest groups in the UK such as the 'Healthy Deaf Minds' series. Participants received £15 vouchers for completing the pilot study.

The information about the study was available in two languages: BSL and English. All of the information was available on the Deaf Well-Being website, and participants could receive hard copies of the information sheet in English. Participants who consented completed the questionnaire online using the SelectSurvey software. They were given the choice of completing the BSL or the English version. The technical side of the BSL version was more complicated because each item needed to be shown in digital video format. Some respondents were subsequently in touch with the researcher undertaking this study to report that particular video items were not playing well.

Participants were requested to complete a simple demographic questionnaire to collect information such as gender, age, preferred language, and age at which they first learnt BSL.

The demographic characteristics of the participants in each group were summarised using frequency counts, percentages, means and standard deviations as appropriate. The internal reliability of the total score or domain was estimated using Cronbach's  $\alpha$ , acceptable values of which are suggested by George and Mallery (2003) as  $> 0.9$  – Excellent,  $> 0.8$  – Good,  $> 0.7$  – Acceptable,  $> 0.6$  Questionable,  $> 0.5$  – Poor, and  $< 0.5$  – Unacceptable.

As data from the CORE-OM and other such measures are almost never Gaussian in distribution in clinical or non-clinical samples and as there is good reason to believe that error variance may also be non-Gaussian (it is almost bound to be so given the short ordinal scale for the items) a non-parametric descriptive approach to comparison of alpha values by reporting 95% confidence intervals

(CIs) for these based on 10,000 bootstrap replications and a bias corrected CI. Basic statistics were computed using SPSS version 19 and bootstrap analyses were conducted using R version 2.14.1 (R development core team, 2012). Where 95% CIs in one sample do not cover the observed value in another sample and *vice versa*, i.e. the CI from the other sample does not cover the observed parameter in the first sample, it can be safely assumed that there is a difference that would be statistically significant at  $p < .05$  in inferential testing (Gardner and Altman, 1986).

#### 4. Results

In December 2010 to March 2011, a total of 136 people took part in the pilot study: 60 completed the BSL version, and 76 completed the English version. It was not possible to estimate a response rate due to the way the data were collected. Not all data were usable. Hard of hearing respondents were excluded. Data analysis was only carried out in the cases where all or almost all responses had been completed (see figure 4 for details).

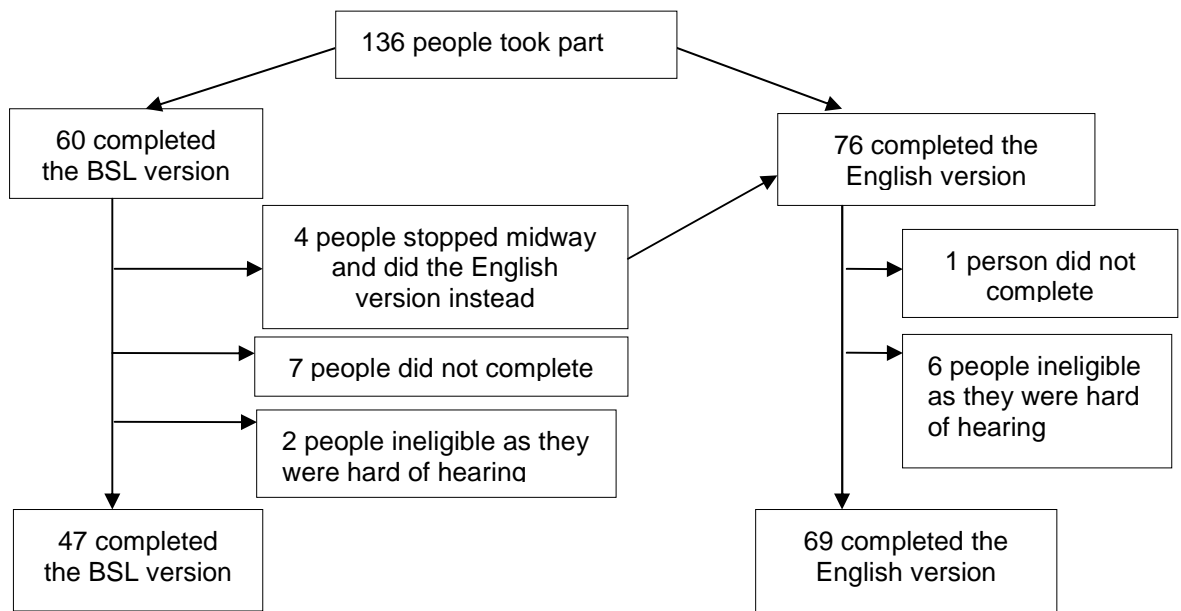


Figure 4. CONSORT-type diagram of participants who took part in the pilot study

In total, for data analysis, there were 69 participants for the English version and 47 for the BSL version. Few participants in the English version and in the BSL version missed between 1 and 3 items out of the whole CORE-OM assessment. Table 1 shows characteristics of the d/Deaf participants.

Table 1

*Demographic details of the d/Deaf participants who did either the BSL or English version of the CORE-OM.*

Characteristics	BSL version (n=47)	English version (n=69)
	N (%)	N (%)
Gender		
Male	14 (29.8)	26 (37.7)
Female	33 (70.2)	43 (62.3)
Age group		
18-24	5 (10.6)	6 (8.7)
25-34	14 (29.8)	24 (34.8)
35-49	18 (38.3)	25 (36.2)
50-64	10 (21.3)	11 (15.9)
65+	0 (0)	3 (4.3)
Ethnic background		
White British	45 (95.7)	58 (84.1)
White Irish	1 (2.1)	4 (5.8)
White other	0 (0)	1 (1.4)
Black or Black British African	0 (0)	1 (1.4)
Asian or Asian British Indian	0 (0)	2 (2.9)
Asian or Asian British Pakistani	0 (0)	1 (1.4)
Chinese	0 (0)	1 (1.4)
Other	1 (2.1)	1 (1.4)

Preferred language		
BSL	38 (80.9)	47 (68.1)
SSE*	7 (14.9)	13 (18.8)
Spoken English	2 (4.3)	9 (13.0)
Age first learned BSL		
From birth	13 (27.7)	22 (31.9)
1-3 yrs old	10 (21.3)	3 (4.3)
4-7 yrs old	6 (12.8)	7 (10.1)
8-11 yrs old	2 (4.3)	1 (1.4)
12-16 yrs old	8 (17.0)	9 (13.0)
17-24 yrs old	8 (17.0)	17 (24.6)
25+ yrs old	0 (0)	9 (13.0)
Never learnt BSL	0 (0)	1 (1.4)
Only deaf person in the family		
Yes	21 (46.8)	38 (55.1)
No	24 (53.2)	31 (44.9)
Part of the Deaf community		
Yes	45 (95.7)	60 (87.0)
No	2 (4.3)	9 (13.0)
Disability		
Yes	22 (46.8)	43 (62.3)
No	25 (53.2)	26 (37.7)
If yes, what disability?		
Deaf	19 (40.4)	23 (33.3)
Usher	1 (2.1)	2 (2.9)
Other**	4 (8.5)	2 (2.9)
Experienced mental well-being difficulties?		
Yes	13 (27.7)	16 (23.2)
No	32 (68.1)	53 (76.8)
If yes, when was it?		

Currently	4 (8.5)	3 (4.3)
Up to 5 yrs	5 (10.6)	7 (10.1)
Over 5 yrs ago	7 (14.9)	5 (7.2)

---

*Note. \* Sign Supported English (SSE) involves speaking or mouthing in grammatical English, with some of the key words being simultaneously signed. This is not the same as British Sign Language (Sutton-Spence & Woll, 1999).*

*\*\* some of those who indicated they had an 'other disability' also included being deaf as disabled.*

#### **4.1. Missing Data**

With regard to the complete sets of data, the BSL version should have 1598 (34 CORE-OM items x 47 participants) items of data, but 18 of data items were missing across 47 participants, which amount to 1.12% of all items. Similarly, 20 items were missing for the English version across 69 participants: fewer than 1% (0.85%) of the total items. There were six items in the BSL CORE-OM that respondent(s) missed, which all but one only has 1-3 missing respondents' data. The exception in the BSL CORE-OM that had the most missing data was CORE-OM 32; 9 respondents missed this item. As previously stated in the procedure section, there were technical issues with some of the videos. CORE-OM 32 was the video that the greatest number of respondents reported being unable to play. For the English version, 13 items in the CORE-OM have missing 1-3 respondents' data. The method chosen for dealing with missing data in this study for those participants who had at least 10% of the items missing for a domain or in total those who have less than 10% of missing items, the data was replaced by the prorates (a mean score across the remaining items was completed).

#### **4.2. Descriptive statistics for CORE-OM**

Table 2 shows means and standard deviations for each domain for both versions of the CORE-OM as well as those for the non-clinical populations in the study by Evans *et al.* (2002).



Table 2

*Means and standard deviations (SD) for all domains of BSL and English CORE-OM in present study and non-clinical populations in Evans et al. (2002)*

CORE-OM	BSL (n=47)*		English (n=69)*		Evans et al. (2002) non-clinical populations (n=1084)	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Well-Being	0.91	0.80	0.93	0.71	0.91	0.83
Problems	0.95	0.65	0.82	0.69	0.90	0.72
Functioning	0.92	0.60	0.88	0.57	0.85	0.65
Risk	0.22	0.49	0.16	0.30	0.20	0.45
ALL ITEMS	0.81	0.55	0.74	0.52	0.76	0.59
Non-risk	0.93	0.61	0.87	0.59	0.88	0.66

*Note.* \* small numbers of missing values were present

With two exceptions, mean scores on the various domains and the total were similar for the BSL version and the English version in the present study, and they were similar to mean scores for the non-clinical sample in Evans *et al.* (2002). The exception was the problems domain, where the mean score for the English version was 0.82, compared with a mean score of 0.95 for the BSL version and 0.90 for Evans *et al.* (2002) and the risk domain with mean score of 0.16 for English version is lower compared to the other two groups.

The non-parametric approach of bootstrapping reported parameters are expressed with 95% confidence intervals.

#### **4.3. Internal Reliability**

Cronbach's alpha was estimated for the domains and overall scales for each version of CORE-OM for (i) the BSL version and (ii) the English version completed by d/Deaf people, as well as for (iii) the non-clinical populations in Evans *et al.* (2002) (Table 3).

Table 3

*Cronbach's alpha ( $\alpha$ ) values for the internal consistency of the items in each domain, with confidence intervals in brackets (95% CI), All Items, and Non-risk domain for a d/Deaf sample using the BSL version, a d/Deaf sample using the English version, and a non-clinical sample using the English version, from the Evans et al. (2002) study.*

	BSL (n=47)	English (n=69)	Evans et al. (2002) non-clinical
	$\alpha$ (95% CI)	$\alpha$ (95% CI)	populations (n=1009)
			$\alpha$ (95% CI)
Well-Being	0.80 (0.67-0.88)	0.73 (0.60–0.83)	0.77 (0.75-0.79)
Problems	0.86 (0.76-0.91)	0.91 (0.86–0.95)	0.90 (0.89-0.91)
Functioning	0.84 (0.70–0.92)	0.79 (0.68–0.87)	0.86 (0.85-0.87)
Risk	0.84 (0.54–0.92)	0.66 (0.48–0.77)	0.79 (0.77-0.81)
ALL ITEMS	0.94 (0.87–0.97)	0.93 (0.88–0.95)	0.94 (0.93-0.95)
Non-risk	0.93 (0.86–0.96)	0.93 (0.88–0.96)	0.94 (0.93-0.95)

For the BSL version, each of the domains, as well as All Items and Non-risk domain, were found to be in the good or excellent range of Cronbach's  $\alpha$  values. Aside from the Problems domain, the rest of the alpha values for the English version were lower than the BSL version similarly in the non-clinical populations in Evans et al. (2002) study. When d/Deaf people completed the English version however, one domain was below the acceptable value; the Risk domain, with a Cronbach's  $\alpha$  value of 0.66, which was questionable (Table 3 and Figure 5).

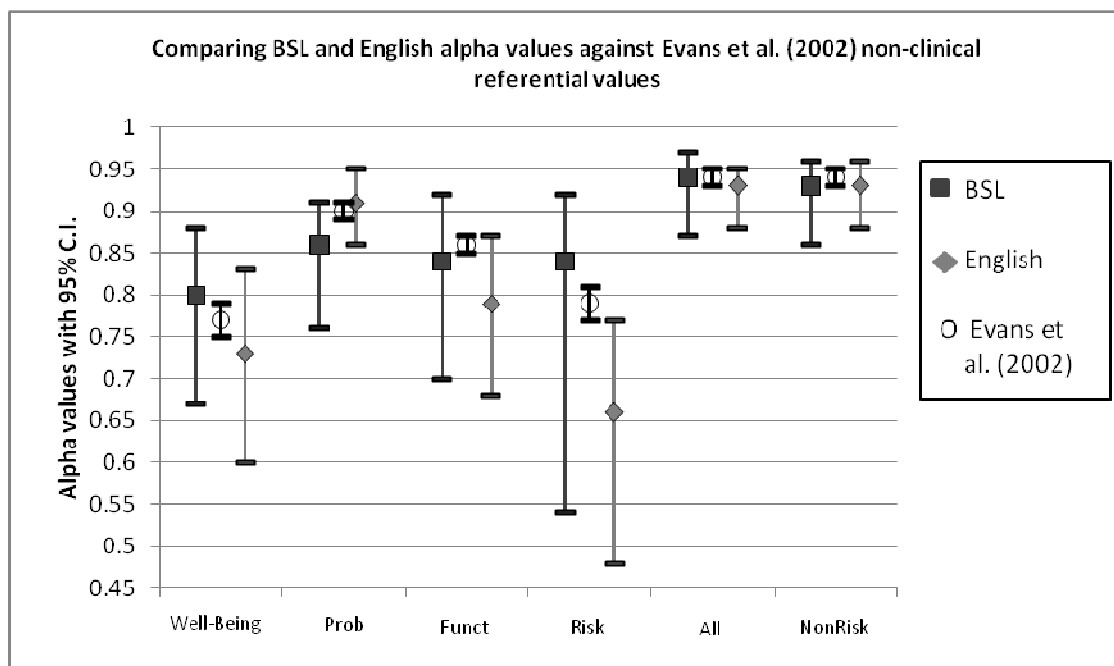


Figure 5. Cronbach's alpha ( $\alpha$ ) values with 95% confidence intervals for the internal consistency of the items in each domain, All Items, and Non-risk domain for a d/Deaf sample using the BSL version, d/Deaf sample using the English version, and a non-clinical sample using the English version in Evans *et al.*'s (2002) study.

#### 4.4. Exploratory analysis of items with corrected item-total correlation

Items with a correlation value of less than 0.3 with the sum of other items score of the domain were considered as not correlating well with other items in the domain (Pett, Lackey, and Sullivan, 2003). All item-domain correlations were examined (Table 4).

Table 4

*CORE-OM items with corrected item-total correlation values less than 0.3 with the overall score in each of the domains for both BSL and English versions completed by d/Deaf people in this study.*

Version	Well-Being	Problems	Functioning	Risk	ALL ITEMS	Non-risk
BSL version	-	CORE-OM 5*	-	CORE-OM 6	CORE-OM 3 CORE-OM 5 CORE-OM 6	CORE-OM 5*
English version	-	-	CORE-OM 3 CORE-OM 33	CORE-OM 6 CORE-OM 22	CORE-OM 6 CORE-OM 8 CORE-OM 9 CORE-OM 16 CORE-OM 19	CORE-OM 8 CORE-OM 19

*Note. \*indicates a negative correlation.*

For some of the items that have a correlation value of less than 0.3 with the overall score or with the domain, removal of the item would result in a value for Cronbach's alpha value that would be increased. An example would be the item CORE-OM 6 in BSL version "I have been physically violent to others", the internal reliability of the risk domain increased from  $\alpha = 0.84$  to  $\alpha = 0.93$ .

#### **4.4.1. Comparing the Cronbach's alphas for each version**

Feldt's approach (as cited in Feldt, Woodruff and Salih, 1987) was used to compare Cronbach's  $\alpha$  for every domain between the BSL and English (d/Deaf sample) versions; the BSL version and the non-clinical populations in the Evans *et al.* (2002) study; and the English (d/Deaf sample) version and non-clinical populations in Evans *et al.*'s study.

Figure 5 showed the plot, comparing the BSL and English versions' alpha values against non-clinical values in Evans *et al.* (2002) study. In that plot (figure 5) for the comparisons of the bootstrap confidence intervals for each of the

domains, All Items as well as Non-risk between the BSL and English versions were completed by d/Deaf people in this study; the only observed difference was the Risk domain. Confidence intervals for the Risk domain in the English version completed by d/Deaf people were lower than the Risk domain in the BSL version.

#### **4.5. Exploratory analysis of Phase Three: Pilot study with a small sample of Deaf people for the revised BSL CORE\_OM items**

The reliability of the BSL CORE-OM items were analysed and it was identified that, from the preliminary findings of item-total correlation and the discussion with translators from the main pilot study, one of the 34 BSL CORE-OM items that was considered needed to be revised in order to improve reliability. The possible item identified was BSL CORE-OM 6. Although the sample size was small, it was suggested that if it was removed the reliability for the risk domain would improve from  $\alpha = 0.84$  to  $\alpha = 0.93$ . Revisions to that item were made after the meeting with the translation team (including both forward and back-translators), and were re-filmed for the new BSL CORE-OM 6 item. At the meeting, it was agreed that the revised BSL CORE-OM 6 was much clearer than the original BSL 6 item. The reason the revised item was piloted was to see if the revised BSL CORE-OM 6 differed from the original BSL item. It was suggested that if the response to the revised CORE-OM BSL 6 was different from the response received from the same participant to the original CORE-OM BSL 6, then the pilot study for the BSL CORE-OM including the newly revised BSL item 6 would be required.

A within-subjects design was used, where the same participants were asked to complete a short BSL questionnaire, which included both the original and the revised BSL CORE-OM 6 item. Using a Wilcoxon Signed Ranks test, a minimum sample size of 24 is required to detect the difference between the original and the new CORE-OM BSL 6 item.

A small sample of Deaf people were asked to complete the secure online survey, in BSL, which includes consent, a short demographic questionnaire and a small number of selected BSL CORE-OM items (including the old and new BSL items CORE-OM 6). After completing the survey, participants each received a £5 voucher to thank them for their time.

A total of 37 people completed the pilot study for the revised BSL item. The results from the Wilcoxon Signed Ranks Test showed that 8 out of 37 received a different score after completing the revised CORE-OM item number 6 compared to the score they received for the original. The changes are not significant at  $z = 0.000$ ,  $p > 0.999$ .

## **5. Discussion**

The aim of the pilot study was to determine the psychometric properties of the CORE-OM for both versions, BSL and English, when used with d/Deaf populations. Reliability for the total and the non-risk scoring showed excellent Cronbach's alpha values indicating there is strong internal consistency for the 34 items in both the BSL and English versions. However, when the Cronbach's alpha values were examined for each of the domains of the CORE-OM (Well-Being, Problems, Functioning, and Risk), a different picture emerges for the English version. The internal consistency for the Risk domain for the English version completed by d/Deaf people was questionable, which means that it was below the acceptable value for reliability. When the reliability of the internal consistency of each of the domains was compared with each other, as well as with the English version with the hearing populations (Evans *et al.*, 2002), two domains (Risk and Functioning) of the English version completed by d/Deaf people were also observed to be lower than those completed by the hearing populations and d/Deaf people completing the BSL version.

Before concluding that the English version of the CORE-OM should not be used with d/Deaf populations it should be noted that the d/Deaf sample for this study were self-selecting. Unsurprisingly this means that they were not a representative sample of the d/Deaf populations. About half of them had d/Deaf family members, i.e. parents and/or siblings whereas in general d/Deaf populations about 95% are born to hearing parents (Michell and Karchmer, 2004), and only about 11% have d/Deaf siblings (Johnston, 2004). A larger proportion who were native signers<sup>6</sup> (those whose first language is BSL from birth/early infancy) took part (49.0% for BSL version and 36.2% for English version). It was interesting to note that 68% of participants stated that their preferred language was BSL, but chose to do the English version; they were not asked why.

Although overall the complete English version is reliable and the items appear to be consistent with the whole items, one possible explanation for the low internal consistency of Risk domain might be that more than one component was incorporated into the Risk domain during the construction of the assessment. It might be that some items in the Risk domain for the English version might have been read as meaning something different (or might have been interpreted differently) by d/Deaf people (Rogers et al., 2013). It is worth stating that the mean score for the risk domain for the English version completed by d/Deaf people in this study were lower than the BSL version and lower than those of the hearing samples in Evans *et al.* (2002) study. Such a reduced mean exacerbates an inevitable “floor effect” when items designed to tap more severe problems in clinical populations are tested in non-clinical populations. It is essentially impossible to disentangle whether the lower mean is an artefact of a reduced (poor) reliability or whether the reliability is underestimated owing to the floor effect. Answers to this can only come from larger samples and from reasonably sized clinical d/Deaf populations.

Another cautionary note concerns the inevitable factor or component complexity of relatively short, multidomain measures like the GHQ (e.g. Goldberg, 1978), CORE-OM, or Outcome Questionnaire (Lambert, Hansen and Harmon, 2010). In order to cover the diversity of clinical and subclinical problems and dysfunction such measures have items covering rather different domains. At the same time, to keep the length of the full questionnaire short enough for use in routine practice, the number of items in any domain can be small. These issues mean that such measures do not show conventional clean factor or principal component analysis structures. Those structures are further complicated as it is hard to have major social or intrapsychic problems with undamaged sense of well-being or to feel serious risk of self-harm while having no other problems and are functioning well. The populations inter-item correlation matrices *are* oblique and complex.

Cronbach's alpha, as he and a number of authors since have understood, is not an index of unidimensionality (Cronbach, 1951; Cortina, 1993; Sijtsma, 2008). It will be interesting and important to build large enough d/Deaf samples, clinical and non-clinical, to explore the complexity of the inter-item correlation structure for the BSL and English language CORE-OM measures, and to see how they may or may not differ from those of non-d/Deaf populations. However, the sample sizes required for such exploration are substantial: a sensible rule is that they must be at least 4x the number of factors expected and larger than that where the referential factor structure is known to be oblique and complex.

Despite the high internal reliability for the risk domain for the BSL CORE-OM (Cronbach's alpha = 0.84), qualitative comments from participants suggested that one item in the BSL version required revising in order to improve comprehension and clarity. The item identified was CORE-OM 6 (two other items, 3 and 5, were also thought to be worth trying to improve but extensive discussion and testing suggested that they could not be improved markedly). For item 6 the issue was



that the term “physically violent” could mean any one of a number of actions including hitting, slapping, pushing or throwing things in order to hurt other people. This is a typical example of a phrase which normally be signed by using signs for several of those with interactive follow-up and no BSL umbrella phrase exists for “physically violent” generically. However, participants and the original translation team had a concern that if such examples were given the item could become experienced as a strongly leading question. It was agreed at an earlier meeting that no examples of actions would be given. In the discussion with the translation team (including forward and back translators), there had been a lengthy debate about how to translate the statement “I have been physically violent to others” into BSL. The revisions were made to the BSL CORE-OM 6, and it was agreed that the revised item was much clearer than the original BSL CORE-OM 6 item. In the revised CORE-OM 6 BSL item, there were also no examples of actions given, however, there was an addition made at the end, which was the aim to physically harm people. From the pilot study for the revised BSL item, it was found that participants’ responses to both the original and the revised BSL CORE-OM 6 item did not differ statistically significantly though the new version was agreed to be linguistically more clear. We concluded that there is no need for the revised BSL item to be piloted again along with the whole other BSL CORE-OM items. As the reliability for the risk domain for the BSL CORE-OM was in a good range we have replaced the original version of item 6 with the revised BSL item in the final version.

The findings of the reliability for the English version and BSL version of the mental health assessment with d/Deaf populations is important to those professional working with d/Deaf people. By producing the reliable assessment in BSL, as achieved in this study, will not only assist in identify the difficulties at the earlier stage but also can be used as a evidence based of the effective of the

services for d/Deaf people by comparing the responses prior and after the series of the therapies. This study also demonstrated that online data could be collected readily from the Deaf community in the UK both via English and BSL. The Deaf community in the UK is very small and geographically dispersed, so the web provides an ideal way of reaching members. BSL is a visual language, and information was communicated to BSL users by means of short videos on web pages. This study tested the reliability of a psychological assessment tool but clearly there is scope to use these methods in other situations.

## **6. Conclusion**

While the online delivery of the English version of the CORE-OM completed by d/Deaf populations in this study showed had excellent reliability for the overall and non-risk scores. However, the domains of Risk and Functioning for the English version completed by d/Deaf people were observed to have lower internal reliability compared to the BSL version and to the English version completed by hearing populations. While these findings should be explored in larger non-clinical, and in clinical d/Deaf samples these findings support concerns about using English language versions of measures with d/Deaf populations.

By contrast, the BSL version of the CORE-OM was found to be as good as, and comparable to, the English version, as tested on non-clinical hearing populations in the study by Evans *et al.* (2002). From this work an online BSL version of the CORE-OM and its shorter forms can now be produced and recommended for use with Deaf populations in the community.

## References

- Barkham M., Evans C., Margison F., McGrath G., Mellor-Clark J., Milne D. & Connell J. (1998). The rationale for developing and implementing core outcome batteries for routine use in service settings and psychotherapy outcome research. *Journal of Mental Health* **7** (1), 35-47. doi:10.1080/09638239818328
- Barkham M., Mullins T., Leach C., Stiles W.B. & Lucock M. (2007). Stability of the CORE-OM and BDI-I prior to therapy: Evidence from routine practice. *Psychology and Psychotherapy: Theory, Research and Practice* **80** (2), 269-278. doi:10.1348/147608306X148048
- Bamford J., Ankjell H., Crockett R. *et al.* (2004). *Evaluation of the newborn hearing screening programme (NHSP) in England: report of the evaluation of the first phase of implementation of the NHSP*. November.
- British Society for Mental Health and Deafness (2010, July). Deaf people's mental wellbeing put at risk by lack of services. Press Release. Retrieved from <http://www.bsmhd.org.uk/news0710.htm#1>
- Cahill J., Barkham M., Stiles W.B., Twigg E., Hardy G.E., Rees A., & Evans C. (2006). Convergent validity of the CORE measures with measures of depression for clients in brief cognitive therapy for depression. *Journal of Counseling Psychology* **53** (2), 253– 259. doi:10.1037/0022-0167.53.2.253
- Connell J., Barkham M., Stiles W.B., Twigg E., Singleton N., Evans O. & Miles, J.N.V. (2007). Distribution of CORE-OM scores in a general population, clinical cut-off points, and comparison with the CIS-R. *British Journal of Psychiatry* **190** (1), 69-74. doi:10.1192/bjp.bp.105.017657
- CORE Partnership (2007). Is initial overall CORE-OM score an indicator of likely outcome? *CORE Partnership Occasional Paper, No 1*. CORE IMS: Rugby.

- Cortina J.M. (1993). What is coefficient alpha? An examination of theory and applications. *Journal of Applied Psychology* **78** (1), 98–104. doi:10.1037/0021-9010.78.1.98
- Cronbach L.J. (1951). Coefficient alpha and the internal structure of tests. *Psychometrika* **16** (3), 297–334. doi:10.1007/BF02310555
- Department of Health (2002). *A Sign of Times: Modernising Mental Health Services for people who are Deaf*. London: HMSO.
- Department of Health (2005). *Mental Health and Deafness - Towards Equity and Access: Best Practice Guidance*. London: HMSO.
- Elfström M.L., Evans C., Lundgren J., Johansson B., Hakeberg M., & Carlsson, S.G. (2012). Validation of the Swedish version of the Clinical Outcomes in Routine Evaluation Outcome Measure (CORE-OM). *Clinical Psychology & Psychotherapy*. doi:10.1002/cpp.1788
- Evans C., Connell J., Barkham M., Margison F., McGrath G., Mellor-Clark J. & Audin, K. (2002). Towards a standardised brief outcome measure: psychometric properties and utility of the CORE-OM. *British Journal of Psychiatry* **180** (1), 51-60. doi:10.1192/bjp.180.1.51
- Evans C. (2008). *Translating and “normalising” CORE system: CORE System Trust (CST) position statement*. Unpublished manuscript.
- Feldt L.S., Woodruff D.J. & Salih F.A. (1987). Statistical Inference for Coefficient Alpha. *Applied Psychological Measurement* **11** (1), 93-103. doi:10.1177/014662168701100107
- Gampe K., Biescad M., Balunova-Labanicova L., Timulak L. & Evans C. (2007). Slovak Adaptation of CORE-OM (Clinical Outcomes in Routine Evaluation – Outcome Measure). *Ces. A slov. Psychiat.* **103** (1), 4-13.

- Gardner M.J. & Altman, D.G. (1986). Confidence intervals rather than P values: estimation rather than hypothesis testing. *British Medical Journal* **292** (6522), 746-750. doi:10.1136/bmj.292.6522.746
- George D. & Mallery P. (2003). *SPSS for windows step by steps: A simple guide and reference*. Boston, MA: Allyn and Bacon.
- Goldberg D. (1978). *Manual of the General Health Questionnaire*. Oxford: NFER-NELSON.
- Hertzog M.A. (2008). Considerations in determining sample size for pilot studies. *Research in Nursing and Health* **31** (2), 180-191. doi:10.1002/nur.20247
- Hindley P. (1993). *Signs of Feeling: A Prevalence Study of Psychiatric Disorder in Deaf and Partially Hearing Children and Adolescents*. RNID, London.
- Johnston T. (2004). W(h)ither the Deaf Community? Population, Genetics, and the Future of Australian Sign language. *American Annals of the Deaf* **148** (5), 358-375. doi:10.1353/aad.2004.0004
- Lambert M.J., Hansen N.B. & Harmon, S.C. (2010). Outcome Questionnaire system (The OQ System): Development and practical applications in healthcare settings. In M. Barkham, G.E. Hardy & J. Mellor-Clark (Eds.), *Developing and delivering practice-based evidence: a guide for the psychological therapies* (pp. 139–154). Chichester, UK: John Wiley & Sons Ltd.
- Marschark M. (2007). *Raising and Educating a Deaf Child: A Comprehensive Guide to the Choices, Controversies, and Decisions Faced by Parents and Educators*. New York: Oxford University Press.
- Mayer C. (2007). What Really Matters in the Early Literacy Development of Deaf Children. *Journal of Deaf Studies and Deaf Education* **12** (4), 411-431. doi:10.1093/deafed/enm020

- Michell R. & Karchmer M. (2004). Chasing the mythical ten percent: Parental hearing status of deaf and hard of hearing students in the United States. *Sign Languages Studies* **4** (2), 138-163. doi:10.1353/sls.2004.0005
- Palmieri G., Evans C., Hansen V. *et al.* (2009). Validation of the Italian version of the clinical outcomes in routine evaluation outcome measure (CORE-OM). *Clinical Psychology & Psychotherapy* **16** (5), 444-449. doi:10.1002/cpp.646
- Pett M.A., Lackey N.R. & Sullivan J.J. (2003). *Making Sense of Factor Analysis: The use of factor analysis for instrument development in health care research*. Thousand Oaks, CA: SAGE Publications.
- R development core team. (2012). *R: A language and environment for statistical computing*. Vienna, Austria: R Foundation for Statistical Computing. Retrieved from <http://www.R-project.org/>
- Roberts C. & Hindley P. (1999). Practitioner Review: The Assessment and Treatment of Deaf Children with Psychiatric Disorders. *Journal of Child Psychology and Psychiatry* **40** (2), 151-157. doi:10.1111/1469-7610.00430
- Rogers, K. D., Young, A., Lovell, K., & Evans, C. (2013). *The challenges of translating the Clinical Outcomes in Routine Evaluation - Outcome Measure (CORE-OM) into British Sign Language*. Manuscript submitted for publication.
- Samady W., Sadler G.R., Nakaji M. & Malcarne V.L. (2008). Translation of the Multidimensional Health Locus of Control Scales for Users of American Sign Language. *Public Health Nursing* **25** (5), 480-489. doi:10.1111/j.1525-1446.2008.00732.x
- Sijtsma K. (2008). On the Use, the Misuse, and the Very Limited Usefulness of Cronbach's Alpha. *Psychometrika* **74** (1), 107–120. doi:10.1007/s11336-008-9101-0

- Sullivan P.M. & Knutson J.F. (2000). Maltreatment and Disabilities: A population-based epidemiological study. *Child Abuse & Neglect* **24** (10), 1257-1273. doi:10.1016/S0145-2134(00)00190-3
- Sutton-Spence R. & Woll, B. (1999). The linguistics of British Sign Language: an introduction. Cambridge, UK: Cambridge University Press.
- Wild D., Grove A., Martin M., Eremenco S., McElroy S., Verjee-Lorenz A. & Erikson, P. (2005). Principles of Good Practice for the Translation and Cultural Adaption Process for Patient-Reported Outcomes (PRO) Measures: Report of the ISPOR Task Force for Translation and Cultural Adaptation. *Value in Health* **8** (2), 94-104. doi:10.1111/j.1524-4733.2005.04054.x
- Woodward J. (1972). Implications for Sociolinguistics Research among the Deaf. *Sign Language Studies* **1**, 1–7.

## **CHAPTER SEVEN: PAPER D**

The British Sign Language Versions of the Patient Health Questionnaire, the  
Generalized Anxiety Disorder – 7 items Scale, and the Work and Social  
Adjustment Scale

Rogers, K. D., Young, A., Lovell, K., Campbell, M., Scott, P. R., & Kendal, S.

Journal of Deaf Studies and Deaf Education, 18(1), 110-122.



## **The British Sign Language Versions of the Patient Health Questionnaire, the Generalized Anxiety Disorder – 7 items Scale, and the Work and Social Adjustment Scale.**

Katherine D. Rogers, Alys Young, Karina Lovell, Malcolm Campbell, Paul R. Scott, & Sarah Kendal

### **1. Abstract**

The present study is aimed to translate three widely used clinical assessment measures into British Sign Language (BSL), to pilot the BSL versions and to establish their validity and reliability. These were the Patient Health Questionnaire (PHQ-9), the Generalised Anxiety Disorder 7-item (GAD-7) and the Work and Social Adjustment Scale (WSAS). The three assessment measures were translated into BSL and piloted with the Deaf signing population in England (n = 113). Participants completed the PHQ-9, GAD-7, WSAS and Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM) online. The reliability and validity of the BSL versions of PHQ-9, GAD-7, and WSAS have been examined and were found to be good. The construct validity for the PHQ-9 BSL version did not find the single-factor solution as found in the hearing population. The BSL versions of PHQ-9, GAD-7 and WSAS have been produced in BSL and can be used with the signing Deaf population in England. This means that there are now accessible mental health assessments available for Deaf people who are BSL users, which could assist in the early identification of mental health difficulties.

Common mental health problems, including anxiety and depression, are experienced by 9% of the general adult population in the UK (Singleton, Bumpstead, O'Brien, Lee, & Meltzer, 2001); however, the prevalence of anxiety and depression is higher in the d/Deaf<sup>1</sup> population (Kvam, Loeb, & Tambs, 2007). In only a minority of cases are mental health difficulties and deafness causally connected, i.e., where the aetiology of deafness is co-incidental with organic origins of mental illness or neurological impairment (Hindley, Hill, McGuigan, & Kitson, 1994; Vernon, 2005). Many d/Deaf children struggle to achieve age appropriate language (whether signed or spoken) (Mayberry, 2002), routinely have significant gaps in social knowledge and have delayed social maturity (Woolfe, Want & Siegal, 2002). One of the reasons for this is due to the language delay and communication barriers faced by d/Deaf people. The incidence of mental health problems in d/Deaf children/young people is around 1.6 times greater than amongst hearing counterparts (Department of Health, 2005).

Access to mental health services for Deaf people is poor in comparison to the hearing population (Department of Health, 2002; Department of Health, 2005). At least 100,000 Deaf people in the UK use British Sign Language (BSL) as their preferred language (BSMHD, 2010). BSL, a visual language with no written form, was officially recognised in its own right by the British Government in 2003. However, access to culturally appropriate mental health services for Deaf people is limited. Improving Access to Psychological Therapies (IAPT), a mental health service in England, whose aim is to support people with depression and/or anxiety, has acknowledged the lack of access to services for those who use BSL. The Department of Health in the UK recognised that health professionals working in primary care services (i.e., in community services such as general practice) failed to identify the early symptoms of possible mental health difficulties in some Deaf people (Department of Health, 2002).

Mental health services increasingly use self-report mental health assessments either to identify or determine the severity of mental health problems. Although there has been some work carried out on translating or adapting assessment tools into BSL (Gascon-Ramos, Young, Petrides, Stone, & Woolfe, 2010; Rogers, Young, Lovell, & Evans, 2012a), there is limited normative data for the Deaf population<sup>2</sup>. The mental health assessments used in the Minimum Dataset in IAPT services in England include the Patient Health Questionnaire (PHQ-9), Generalised Anxiety Disorder – 7 items (GAD-7), and Work and Social Adjustment Scale (WSAS). Once BSL versions of these three assessments have been validated, they could be used in primary care to assist in determining the severity of mental health difficulties experienced by Deaf people at an earlier stage (IAPT, 2012). Early identification of mental health difficulties could mean that Deaf people might benefit from appropriate support at primary and secondary care levels. Access to appropriate mental health support could lead to improved mental health in the Deaf population.

The aim of the present study was to evaluate the BSL versions of the mental health assessments with Deaf adults in England. The psychometric properties of the BSL versions of PHQ-9, GAD-7 and WSAS were examined by conducting a pilot study with a sample of Deaf people in England, whose language is BSL. The BSL version of the Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM) was additionally used to establish the convergent validity of the three newly translated BSL mental health assessments.

## **2. Methods**

### **2.1. Materials**

**2.1.1. The Patient Health Questionnaire.** The Patient Health Questionnaire (PHQ-9) was developed by Spitzer, Kroenke, and Williams (1999) and measures depression. PHQ-9 contains nine items and covers nine criteria listed in the DSM-

IV on depression (Kroenke, Spitzer, & Williams, 2001), requiring respondents to rate the frequency of present difficulties over the past two weeks. Scores indicate presence and the severity of the depression, with a maximum score of 27 and a minimum score of 0. Scores of 5, 10, 15, and 20 indicate mild, moderate, moderately severe, and severe depression respectively. The internal reliability of the English version of the PHQ-9 with a clinical, hearing population was in the range of 0.86-0.89 (Kroenke et al., 2001), which indicates good reliability. The cut-off score ('grey zone') for PHQ-9 is 10-15 (Kroenke et al., 2001). This denotes the minimum score that must be met in order to raise concerns as to the level of severity of the person's mental health state. Factor analyses of the English version of PHQ-9 have found a single-factor solution (Dum, Pickren, Sobell & Sobell, 2008; Hepner, Hunter, Edelen, Zhou, and Watkins, 2009; Spitzer, Kroenke, Williams, & Löwe, 2006), which indicates that there is one distinct facet of depression in the hearing population.

The PHQ-9 has been translated into several other languages, including Swedish (Hansson, Chotai, Nordstrom & Bodlund, 2009), Thai (Lotrakul, Sumrithe, & Saipanish, 2008), and Greek (Hyphantis et al., 2011). Many translated versions of PHQ-9 have also extracted a single factor (Hansson et al., 2009, for a Swedish population; Liu et al. (2011) for a Chinese population; Huang, Chung, Kroenke, Delucchi, & Spitzer 2006, with four different ethnic populations in USA). Interestingly, the English version for an Australian population did not extract a single factor solution (Titov et al., 2011). Titov et al. (2011) suggested that the failure to extract a single factor might be owing to homogenous characteristics of the sample in their study, as many of them were clinically depressed.

**2.1.2. The Generalised Anxiety Disorder 7-item scale.** Spitzer et al. (2006) created the Generalised Anxiety Disorder 7-item (GAD-7) to measure generalised anxiety disorder (GAD). Scores of 5, 10, and 15 indicate mild, moderate, and

severe anxiety. The reliability of the GAD-7 English version in a hearing population was found to be excellent ( $\alpha = 0.92$ ) and factor analysis of GAD-7 has found that all items in GAD-7 load into one factor (Spitzer et al., 2006).

GAD-7 has been translated into other languages, for example, Dutch (Donker, van Straten, Marks, & Cuijpers, 2011), Bengali, Gujarati, Hindi, Punjabi, Urdu, and Polish (IAPT, 2012). Like the English version, the Spanish version of GAD-7 extracted a single factor (Garcia-Campayo et al., 2010), as did the Dutch version (Donker et al., 2011).

**2.1.3. The Work and Social Adjustment Scale.** Mundt, Marks, Shear, and Greist (2002) developed the Work and Social Adjustment Scale (WSAS). The purpose of WSAS is to measure impairment in functioning and includes five items related to work and social functioning. The first item on the WSAS relates to work. If respondents are retired or are not in work for reasons unrelated to their problems, then they can select 'not applicable' and the score for question one can be substituted with the mean score from the rest of questions. The internal reliability for the English version of WSAS with a hearing population ranged from 0.79 to 0.94. The principal component analysis of the WSAS English version extracted a single factor (Mataix-Cols et al., 2005; Mundt et al., 2002).

**2.1.4. The Clinical Outcomes in Routine Evaluation – Outcome Measure.** The Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM) measures global distress (Barkham et al., 1998). It measures a range of mental health problems including depression, anxiety, functional capacity and risk. It has been translated into other written languages, including Slovak (Gampe, Biešcad, Balúnová-Labanicová, Timulák, and Evans, 2007) and Italian (Palmieri et al., 2009). The BSL version of CORE-OM has been produced and validated by Rogers, Evans, Campbell, Young, & Lovell (2012b) as part of a separate research

study. The reliability for all items in the BSL CORE-OM was found to be 0.94. It was included with the other assessments in the present study.

## **2.2. Procedure**

**2.2.1. Translating the mental health assessments into BSL.** To produce BSL versions of the GAD-7, PHQ-9 and WSAS, a translation process was carried out following the five-stage procedure outlined by Evans (2008). It was adapted slightly to accommodate the fact that BSL is a visual language with no written form, in that the various BSL versions produced through this process were filmed.

1. At the first stage, five Deaf people who were bilingual in English and BSL but from different backgrounds (including a mental health professional; a qualified interpreter; a lay person) each independently carried out forward translations from English into BSL (first draft).
2. During the second stage, the first author of this paper and one of those involved in the creation of the original mental health assessments met with the forward translators. Together, they reviewed the differences between the five BSL versions of each tool. The meaning of the English versions was clarified and used as a reference point for the identification of the preferred BSL version of each assessment.
3. This was followed by the production of a revised BSL version of each assessment tool (second draft).
4. The second draft of the BSL versions was then translated back into English by two individuals not previously involved in the study. In parallel, five BSL users were asked to complete the assessments online to check whether they had any difficulties with the BSL versions.
5. Feedback from the five people who completed the assessments and those who back translated them was incorporated, following further discussion with the person who created the original version about any issues arising. This led

to the production of the final versions of the three assessment tools in BSL, ready to be piloted.

These final versions in BSL were produced in a visual (filmed) format, not a written form (as were the interim versions). For further details of the translation process and the challenges faced see Rogers et al. (2012a).

**2.2.2. Pilot study of the PHQ-9, GAD-7 and WSAS with a Deaf population.** A bespoke website was developed for this project, in BSL and English, which hosted the information sheet explaining the purpose of this project for both participants and professionals working with Deaf people. It was explained that they will only do the BSL versions of the mental health assessments, with no written English versions involved in the assessments. Lists of the inclusion and exclusion criteria for participation in the study were included on the website. Professionals working with Deaf people (e.g., counsellors, community mental health nurses and clinical psychologists) were asked to pass on the information to those who might satisfy the inclusion criteria, in order for them to take part. Deaf people were then able to decide whether they wished to take part or not. The process included consenting to take part, the completion of a demographic questionnaire and the four mental health assessments in BSL. When they had completed the pilot versions of the three assessments, participants were taken directly to the 'support' page of the project website, which hosted additional resources for Deaf people. These included information about the SignHealth Therapy Service, which is a specialist service for Deaf people in the UK, supporting those who experience mental health difficulties.

In addition to the three mental health assessments, participants were also invited to complete the CORE-OM, the BSL version of which had previously been created and checked for reliability (Rogers et al., 2012b). The purpose of using the CORE-OM was to establish convergent validity for each of the other mental health

assessments. Examination of the convergent validity of an assessment in the target language by means of measuring a similar area to that measured by a new version of an assessment, is an approach that has been used in previous studies undertaken with the hearing population (e.g., Garcia-Campayo et al., 2010).

### **2.3. Recruitment**

**2.3.1. Inclusion criteria.** The inclusion criteria were that participants had to be Deaf BSL users aged 16 years or over and reside in England.

**2.3.2. Exclusion criteria.** Participants were excluded if they were not Deaf, did not use BSL, had a learning disability, had psychosis, or were current inpatients on mental health wards, as the norms may be different for these groups. Those who were unable to access signed information through the visual interface of a computer screen, such as those who were Deaf-blind, were also excluded.

A broad recruitment strategy was employed including advertising to the general Deaf population via emails, adverts in magazines/online and presentations at Deaf forums/clubs across England. Information about the present study was also passed on to service users of specialist mental health services for Deaf people, such as National Deaf Child and Adolescent Mental Health Services (a national service in England for d/Deaf children and young people who experience mental health difficulties), SignHealth and the nine local National Health Service trusts<sup>3</sup> in England.

This project was approved by the National Research Ethics Service (NRES) Committee for Yorkshire and the Humber – Leeds West. REC number: 11/YH/0180. The project had ethical approval from nine local NHS organisations.

### **2.4. Participants**

In total, 136 people provided demographic details and completed the mental health assessments. However, 6 did not meet the inclusion criteria (3 were hearing



and 3 hard of hearing), 1 person subsequently withdrew consent and 14 provided incomplete data, which left a total of 113 sets of data sets with few missing items.

**2.4.1. Demographics.** The majority of the 113 participants were female (60%); 86% were White British, 4% were Asian British (Indian), 3% were White Irish, 3% were White with other backgrounds, and there was one person in each of the Asian British (Pakistani), Asian British with other background, Mixed, and Chinese ethnic groups. The age of the participants ranged from 19–65 years old; 19% were 19-24 years old, 38% were 25-34 years old, 24% were 35-49 years old, 19% were 50-64 years old, 1% were in the 65 plus years old, and 4% of responses were missing this information. Just over half (51%) stated that they were the only Deaf person in their family. Regarding language, 76% reported being BSL users, 16% preferred to use Sign Supported English<sup>4</sup> and 7% generally used spoken English. Most first learned BSL as a child: 30% learned from birth, 14% aged 1-3 years old, 13% 4-7 years old, 7% 8-11 years old, 12% 12-16 years old, 18% 17-24 years old and 6% at over 25 years old. The majority of the participants reported being involved in the Deaf community (83% reported often/very much involved), felt they belonged to the Deaf community (81% reported quite so/very much so), and identified themselves as culturally Deaf (83% reported quite so/very much so).

The sample was divided into two groups: Group 1 included those who reported no mental health difficulties in the past 12 months ( $n = 88$ ), and Group 2 included those who reported some mental health difficulties in the past 12 months ( $n = 25$ ). Group 2 was additionally sub-divided depending on whether the participant was receiving professional support at the time of the study ( $n = 6$ ), had received support within the previous 12 months but not at the time of the study ( $n = 7$ ), or had not had any professional support ( $n = 12$ ) (see Table 1). We reserved the right as part of the consent procedure to contact a participant's GP should their responses, when analysed, raise cause for concern about their mental well-being.

Contact with the GP was made if there had been any cause for concern in response to items PHQ-9 No.1, CORE-OM No. 16, 24, and 34. In total, 23 participants' GPs were contacted; 6 out of 88 participants in Group 1, 17 out of 25 participants in Group 2 (In Group 2; 6 out of 6 who were receiving professional support at the time of study, 2 out of 7 participants who had received professional support in the past 12 months but not at the time of study, and 9 out 12 participants who had had no professional support).

Table 1

*Number of participants in each mental well-being group, including those whose GPs had been contacted*

Group	Professional support received	Sample size (n=number of GPs contacted)
Group 1: No mental well-being difficulties in the past 12 months		88 (contact GP n=6)
Group 2: Had mental well-being difficulties in the past 12 months		
	Have professional support at the present time	6 (contact GP n=6)
	Had professional support in the past 12 months but not now	7 (contact GP n=2)
	Had no professional support	12 (contact GP n=9)

## 2.5. Statistical analyses

Data were analysed using SPSS Release 16. The analysis of the reliability and validity were carried out by including data from both Group 1 and Group 2, owing to the small sample size for Group 2 (n = 25). However, for the mean comparison between Group 1 and Group 2, a Mann-Whitney U test was carried out.

The reliability of each assessment was examined in terms of the internal consistency of the items using Cronbach's alpha values. The BSL assessments were examined for construct validity and convergent validity. Construct validity determines how much the operational measures of items in the assessment cover

what they are intended to measure of the theoretical construct. Convergent validity tests the degree to which a particular assessment correlates with another assessment that measures similar domains. The way in which missing items were dealt with was dependent on the type of analysis. For the mean and standard deviation analysis and convergent validity analysis (pairwise involved using the total score), the missing items were substituted with mean scores across the other items for the participant. A maximum of one missing item of data was allowed for the PHQ9, GAD7, and WSAS (including the first question), and a maximum of three missing items for the CORE-OM. For the reliability analysis and principle component analysis, actual responses to the individual items were analysed, and missing data were dealt with by listwise deletion.

Principal component analysis with Varimax rotation was carried out to establish construct validity. Components were extracted if their eigenvalues were greater than 1 (absolute values of loadings less than 0.4 are suppressed in the output for clarity). A recommended minimum sample size to carry out principal component analysis is at least five and preferably ten times as many observations per variable (Hair, Black, Babin, Anderson & Tatham, 2006). This means, for example, that for the 9-item PHQ-9, the sample size should be approximately 45-90.

Convergent validity for each of PHQ-9, GAD-7, and WSAS was assessed by estimating Pearson's correlation with CORE-OM depressive items (No. 5, 9, 23, and 24), CORE-OM anxiety items (No. 2, 11, and 15), and the functioning domain of CORE-OM (No. 1, 3, 7, 10, 12, 19, 21, 25, 26, 29, 32, and 33) respectively.

### **3. Results**

#### **3.1. Descriptive statistics**

Table 2 shows the mean and standard deviation (SD) scores of the total score for each BSL assessments for all data (both Group 1 and Group 2), for those who reported no mental health difficulties in the past 12 months (Group 1) and for those

who did (Group 2). Means and standard deviations were higher in Group 2, indicating increased levels of and greater variability in depression, anxiety, impaired function and global distress.

Table 2

*Participants' scores for Patient Health Questionnaire (PHQ-9), Generalised Anxiety Disorder (GAD-7), Work and Social Adjustment Scale (WSAS) and Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM) by mental well-being group*

	Mean (Standard deviation)			
	PHQ-9	GAD7	WSAS	CORE-OM
Group				
Both Group 1 and 2	5.34 (4.71)	3.25 (3.76)	4.71 (6.20)	0.76 (0.58)
Group 1	3.25 (3.25)	2.14 (2.46)	2.68 (3.45)	0.58 (0.37)
Group 2	11.61 (4.12)	7.61 (4.76)	12.93 (7.95)	1.46 (0.68)

### 3.2. Comparing means between Group 1 and Group 2

Group 2 differed in their scores on the BSL versions of PHQ-9, GAD-7, WSAS and CORE-OM from Group 1. A Mann-Whitney U test showed that on PHQ-9, Group 2 (median = 12.00) scored significantly higher than Group 1 (median = 3.00),  $U = 151.50$ ,  $p < 0.001$ . GAD-7 scores for Group 2 (median = 7.00) were significantly higher than for Group 1 (median = 2.00),  $U = 245.50$ ,  $p < 0.001$ . Significantly higher scores were also noted for WSAS for Group 2 (median = 12.00) compared to Group 1 (median = 1.00),  $U = 178.50$ ,  $p < 0.001$ . Differences between Group 1 and Group 2 for the CORE-OM were also significant, with Group 2 (median = 1.26) higher than Group 1 (median = 0.53),  $U = 159.50$ ,  $p < 0.001$ .

### **3.3. Psychometric properties of BSL versions of PHQ-9, GAD-7, and WSAS**

**3.3.1. PHQ-9 BSL version.** Internal consistency for both Group 1 and Group 2 together is  $\alpha = 0.81$ , which indicates the reliability of the PHQ-9 is good (George & Mallery, 2003). However, one item (no. 1) has an item-total correlation lower than 0.3. The Cronbach's alpha value would increase very slightly ( $\alpha = 0.82$ ) if it were to be removed, which indicates that that PHQ-9 item no.1 may possibly need revising, or at least review, to increase the overall reliability of the PHQ-9 BSL.

The construct of the PHQ-9 BSL version for the Deaf population showed two factors. Principal components analysis with Varimax rotation also extracted two components. Component one contained item numbers: 2, 3, 5, 6, 7, 8, and 9; and component two contained item numbers: 1, 4, and 8 (Table 3). Component one represented 42.28% of total variance, and component two accounted for 14.10% of total variance, with communality values ranging from 0.358 to 0.753. Convergent validity was examined by looking at the correlation between PHQ-9 score and CORE-OM BSL depressive items, and was found to be significant ( $r = 0.68$ ,  $n = 90$ ,  $p < 0.001$ ). This indicated that the BSL version of the PHQ-9 was convergent with the CORE-OM depressive items.

Table 3

*Component loadings of the Patient Health Questionnaire (PHQ-9) British Sign Language (BSL) items after principal components analysis with Varimax rotation*

PHQ-9 BSL Items	Component 1	Component 2
No. 1: Little interest or pleasure in doing things		0.85
No. 2: Feeling down, depressed, or hopeless	0.74	
No. 3: Trouble falling or staying asleep, or sleeping too much	0.50	
No. 4: Feeling tired or having little energy		0.74
No. 5: Poor appetite or overeating	0.71	
No. 6: Feeling bad about yourself, or that you are a failure or have let yourself or your family down	0.85	
No. 7: Trouble concentrating on things, such as reading the newspaper or watching television	0.58	
No. 8: Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual	0.58	0.50
No. 9: Thoughts that you would be better off dead or of hurting yourself in some way	0.76	

*Note.* Component loadings < 0.40 have been suppressed for clarity. Kaiser-Meier-Olkin measure of sampling adequacy = 0.832.

**3.3.2. GAD-7 BSL version.** The internal reliability of the GAD-7 BSL version was found to be in the good range of Cronbach's alpha value ( $\alpha = 0.88$ ). None of the items in GAD-7 had less than a 0.3 corrected item-total correlation, which indicates that they do not need to be revised to improve reliability.

The validation of the GAD-7 was completed by checking the construct of the assessment itself, as well as its convergent validity with another similar assessment (the CORE-OM BSL). Like the English version of GAD-7 used with a

hearing population (Spitzer et al., 2006), the BSL version of GAD-7 used in the present study with a Deaf population also had a single-component solution (Table 4), accounting for 58.08% of total variance, of which the communality loadings of each item onto the one component were in the range of 0.518 to 0.717. This means that the concept of anxiety as expressed in items in GAD-7 are common to individuals from both the Deaf population using the BSL version and individuals from the hearing population using the English version. The anxiety items in CORE-OM BSL had a positive correlation with GAD-7 items ( $r = 0.75$ ,  $n = 95$ ,  $p < 0.001$ ).

Table 4

*Component loadings of the Generalised Anxiety Disorder (GAD-7) British Sign Language (BSL) items after principal components analysis*

GAD-7 BSL Items	Component 1
No. 1: Feeling nervous, anxious or on edge	0.73
No. 2: Not being able to stop or control worrying	0.85
No. 3: Worrying too much about different things	0.79
No. 4: Trouble relaxing	0.77
No. 5: Being so restless that it is hard to sit still	0.74
No. 6: Becoming easily annoyed or irritable	0.72
No. 7: Feeling afraid as if something awful might happen	0.74

*Note.* Kaiser-Meier-Olkin measure of sampling adequacy = 0.845.

**3.3.3. WSAS BSL version.** The internal consistency of items within the BSL version of the WSAS was good ( $\alpha = 0.88$ ). The construct validity of the WSAS was also found to be good. A single-component solution was extracted (Table 5), accounting for 68.68% of the total variance in one component. The communalities ranged from 0.487 to 0.812. The BSL version of the WSAS had a positive

correlation with the functioning domains of the CORE-OM BSL ( $r = 0.70$ ,  $n = 83$ ,  $p < 0.001$ ).

Table 5

*Component loadings of the Work and Social Adjustment Scale (WSAS) British Sign Language (BSL) items after principal components analysis*

WSAS BSL Items	Component 1
No. 1: Because of my [problem] my ability to work is impaired.	0.90
No. 2: Because of my [problem] my home management is impaired.	0.78
No. 3: Because of my [problem] my social leisure activities is impaired.	0.90
No. 4: Because of my [problem], my private leisure activities are impaired.	0.70
No. 5: Because of my [problem], my ability to form and maintain close relationships with others, including those I live with, is impaired.	0.85

*Note.* Kaiser-Meier-Olkin measure of sampling adequacy = 0.839.

**3.3.4. CORE-OM BSL version.** The internal consistency of the items for each domain of the CORE-OM BSL, as well as all items and items minus risk, were in the range of acceptable to excellent, as suggested by George and Mallery (2003). The Cronbach's alpha values were:  $\alpha = 0.94$  for all items;  $\alpha = 0.79$  for well-being;  $\alpha = 0.92$  for problems;  $\alpha = 0.83$  for functioning,  $\alpha = 0.72$  for risk, and  $\alpha = 0.94$  for items minus risk. This indicates that the response to the items in CORE-OM BSL were consistent with other items in each domain.

#### 4. Discussion

The reliabilities of the BSL versions of the PHQ-9, GAD-7, and WSAS were found to be good. The only item that reduced reliability was item no. 1 in the PHQ-9, yet removing this item gave only a minor increase in reliability (0.01). This suggests that the current BSL item for no. 1 is acceptable for use and may not



need to be revised. The validation of the GAD-7 and WSAS were examined by checking the construction of the BSL assessment itself in comparison with the hearing population. The BSL items of anxiety and functioning in GAD-7 and WSAS respectively had one underlying component for anxiety and functioning, as in the hearing population. However, for the PHQ-9, construct validation showed that there were two components for depression in a Deaf population. The sample size in the present study is too small to carry out a confirmatory factor analysis for the PHQ-9.

The extraction of at least two components has been noted in another study. Titov et al.'s (2011), psychometric comparison study of the PHQ-9 and BDI-II for measuring response during treatment of depression also did not extract a one factor solution. However, unlike in that study, not all Deaf people in the present study were clinically depressed. Other research not concerned with depression, has also demonstrated inconsistencies between a Deaf and hearing population in the investigation of psychometric properties. Crowe's (2002) study of the American Sign Language version of the Rosenberg Self-Esteem Scale extracted a three component solution in comparison with other studies with a hearing population that showed either one or two components.

There are two potential explanations. First, it might be that the concept of depression, as assessed through the PHQ-9, from a Deaf population perspective, has two distinct facets. Depression in various ethnic hearing populations has been found to be culturally determined, which affects responses to standardised assessments (Huang et al., 2006; Spitzer et al., 2006). Depression might not be the same for Deaf BSL users as it is for hearing people in its cultural meaning and expression. Second, it might be that the items that fall outside of group one (items 1 and 4) need to be revised in the BSL version. However, PHQ-9 item 4 has item-total correlation greater than 0.3, which shows that it is reliable and does not need

to be revised. This points towards the first explanation being the most likely reason, i.e., that the concept of depression has two distinct facets within the Deaf population.

Interestingly, both item 1 and item 4 in the PHQ-9 are related to motivation. Poor motivation is indicative of depression, hence items in the PHQ-9 seek to measure it. However, there are other reasons why someone might express poor motivation. Amongst Deaf people who face daily challenges in a largely uncommunicating world as well as regular instances of direct and indirect discrimination, poor motivation may have different causes or be more common for reasons other than depression. For instance, the motivation related item in the CORE-OM (“I have felt totally lacking in energy and enthusiasm”), elicited a response of “sometimes” in most Deaf people, demonstrating that it is not an unusual self-perception. Perhaps a Deaf person’s motivation depends on social context. For example, a Deaf person may give a different answer if they are asked whether they have the energy to do things in a hearing social environment as opposed to a Deaf social environment. For Deaf young people in an educational context, Stinson and Whitmire (2000) pointed out that difficulties with language skills might affect some Deaf people’s motivation. It would be interesting for future research to explore Deaf people’s perspectives on motivation in a variety of culturally and linguistically distinct contexts in order to understand its roots and the nature of its association with depression. A contextualised approach to research design through the collection of qualitative data would enable such exploration.

While this was a pilot study, for research purposes we included in the design the means of identifying any participants whose responses might indicate they were experiencing mental health difficulties which were of immediate concern. Deaf people face barriers to health services and it is possible health professionals may not have spotted the concerns of the Deaf people (Alexander, Ladd, &

Powell, 2012; Fellingner, Holzinger, & Pollard, 2012). Of the 136 who participated in the present study, 23 participants' scores raised such concerns and their GPs were informed. Nine of these were drawn from Group 2 ( $n = 25$ ), the group who had reported having had mental well-being difficulties in the past 12 months. All were amongst those who also had had no contact with any professional support in the past 12 months. The other 14 whose GP's were contacted came from Group 1 ( $n = 88$ ), the group who reported having had no mental health difficulties in the past 12 months.

Although not an intended outcome, the referral of these 23 participants showed that without having reliable and validated BSL versions, these participants' mental health difficulties might not have been identified in a timely fashion and they would probably have continued to go without support. This is of particular importance since these assessments are only designed to identify the most serious of difficulties that would lead to hospitalisation. They are much more commonly managed on an everyday basis in the community. However, without support the distress and difficulty caused can become chronic leading to much lower general states of well-being than would be necessary.

The Deaf population in England is small and geographically dispersed, with few centres of concentrated numbers of Deaf people in the same location. This presents significant challenges in piloting translated versions of assessments with large enough numbers of people at a reasonable cost and in a time-efficient manner. However, collecting the data securely online has made it possible to recruit a satisfactory number of Deaf people quickly. Deaf people throughout the world have been enthusiastic adopters of information technology and the internet is widely used by Deaf people and so is an acceptable means of engagement posing few barriers when the content is delivered directly in signed languages (Power, Power, & Rehling, 2007; Valentine & Skelton, 2008).

The present study has shown that it is feasible to translate standardised mental health assessments, both linguistically and culturally, into signed languages, and supports a small body of similar work elsewhere (for example: Crowe, 2002 for American Sign Language; Fellingner et al., 2005a for Austrian Sign Language; Graybill et al., 2010 for American Sign Language). For more detailed translation procedure, with particular reference to translating the CORE-OM into BSL, see Rogers et al. (2012a). Successfully translating/adapting standardised assessments into signed languages, in this case BSL, is only the first step in establishing normative data for a signing Deaf population.

This paper did not set out with the aim of comparing Deaf and hearing norms and it was not possible to do this from the data collected here because this is only a pilot study and the sample size for Group 2 is too small. In order to confirm the screening data and identify the potential difficulties, clinical interview would be necessary. Deaf people tend to be compared against the normative data from a hearing population for any particular assessment. However, as Deaf people have a different language and culture from their hearing counterparts, as well as having different life experiences, it may not be correct to compare a Deaf individual against normative data derived from a hearing population, even if the means of collecting that data is linguistically accessible and its reliability and construct validity established. Comparisons with normative data from a hearing population tend to show Deaf people as apparently having more severe difficulties. For example, the results of the General Health Questionnaire - 12 Austrian Sign Language version from a Deaf population were compared to normative data for the general hearing, German-speaking population and it was found that Deaf people scored significantly higher for having mental health difficulties (Fellinger, et al., 2005b). Without normative data from a Deaf population, however, it is not possible to accurately interpret the results of assessments because the cut-off

scores for the level of severity of mental health difficulties have not been established for that particular population. This is an observation widely reported in translations of standard assessments used in a culturally distinct hearing population (Niclasen et al., 2012; Scholte et al., 2011). However, because the cultural-linguistic identity of Deaf people is not always acknowledged or accepted (Alexander et al., 2012) this issue is not fully investigated because 'deaf' people are presumed to be hearing people who do not hear. We intend in future studies with larger numbers to use the BSL assessments whose reliability and validity we have now established, to ascertain Deaf population norms and recommended cut-offs.

#### **4.1. Limitations**

The present study has several limitations:

- The diversity of participants. Whilst the study achieved a good spread of age, gender, hearing status of family members of participants, and the age of when first learned BSL, the majority of the participants in the present study are White British. Information on socio-economic status of participants was not collected, therefore we are unable to comment on any potential sampling bias resulting from SES.
- The study required the self-declaration of mental well-being difficulties. It is known that the health information in the Deaf community is poor, and it is possible that some participants might not have been aware that what they might have been experiencing was associated with mental well-being difficulties. However, from the information of those ( $n = 23$ ) whose GPs were contacted as a result of the concerns raised from their responses, the majority ( $n = 17$ ) had reported that they have had mental well-being difficulties in the past 12 months.

- The study required access to a computer to participate which might have created a sampling bias. Whilst access to computers is widespread amongst Deaf people in England and there is much public availability in addition to private ownership, the necessity to complete the assessments online might have created a barrier. However, research indicates that Deaf people in the UK are greater adopters of online technologies than hearing people and that literacy in the written word is not as great a barrier to confident computer use as one might assume (Valentine & Skelton, 2008).
- Although the literacy skills are not required in the pilot study, there might be a bias in the selection because the information available about this project was presented in both BSL and English. The information explaining the purpose of the present study being available in English as well as BSL might have assisted with the recruitment, such as for educated and literate Deaf people.
- The inclusion and exclusion criteria were clearly displayed on the website as well as in the information sheet, however, as this is a self participation study it is difficult to confirm that they understood the exclusion criteria to be eligible to take part.

## **5. Conclusion**

This project has produced mental health assessments in BSL that can be used in mental health services as well as in other practices working with Deaf BSL users. That means that Deaf people will be able to have access to assessments in their preferred language, BSL. The BSL versions of the PHQ-9, GAD-7, and WSAS have been adopted as part of BSL Healthy Minds project, a specialised IAPT service for Deaf people in some parts of England, and will be used in their final online format. Their wide use over a period of time will afford the opportunity to establish normative data on a Deaf population for common mental health difficulties such as anxiety and depression and thus eventually establish

population specific cut-offs for these assessments in practice. Further work is needed to understand what the concept of depression might mean to culturally Deaf people. The online delivery of the assessments, which does not rely on the variable skills of whomever might be signing, will ensure a high level of consistency of delivery and validity of data.

## **Notes**

<sup>1</sup> Capital 'D' is used when referring to a person whose first language is Sign Language such as British Sign Language (BSL) and who is culturally Deaf. d/D is used to indicate that those referred to are deaf without specific differentiation.

<sup>2</sup> We acknowledge that there are diversities of Deaf people within Deaf populations. However, for simplicity this paper will use population as singular rather plural (populations).

<sup>3</sup> The nine National Health Service (NHS) Trusts in England who passed on information about the study to potential participants were: <sup>2</sup>gether NHS Foundation Trust, Avon and Wiltshire Mental Health Partnership NHS Trust, Birmingham and Solihull Mental Health NHS Foundation Trust, Greater Manchester West Mental Health NHS Foundation Trust, Northumberland, Tyne & Wear NHS Foundation Trust, Nottinghamshire Healthcare NHS Trust, York Hospitals NHS Foundation Trust, Somerset Partnership NHS Foundation Trust, and South West London and St George's Mental Health NHS Trust.

<sup>4</sup> Sign Supported English is a visual version of English which borrows signs from BSL but adopts the grammar and word order of English, often with the addition of spoken English used simultaneously (Sutton-Spence & Woll, 1999).

## **Funding**

British Society for Mental Health and Deafness (BSMHD1101); Katherine D.

Rogers's doctoral research fellowship by the National Institute for Health Research (Award reference number: DRF-2009-02-118).

## References

- Alexander, A., Ladd, P., & Power, S. (2012). Deafness might damage your health. *The Lancet*, 379(9833), 979-981. doi:10.1016/S0140-6736(11)61670-X
- Barkham, M., Evans, C., Margison, F., McGrath, G., Mellor-Clark, J., Milne, D. & Connell, J. (1998). The rationale for developing and implementing core outcome batteries for routine use in service settings and psychotherapy outcome research. *Journal of Mental Health*, 7(1), 35-47. doi:10.1080/09638239818328
- British Society for Mental Health and Deafness. (2010, July) *July 2010 – Latest News: Deaf people’s mental well-being put at risk by lack of services*. Retrieved from <http://www.bsmhd.org.uk/news0710.htm>
- Crowe, T. V. (2002). Translation of the Rosenberg Self-Esteem Scale into American Sign Language: A principal components analysis. *Social Work Research*, 26(1), 57-63. doi:10.1093/swr/26.1.57
- Department of Health. (2002). *A Sign of the Times: Modernising Mental Health Services for people who are Deaf*. London, UK: HMSO.
- Department of Health. (2005). *Mental Health and Deafness – Towards Equity and Access: Best Practice Guidance*. London, UK: HMSO.
- Donker, T., Straten, A. V., Marks, I., & Cuijpers, P. (2011). Quick and easy self-rating of Generalized Anxiety Disorder: Validity of the Dutch web-based GAD-7, GAD-2 and GAD-SI. *Psychiatry Research*, 188(1), 58-64. doi:10.1016/j.psychres.2011.01.016
- Dum, M., Pickren, J, Sobell, L. C., & Sobell, M. B. (2008). Comparing the BDI-II and the PHQ-9 with outpatient substance abusers. *Addictive Behaviors*, 33(2), 381-387. doi:10.1016/j.addbeh.2007.09.017
- Evans, C. (2008). *Translating and “normalising” CORE system: CORE System Trust (CST) position statement*. Unpublished manuscript.



- Fellinger, J., Holzinger, D., Dobner, U., Gerich, J., Lehner, R., Lenz, G., & Goldberg, D. (2005a). An innovative and reliable way of measuring health-related quality of life and mental distress in the deaf community. *Social Psychiatry and Psychiatric Epidemiology*, 40(3), 245-250. doi:10.1007/s00127-005-0862-9
- Fellinger, J., Holzinger, D., Dobner, U., Gerich, J., Lehner, R., Lenz, G., & Goldberg, D. (2005b). Mental distress and quality of life in a deaf population. *Social Psychiatry and Psychiatric Epidemiology*, 40(9), 737-742. doi:10.1007/s00127-005-0936-8
- Fellinger, J., Holzinger, D., & Pollard, R. (2012). Mental health of deaf people. *The Lancet*, 379(9820), 1037-1044. doi:10.1016/S0140-6736(11)61143-4
- Gampe, K., Biešcad, M., Balúnová – Labanicová, L., Timulák, L., & Evans, C. (2007). Slovenská adaptácia metódy CORE-OM (Clinical Outcomes in Routine Evaluation – Outcome Measure). [A Slovak adaptation of CORE-OM (Clinical Outcome in Routine Evaluation – Outcome Measure)]. *Ceská a slovenská psychiatrie. [Czech and Slovak Psychiatry]*, 103(1), 4–13. Retrieved from <http://www.cspsychiatr.cz/detail.php?stat=312>
- Garcia-Campayo, J., Zamorano, E., Ruiz, M. A., Pardo, A., Perez-Paramo, M., Lopez-Gomez, V., ... Rejas, J. (2010). Cultural adaption into Spanish of the generalized anxiety disorder-7 (GAD-7) scale as a screening tool. *Health and Quality of Life Outcomes*, 8, 8. doi:10.1186/1477-7525-8-8
- Gascon-Ramos, M., Young, A. M., Petrides, K. V. Stone, C., & Woolfe, T. (2010). *TEIQue British Sign Language Version - a pilot project*. Final report to the Nuffield Foundation, February 2010.
- George, D. & Mallery, P. (2003). *SPSS for windows step by steps: A simple guide and reference*. Boston, MA: Allyn and Bacon.

- Graybill, P., Aggas J., Dean, R. K., Demers, S., Finigan, E. G., & Pollard, R. Q. (2010). A community participatory approach to adapting survey items for Deaf individuals and American Sign Language. *Field Methods*, 22(4), 429-448. doi:10.1177/1525822X10379201
- Hair, J. F., Black, W. C., Babin, B. J., Anderson, R. E., & Tatham, R. L. (2006). *Multivariate Data Analysis* (6<sup>th</sup> edition). Upper Saddle River, NJ: Pearson Prentice Hall.
- Hansson, M., Chotai, J., Nordstrom, A., & Bodlund, O. (2009). Comparison of two self-rating scales to detect depression: HADS and PHQ-9. *British Journal of General Practice*, 59(566), e283-e288. doi:10.3399/bjgp09X454070
- Hepner, K. A., Hunter, S. B., Edelen, M. O., Zhou, A. J., & Watkins, K. (2009). A comparison of two depressive symptomatology measures in residential substance abuse treatment clients. *Journal of Substance Abuse and Treatment*, 37, 318–325. doi:10.1016/j.jsat.2009.03.005
- Hindley, P., Hill, P. D., McGuigan, S., & Kitson, N. (1994). Psychiatric Disorder in Deaf and Hearing Impaired Children and Young People: A Prevalence Study. *Journal of Child Psychology and Psychiatry*, 35(5), 917-934. doi:10.1111/j.1469-7610.1994.tb02302.x
- Huang, F. Y., Chung, H., Kroenke, K., Delucchi, K. L., & Spitzer, R. L. (2006). Using the Patient Health Questionnaire-9 to Measure Depression among Racially and Ethnically Diverse Primary Care Patients. *Journal of General Internal Medicine*, 21(6), 547-552. doi:10.1111/j.1525-1497.2006.00409.x
- Hyphantis, T., Kotsis, K., Voulgari, P. V., Tsifetaki, N., Creed, F., & Drosos, A. A. (2011). Diagnostic Accuracy, Internal Consistency, and Convergent Validity of the Greek Version of the Patient Health Questionnaire 9 in Diagnosing Depression in Rheumatologic Disorders. *Arthritis Care & Research*, 63(9), 1313-1321. doi:10.1002/acr.20505

- Improving Access To Psychological Therapies. (2012). *Translations*. Retrieved from <http://www.iapt.nhs.uk/equalities/translations/?keywords=gad>
- Improving Access to Psychological Therapies. (2012). *British Sign Language*. Retrieved from <http://www.iapt.nhs.uk/equalities/british-sign-language-bsl/>
- Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: Validity of a Brief Depression Severity Measure. *Journal of General Internal Medicine*, 16(9), 606-613. doi:10.1046/j.1525-1497.2001.016009606.x
- Kvam, M. H., Loeb, M., & Tambs, K. (2007). Mental Health in Deaf Adults: Symptoms of Anxiety and Depression Among Hearing and Deaf Individuals. *Journal of Deaf Studies and Deaf Education*, 12(1), 1-7. doi:10.1093/deafed/enl015
- Liu, S., Yeh, Z. T., Huang, H. C., Sun, F. J., Tjung, J. J., Hwang, L. C., ... Yeh, A. W. (2011). Validation of Patient Health Questionnaire for depression screening among primary care patients in Taiwan. *Comprehensive Psychiatry*, 52(1), 96-101. doi:10.1016/j.comppsy.2010.04.013
- Lotrakul, M., Sutida, S., & Saipanish, R. (2008). Reliability and validity of the Thai version of the PHQ-9. *BMC Psychiatry*, 8(1), 46. doi:10.1186/1471-244X-8-46
- Mataix-Cols, D., Cowley, A. J., Hankins, M., Schneider, A., Bachofen, M., Kenwright, M., ... Marks, I. M. (2005). Reliability and validity of the Work and Social Adjustment Scale in phobic disorders. *Comprehensive Psychiatry*, 46(3), 223–228. doi:10.1016/j.comppsy.2004.08.007
- Mayberry, R. I. (2002). Cognitive development of deaf children: The interface of language and perception in neuropsychology. In S. J. Segalowitz & I. Rapin (Eds.) *Handbook of Neuropsychology*, 2nd Edition, Volume 8, Part II (pp. 71-107). 2nd Edition. Amsterdam, the Netherlands: Elsevier.

- Mundt, J. C., Marks, I. M., Greist, J. H., & Shear, K. (2002). The Work and Social Adjustment Scale: A simple accurate measure of impairment in functioning. *The British Journal of Psychiatry*, 180, 461-464. doi:10.1192/bjp.180.5.461
- Niclasen, J., Teasdale, T. W., Andersen, A-M. N., Skovgaard, A. M., Elberling, H., & Obel, C. (2012). Psychometric Properties of the Danish Strength and Difficulties Questionnaire: The SDQ Assessed for More than 70,000 Raters in Four Different Cohorts. *PLoS ONE* 7(2): e32025. doi:10.1371/journal.pone.0032025
- Palmieri, G., Evans, C., Hansen, V., Brancaloni, G., Ferrari, S., Porcelli, P., ... Rigatelli, M. (2009). Validation of the Italian version of the clinical outcomes in routine evaluation outcome measure (CORE-OM). *Clinical Psychology & Psychotherapy*, 16(5), 444-449. doi:10.1002/cpp.646
- Power, D. J., Power, M. R., & Rehling, B. (2007). German Deaf People Using Text Communication: Short Message Service, TTY, Relay Services, Fax, and E-Mail. *American Annals of the Deaf*, 152(3), 291-301. doi:10.1353/aad.2007.0030
- [author reference paper] (2012). *The reliability of British Sign Language and English versions of the CORE-OM with d/Deaf populations in the UK: a pilot study*. Manuscript submitted for publication.
- [author reference paper] (2012). *The challenges of translating the Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM) into British Sign Language*. Manuscript submitted for publication.
- Scholte, W. F., Verduin, F., Kamperman, A. M., Rutayisire, T., Zwinderman, A. H., & Stronks, K. (2011). The Effect on Mental Health of a Large Scale Psychosocial Intervention for Survivors of Mass Violence: A Quasi-Experimental Study in Rwanda. *PLoS ONE* 6(8): e21819. doi:10.1371/journal.pone.0021819

- Singleton, N., Bumpstead, R., O'Brien, M., Lee, A., & Meltzer, H. (2001). *Psychiatric Morbidity Among Adults Living In Private Households 2000*. London, UK: The Stationery Office.
- Spitzer, R. L., Kroenke, K., & Williams, J. B. W. (1999). Validation and utility of a self-report version of PRIME-MD: the PHQ Primary Care Study. *The Journal of the American Medical Association*, 282(18), 1737-1744. doi:10.1001/jama.282.18.1737
- Spitzer, R. L., Kroenke, K., Williams, J. B. W., & Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder: the GAD-7. *Archives of Internal Medicine*, 166(10), 1092-1097. doi:10.1001/archinte.166.10.1092
- Stinson, M. S., & Whitmire, K. A. (2000). Adolescents Who Are Deaf or Hard of Hearing: A Communication Perspective on Educational Placement. *Topics in Language Disorders*, 20(2), 58-72.
- Sutton-Spence, R., & Woll, B. (1999). *The Linguistics of British Sign Language: An Introduction*. Cambridge, UK: Cambridge University Press.
- Titov, N., Dear, B. F., McMillan, M., Anderson, T., Zou, J., & Sutherland, M. (2011). Psychometric Comparison of the PHQ-9 and BDI-II for Measuring Response during Treatment of Depression. *Cognitive Behaviour Therapy*, 40(2), 126-136. doi:10.1080/16506073.2010.550059
- Valentine, G. & Skelton, T. (2008). Changing spaces: the role of the internet in shaping Deaf geographies. *Social & Cultural Geography*, 9(5), 469-485. doi:10.1080/14649360802175691
- Vernon, M. (2005). Fifty Years of Research on the Intelligence of Deaf and Hard-of-Hearing Children: A Review of Literature and Discussion of Implications. *Journal of Deaf Studies and Deaf Education*, 10(3), 225–231. doi:10.1093/deafed/eni024

Woolfe, T., Want, S. C., & Siegal, M. (2002). Signposts to development: Theory of mind in deaf children. *Child Development*, 73(3), 768-778. doi:10.1111/1467-8624.00437

## **CHAPTER EIGHT: PAPER E**

Deaf people's perspective on mental well-being: childhood experience linked to adulthood well-being, the barriers and protective factors.

Rogers, K. D., Young, A., & Lovell, K.

To be submitted.

## **1. Abstract**

There is a paucity of literature exploring Deaf people's perspectives on mental well-being despite the prevalence of mental health difficulties being higher in d/Deaf populations than in hearing populations. This study examined how Deaf people viewed their mental well-being since childhood and the barriers and protective factors they considered to be important in maintaining their mental well-being. Four focus groups, with 27 Deaf participants, were undertaken in England. The key issues identified from childhood associated with well-being in adulthood were experiences of communicating with others, managing the experience of school, bullying, transition to adulthood, emerging identity and 'can do' attitudes. Communication difficulties, lack of support, lack of awareness and misconceptions by others were regarded as barriers to achieving positive mental well-being in adulthood. Examples of protective factors that were highlighted included support networks, having a sense of belonging and experiencing positive involvement. Conscious awareness of barriers to achieving mental well-being and having strategies in place to overcome were also seen as important.



## 2. Introduction

The aim of this study was to explore how Deaf sign language users viewed their own mental well-being and in particular if their well-being in childhood was linked to their current well-being as an adult. The rationale for the study is that there are an increasing number of studies concerning mental health and deafness, both amongst children and adults (Fellinger, Holzinger, & Pollard, 2012; Hindley, Hill, McGuigan, & Kitson, 1994), but little understanding of the pathways from childhood to adulthood with respect to mental well-being (Rogers & Young, in press). d/Deaf<sup>7</sup> people have very particular kinds of childhood experience as a consequences of deafness, including parental adjustment (Hintermair, 2006), society's attitudes (Bat-Chava, 1993), development of identities (Skelton & Valentine, 2003; Leigh, 2009), approaches to education (Hindley et al., 1994; Oliva, 2004), and a professional perspective which generally views d/Deaf children to be disabled (Young et al., 2006). The term 'well-being' rather than 'mental health' is used in this study as it incorporates both positive and negative aspects and gives emphasis to the importance of a more holistic and general feeling of mental well-being, rather than the term 'mental health difficulties' which has more negative connotations.

It has been established, largely through clinical assessment and making comparisons with the hearing population, that d/Deaf children and adults have poorer mental well-being than their hearing counterparts (Department of Health, 2005; Fellinger et al., 2012; Hindley et al., 1994). Additionally, although some efforts have been made to ensure that assessment measures are linguistically accessible and culturally appropriate, the dominant approach to understanding well-being has been one of quantitative measurement rather than qualitative information from d/Deaf people's perspectives.

d/Deaf people's perception of the factors associated with mental well-being has been rarely explored. Yet, it is important to understand how a concept, or personal

---

<sup>7</sup> Deaf (with a capital 'D') refers to the community of people who use sign language as their first or preferred language and for whom being Deaf is akin to a cultural-linguistic identity (Padden & Humphries, 1988). When deaf is written with a small 'd' it refers to those who use spoken language and/or have a view of deafness as an impairment or disability for example those who have lost their hearing in later life. d/Deaf is an all inclusive term and often is used with respect to children where their core identity is not yet formed or is unclear.

state, is defined and the factors that are considered relevant; “theories of psychological well-being are shaped by cultural beliefs concerning the fundamental nature of the person” (Suh, 2002, pp. 1378). Although not universally recognised, being Deaf is perceived as a cultural identity by sign language users who are members of a Deaf community. Holte and Dinis (2001) found the concept of self-esteem was viewed differently by hearing and d/Deaf women.

The pre-existing literature on how d/Deaf people understand a range of mental states also points to the significance of a different approach to well-being in comparison with hearing populations. In the study of Deaf people who had experienced depression, Sheppard and Badger (2010) reported the importance that a sense of belonging to the Deaf community had in relation to contributing to self-worth. Griggs (1998) identified that self-acceptance of being deaf, and coping mechanisms associated with being deaf were key features linked to positive mental well-being. In a study of resilience, the ability to be comfortable with one’s own company was found to be more salient for d/Deaf young people in comparison with their hearing counterparts (Rogers, Muir, & Evenson, 2003).

### **3. Methods**

The aim of this study was to explore Deaf people’s perceptions of their own mental well-being since childhood, and their views about the barriers and protective factors in the pathway from childhood to adult well-being. The exploratory nature of the question signalled the use of a qualitative approach (Murphy, Dingwall, Greatbatch, Parker, & Watson, 1998) which would enable issues of importance from a personal or collective perspective to emerge, rather than be pre-defined. It also enables the conceptualisations of individuals to be identified in their own right, building a reflection of realities from lived experience and how that is perceived. Focus groups were used to gather data because it has been demonstrated that this is an approach which works well with groups who are more orientated toward a collective culture of shared knowledge through mutual discussion and/or story telling. The Deaf community has been identified previously as a more collective and less individualistic culture (Ladd, 2003) and focus groups have been used successfully previously in studies with Deaf people (Griggs, 1998; Steinberg, Sullivan, and Loew, 1998; Rogers & Young, 2011).

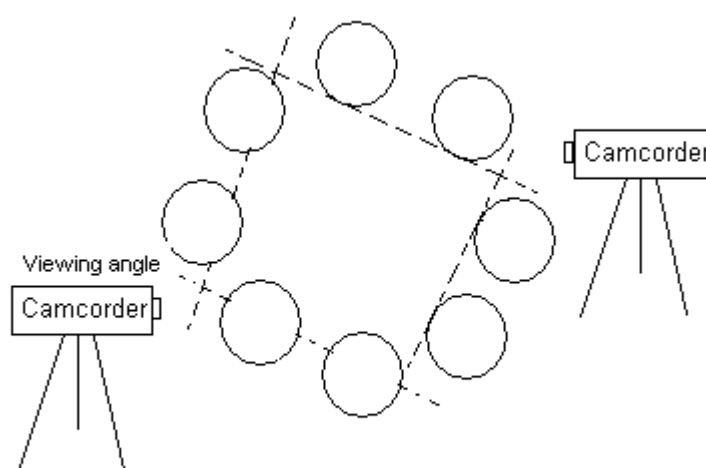
This study was given ethical approval by the School of Nursing, Midwifery and Social Work Research Ethics Committee, University of Manchester.

### **3.1. Recruitment**

Participants were recruited by mailing out to approximately 30 Deaf individuals and also by asking key persons in the d/Deaf community within different areas of England to distribute information relating to the project. Information was placed on the website and was available in both BSL and English. The criteria for taking part in this study were that participants needed to be d/Deaf and over 18 years of age.

### **3.2. Procedure**

Prior to the focus groups, participants were asked to complete an online questionnaire to ascertain demographic information. This covered personal information such as education, employment, and health. They were also asked to complete two mental well-being assessments namely the Clinical Outcomes in Routine Evaluation – Outcome Measure (Barkham et al., 1998) and the Trait Emotional Intelligence Questionnaire (Petrides & Furnham, 2003). A guide for the focus groups was determined by the first author to ensure exploration of key areas including participants' views on their mental well-being, key turning points in their life, relationships with others, key successes, stress factors, and supportive strategies. The questions acted as a guide only to allow the researcher space for the free flow of interaction between group members whilst ensuring that the main topics were adhered to. The focus groups were video recorded and each session lasted approximately an hour and half. The participants and the researcher sat in a circle and were filmed by two cameras each facing a half of the group (see figure 1 for a diagram of focus group layout). All were reminded about confidentiality at the outset.



*Figure 1.* Diagram of a bird's eye view of the focus group with the researcher and the participants in a circle. Outside the circle where the participants are seated, are two camcorders which are positioned so that each one faces half of the participants and the researcher.

### **3.3. Analysis**

The focus group data was analysed using a thematic analysis framework (Braun & Clarke, 2006; Silverman, 2011) because of its theoretic and epistemological independence which enables analysis to be flexible in providing a wealth of significant data (Braun & Clarke, 2006). Analysis of the focus groups was carried out using both the videos (in BSL) and the transcripts (translations into English). The English transcripts/translations provided an easy point of searchable reference when seeking to access the data. The BSL original provided a means of keeping the nuances of expression and fidelity to the meaning expressed in the original language. In this way, functionally the transcripts could be coded and segmented using the QSR NVIVO package, but the original meanings in the source language could lead the inductive process of analysis. Whilst it is now possible to segment and code data in a visual language without the requirement for transformation into a written form, it was considered too time consuming and laborious to do this. However, direct quotes were translated from BSL to English.

Using an inductive approach the researcher read and reread the transcripts and scrutinised the BSL videos, coding the data accordingly. This approach was laborious but effective in ensuring that all participants' views were recorded. By use of an interpretative approach to analysis, it was possible to identify latent

themes and subthemes which were pertinent to the research question. The coded data was subsequently organised and presented into three key themes; (a) childhood experiences linked with adult well-being, (b) barriers, and (c) protective factors.

## **4. Results**

### **4.1. Participants**

Four focus groups were conducted with a total of 27 participants. The demographic information of the participants<sup>8</sup> is shown in table 1.

---

<sup>8</sup> Four participants failed to complete the demographic questionnaire.

Table 1

*Demographic information of the participants*

Demographic information	<i>N</i>
Gender	
Female	22
Male	5
Ethnicity background	
White British	25
White Irish	1
Asian	1
Mean age (range 26 to 67)	48
Hearing status of parents	
Hearing parents	19
Deaf parents	8
Preferred language (although all used BSL)	
British Sign Language	15
Signed Support English	3
English	3
Marital status	
Married or in civil partnerships	16
Divorced or have had civil partnerships dissolved	6
Single	1
Widowed	1
Do have children	17
Type of secondary school attended	
Deaf residential schools	15
Deaf day schools	4
Mainstream with specialist units for the deaf	3
Mainstream school without a specialist unit	1
Number of participants who are in employment	14

*Note.* There is some missing information from the participants.

All participants reported some degree of involvement with the Deaf community, and the majority felt they belonged to the Deaf community to some degree. The majority also indicated a strong affiliation with a culturally Deaf identity.

## **4.2. Deaf perspectives on mental well-being**

The data from the analysis is presented around three key themes: (a) childhood experiences linked with adult well-being; (b) barriers; and (c) protective factors.

### **4.2.1. (a) Childhood experiences linked with adult well-being**

Subthemes raised in relation to the link between childhood experiences and later adulthood well-being were: (i) communication, (ii) managing in school, (iii) bullied, (iv) transition, (v) identity and (vi) 'can do' attitudes.

#### **4.2.1.1. Communication**

Participants in all four focus groups felt strongly that the experience of communication difficulties in their childhood had affected their mental well-being in later life. Direct connections were drawn between oralism ('oralism' was variously defined as the use by educational establishments of spoken language only, being placed in a mainstream school or the denial of Deaf identity) and later mental well-being difficulties. For some the main issue was the sense of isolation, particularly when they were the only deaf child at school. In three focus groups they felt that that placing a deaf child in mainstream situations can inhibit their sense of security and affect their future mental well-being.

Many participants from hearing families also reported experiencing communication difficulties within their own families particularly as some families never learnt how to sign. They believed that this experience had affected their childhood and was linked by participants to later mental well-being difficulties. For example, one participant felt that emotional problems around growing up deaf and struggling to communicate with their family had never receded and still triggered similar emotions today:

*"It's always on your mind and if it comes up; it can make you feel anxious"*  
[FG1, p6]

Communication is, of course, a two way process and the perceived lack of effort from others was significant for many participants. The impact of hearing family members not adjusting their communication modes and their lack of deaf awareness was raised in all groups. The impact of this was described as feelings of frustration, as one person stated:

*“She was always going off mid-conversation. We’d be talking away, voice and gesture, then suddenly she’d be off to see to something and I’d be screaming mad. .... And that was hard for me to cope with. It still happens now, like if my son or daughter interrupts to ask Nanna something, she’d just go off. I always got the feeling that when I was talking she was only half interested.” [FG4, p7]*

This was reported to lead to feelings of exclusion and to detachment or distance in relationships with hearing family members:

*“I always try to make sure I’m only seeing one person at a time, and try to avoid large family gatherings. If I do have to go, I always end up ditching it and going off by myself to do something else.” [FG1, p3]*

Many participants described having one key family member who would facilitate the communication between family members:

*“My family aren’t ignorant, they know I’m Deaf but they won’t adjust their communication for me. The only person I can communicate with in the whole of my family is my mother; she relays for me.” [FG3, p5]*

The impact of being unable to have a meaningful conversation with family members was highlighted in all the focus groups.

*“Its okay talking about everyday things but I can’t really have a deep conversation about anything” [FG1, p2]*

All groups emphasised the importance of good communication and language skills for a d/Deaf child’s development, and in particular the need to ensure that communication was accessible for them (i.e. visual) within their family.

*“I feel it is important for a deaf child’s well-being that they have language .... They need to fit in .... If they can’t express themselves, they end up thinking differently and grow up with a lots of anger about lots of different things” [FG2, p3]*

#### **4.2.1.2. Managing in school**

Participants’ also reflected on difficulties that were experienced within the school setting and how this linked to their well-being regardless of whether they originated from Deaf or hearing families. They reported difficult experiences within



educational settings that adopted an oralist approach and such difficulties went beyond the problem of communication.

*“The oral system was too much effort; it was too hard and too tiring. You miss so much” [FG4, p7]*

Some participants recalled being forced to use speech and having to guess what was being said without being allowed to lip-read:

*“The teachers used to cover their mouths so we couldn’t lip-read them” [FG4, p5]*

Others recalled being punished for signing:

*“If you signed you’d get your hands slapped” [FG4, p3]*

Many participants felt that the issue of being forced to speak rather than sign had resulted in a long term negative impact:

*“It has affected my life, for sure .... It may well have affected my mental health, yes, but it’s certainly made me stubborn.” [FG4, p4].* Conversely however, they also said that it has served to make them tougher.

Participants reflected upon the unrealistic expectations of others during their schooling. Others reported that they had been led to believe that they had clear, intelligible speech but later found out that this was not the case. Such experiences meant they felt ill prepared for the hearing world and this in turn affected their level of confidence and well-being.

*“When I got there [job] it was such a culture shock. School simply hadn’t prepared me for that at all. I’d been given false expectations.” [FG1, p6]*

#### **4.2.1.3. Bullying**

In all four focus groups, one or more participants reflected on their experience of being bullied either at school or in the workplace and being d/Deaf was cited as the main reason for the bullying. Although some participants said that being bullied had made them more resilient, most felt that these early experiences had had a detrimental affect on them as adults:

*“I was bullied badly and that has affected my life” [FG2, p2]*

*“I had a bullying problem with friends and students, my mental health went down” [FG3, p6]*

A few participants reported they had resorted to bullying others in an attempt to prevent being bullied themselves.

*“... And I was totally lost. I couldn’t understand anything. I was a bit of a bully to be honest, because I was the only deaf kid and I wanted them to pay attention to me. I used to get quite aggressive because I was so frustrated with the whole thing.” [FG1, p2]*

#### **4.2.1.4. Transitions**

For some participants, the key link between childhood experiences and later mental well-being revolved around transition periods in their life such as leaving school and entering employment. Some described feeling ill prepared for leaving school and this was the case whether they had attended a mainstream or a deaf school. A few participants likened it to a “culture shock”.

The experience of leaving school had been difficult for many participants, primarily because they were no longer surrounded by their d/Deaf peers and in many cases felt in the minority as the only d/Deaf person within their new environment. This was the case regardless of their ability to communicate with hearing people.

*“I left school when I was 16 because my mum and dad thought it would be better for me to leave school and join the hearing world. ... I’ll try things my parents’ way. ... When I left school, I was floundering a bit. I’d lost my world and I withdrew inside myself a bit. That became my world and I didn’t have much to do with anybody else.” [FG4, p9]*

#### **4.2.1.5. Identity**

The link between childhood and adult experiences of well-being were described by some as being about the development of a positive identity. In referring to identity, participants described the importance of an acceptance of themselves as being d/Deaf people as well as a feeling that they belong to a group. For those who became progressively deaf, experiencing identity issues was a particularly significant issue.

Some participants felt unsure about their own identity and/or described feeling torn between the Deaf and hearing community. Participants believed that a poor view of oneself has an adverse effect. They attributed confusion about identity as

emanating from communication difficulties during their childhood – both at home and at school.

*“I felt very confused about my own identity, where I fitted in and it wasn’t until I went to [deaf school name] that the penny dropped for me.” [FG1, p2]*

Attempts by individuals to ‘fit in’ with peers, whilst possibly denying one’s own identity, also caused confusion for some participants.

*“I felt unsure about whether I saw myself as deaf or hearing” [FG4, p8]*

Another participant spoke of their “roller coaster of emotions through school because of my hearing problems”, noting that in adulthood her mood could still “plummet like it did when I was a child” [FG3, p1]. She described feeling shocked the first time that she encountered a signing Deaf environment at an annual Deaf event. She said that she felt “small” and unable to fit in because she could not sign and as a result has “pulled away” from the Deaf community.

The notion of acceptance by others was discussed in all of the focus groups. Participants expressed concerns about both professionals and hearing parents who aspired for the d/Deaf child to be able to speak and hear.

*“I blame the medical establishment and the education system for having such a rigid opinion that d/Deaf people must learn to speak and lip-read ... I’m sorry, but that is for their benefit – it doesn’t do anything for us” [FG3, p4]*

*“My parents were hearing and they wanted me to speak because they felt speech was more important than sign” [FG4, p3]*

A few participants reported that family members had suggested they have a cochlear implant because, in their view, their families had never accepted their deafness. This in turn had affected their self-esteem and a view that they were not accepted for who they were.

*“I was crushed. I felt like he couldn’t accept me for who I am” [FG3, p5]*

The acceptance of their child being d/Deaf was reported to be difficult for some hearing parents. One participant gave an example that their parents were relieved when they learnt that their grandchild was hearing.

*"I was really quite hurt to see that she'd announced the birth (of my child), then put, 'I'm pleased to report that she has perfect hearing; ... I was shocked to discover that that negative attitude was still so entrenched" [FG2, p6]*

#### **4.2.1.6. 'Can do' attitudes**

The notion of a 'can do' attitude in relation to positive well-being was discussed in all of the focus groups:

*"... it's about feeling satisfied with yourself, how you are; about feeling you can do the things you want to do. That word, 'can', the positive attitude – that's important" [FG1, p3]*

Some participants' reported being told by others that they could not do something because they were deaf. Participants were able to provide examples of things they had been told that they could not achieve, mainly from hearing people, such as teachers at school and career advisers.

*"... they [teachers] asked me what career I wanted to do in the future. I said I would like to be a P.E. teacher, and they were surprised and said, "Well, how can you hear the whistle if you take your hearing aids off?" .... They said, " Oh well, no one would employ you to do that job if you were unable to hear." That really did make me think, "Hmm, that is true" and I was very frustrated about that. It is like reinforcing the negative – can't, can't, can't. ... typical of hearing people ..." [FG2, p3]*

*"Because the assumption is always 'Hearing knows best'" [FG3, p5]*

Participants felt that the encouragement of self-belief to aid positivity and a 'can do' attitude stemmed from others. Having someone, whether it be parents/teachers /employers, who believed in them, influenced some participants to believe in themselves. This in turn made them feel good about themselves. One person reflected how her previous employer encouraged her to apply for a manager position and how he helped her overcome her doubts that she was able to do the job:

*"That man is always permanently fixed in my mind. I can picture that day as clear as anything – me saying I can't and him telling me he believed I could." [FG2, p2]*

#### 4.2.2. (b) Barriers to maintaining positive mental well-being

Participants discussed the frustrations they felt as a result of the day to day barriers that they faced. Discussion of the barriers is therefore highlighted in this theme. One such barrier is communication difficulties with others as discussed earlier. There was also discussion around the difficulties that Deaf people can experience in accessing services and it was perceived that this can also impact on one's well-being for example difficulties in communicating with those who should be seen as supportive, such as the GP, were reported.

Nearly all participants discussed the significance and impact of difficulties in having a conversation that was more than at a very basic level. The *"shared understanding"* [FG1, p2] that takes place when an intense conversation happens was seen as vital to mental well-being. Most of the participants were able to give examples of situations in which they had been made to feel frustrated and stressed as a direct result of missing out on conversations, having to rely on a third party to relay the information, and their dependence on others who judge what information should be passed on to them:

*"We had been eating out a lot and they had chatted though the meals without a thought for me, but that was 'my family'. One evening I just lost it, I'd had enough; I turned my back on them and started to watch the people passing by. Eventually, they noticed and asked me what was the matter? I went mad, I told them "oh you've finally noticed me now have you" They looked sheepish and uncomfortable, I gave it to them telling them how I felt being left out. "I am Deaf". I was using my voice and they tried to shush me as I was causing a scene, but I didn't care, I just carried on. I ranted that it wasn't the first time and that they needed to realise that "I WAS HERE!" I'd had enough of being treated like this. Years of it."* [FG3, p6]

Barriers faced in the workplace and in educational settings were also reported. One participant reported there was a lack of support in college *"... I received no support there, no radio aid, no support person, nothing. It was a nightmare"* [FG3, p3]. There were also reports of limited access to further education within mainstream settings.

Whilst it is currently acknowledged that Deaf people's rights in respect to, for example, employment are enshrined in legislation this has not always been the case.

*"There was no Access To Work funding at that time ... I really struggled" [FG2, p1]*

There was a view despite legislation, not only in employment, that opportunities and choices for Deaf people remain limited.

Participants also gave examples of how communication difficulties at work had had a negative effect on them.

*"I couldn't follow who was saying what ... it was rubbish. I moved to my current job about 2 years ago and I'm working in a deaf environment there, where everyone has to sign." [FG3, p3]*

Lack of support within families was also highlighted as a barrier and participants believed that this inhibited them from achieving their potential and prevented them from developing or maintaining a positive well-being. At home, Deaf people described feeling excluded; families were seen as ignorant and/or not willing to learn sign language and therefore perceived to be "lazy".

*"... my father won't even put the subtitles on for me. It is not allowed." [FG3, p5]*

Misconceptions by others about d/Deaf people were also considered to be problematic. For example, when a d/Deaf person is mistaken for having mental health difficulties, or described as having learning difficulties solely because they are deaf:

*"I've noticed a real problem in attitude from [business name] ... who help people find jobs. I went to talk to them about what jobs were available and straight away they started talking about 'learning difficulties'. I was like, hold on, what did you say? ... They described me as having a learning difficulty, because I'm deaf. [FG4, p2]*

Participants felt that Deaf people do not always access the help that they need because of issues of stigma. They felt that mental health difficulties are still considered a taboo subject and there was a view that physical and mental health

issues are dealt with differently in the Deaf community compared to the in the general population:

*“Mental health is still such a taboo issue ... no one talks about it, so consequently everyone is alone with their problems.” [FG1, p3]*

In a similar way, lack of awareness concerning what support is available for Deaf people with mental health difficulties is also considered to be a barrier. Discussions across the focus groups regarding lack of information, knowledge, and access to services, depicts issues pertaining to difficulties around a d/Deaf person's access to information which in turn may impact on well-being. There was consensus among participants that d/Deaf people did not always access information relating to health:

*“A lot of deaf people simply don't know what health means ... I think it's important for people to understand concepts of health and well-being so they can live well.” [FG2, p6]*

One focus group consisted of people who worked within professional roles. In their view, as professionals, they felt that they had better access to information or at least knew where to find it *“... but I think it's worse for other people because how can they get the information they need if they cannot read well or talk to their friends” [FG1, p2].*

Finally it was suggested that the term 'mental health' had only been used recently by the Deaf community and as a result there had been an increase in the understanding of its definition.

#### **4.2.3. (c) Protective factors relating to the maintenance of mental well-being**

This theme concentrates on what the participants' viewed as being of value in enabling them to achieve a positive mental well-being both now and in the future. For some participants, value meant those things that are important and have positive impacts on them, such as strong family bonds and encouragement from others. Friendships were certainly seen as valuable in terms of maintaining mental well-being.

*"I value my friends, my partner, my work. That's what's kept me going through the years" [FG3, p5]*

Accessing help in relation to mental well-being either from professionals or friends was also viewed as a supportive strategy:

*"accessing counselling and learning how to open up to friends" [FG3, p1]*

Support from family members to enable a d/Deaf person to develop their own identity was seen as important. *"...that's helps with confidence, self-esteem and identity, linked with who you are."* [FG2, p6]. This was considered to be a particular issue for hearing parents who have no contact with the Deaf community.

Not surprisingly, given the very nature of being d/Deaf, communication was clearly viewed as a key issue to the maintenance of mental well-being. However the importance of communication was not only functional – being able to understand others and make oneself understood is fundamental. Communication was also central to other factors, such as being able to discuss and work through problems and having the ability to develop trusting relationships. Not only was it seen as vital to be able to communicate and to be able to express oneself freely, but also seen as valuable in order to build confidence. Being able to talk through problems with someone who one could trust was considered important.

*"I'll get together with someone for half an hour 'worry time'... and it makes me feel so much better" [FG1, p]*

The recognition of the importance of communication for maintaining one's well-being leads many participants to feel that the sense of belonging in the Deaf community is vital. This seemed to be the case whatever their history. The Deaf community was viewed by many as a life line - somewhere they could relax without pressure and where they could be themselves. Value was also attributed to having a social life and hobbies.

*"... I tried to fit into the hearing world, because that's what the school had told us we had a duty to do.... My mum kept trying to get me to go to the deaf club – they had a youth club there at that time. Eventually I agreed to go along and as soon as the door opened and I walked in, I was home. I still remember walking through those double doors into a room full of deaf people and just feeling so excited, knowing I was home. My confidence came back. It was only*



*then that I felt I could cope in the hearing world, once I knew I was back in the deaf world. But I had no confidence for a year. It was an awful time.” [FG1, p3]*

Participants highlighted a variety of strategies used to manage difficult situations and aid the maintenance of a positive well-being. These were not necessarily linked to them being d/Deaf. Strategies included examples such as taking personal responsibility for dealing with a situation; learning how to cope; and thinking positively. Being able to see something through was also seen as having a positive impact:

*“If you say to yourself that you want to do something, then you see it through, it can make you feel pleased with yourself. It can make you feel good” [FG1, p6]*

Having resilience, a type of reserve which enables one to *“cope with whatever life throws at you” [FG1, p6]* was also considered important.

Additionally, having good literacy skills and access to interpreters were seen as valuable in terms of being able to access information. One person reflected on the significance of interpreters for their own personal well-being:

*“Without interpreters I wouldn’t have access to a lot of things” [FG2, p5]*

Beyond issues of identity and involvement, participants also described the importance of a sense of belonging. Belonging was not defined solely by being involved or knowing who you are. It was more akin to fitting into something or being with people that create positive feelings of attachment and security. Feelings of belonging were universally identified as central to positive mental well-being: *“I must have a sense of belonging” [FG1, p3]*. In most cases, that feeling of belonging resided firmly in to the Deaf community. This was for a variety of factors including having the ability to communicate with ease and to maintain friendships:

*“I think that is because I can express myself more easily in sign” [FG1, p2]*

*“I don’t understand it (hearing world) ... I choose to be in the Deaf world” [FG3, p5]*

In summary, the impact of Deaf culture and the Deaf community on a Deaf person’s sense of belonging cannot be ignored, as being in a Deaf environment gives people a sense of security, a “Deaf space”.

## **5. Discussion**

The aim of this study was to understand how d/Deaf people make sense of their mental well-being, its links to their individual histories and what the barriers and protective factors are perceived to be in relation to well-being. In the past, whilst considering the mental well-being of d/Deaf people, it was thought that the person's deafness was the main issue. However, with the recognition of sign language and the acceptance of Deaf culture, factors other than deafness itself began to be examined in the context of mental health and d/Deaf people (Leigh & Pollard, 2003). Participants in this study were able to identify a link between certain facets of their childhood and their mental well-being in adulthood. Issues around communication, the school environment, bullying, transition periods, identity and 'can do' attitudes were discussed in some detail.

Given that the majority of d/Deaf people are from hearing families; about 95% are born to hearing parents (Mitchell & Karchmer, 2004), it is not surprising that issues in relation to communication within families were raised. d/Deaf young people might not have acquired sufficient cultural capitals (e.g. familial and linguistic) (Listman, Rogers, & Hauser, 2011). An example would be a d/Deaf individual in a hearing family might have been excluded from daily family discourse (e.g. at the dinner table – "dinner table syndrome") because of communication difficulties, which in turn could impact on their well-being. Some participants in this study reported feeling hurt when they were excluded or when their conversation with family members was interrupted by other people. Feelings of exclusion were also reported in the study by Gregory, Bishop and Sheldon (1995). This enforced exclusion and isolation can become a norm for some d/Deaf people and could affect their adult well-being. Without effective communication and opportunities to communicate at ease with others, the development of appropriate interaction and social skills is challenging. Ineffective communication can also hinder the development of coping mechanisms and the skills needed to navigate one's way in society.

Deaf people's memories of their school days were relayed in terms of their recollections of being punished for using sign language and expectations that they should aspire to being like hearing children. Participants in this study discussed the false expectations of others and how this made them feel - particularly in terms

of their ability to trust others. Literature on deaf children and bullying suggests that deaf students are considered to be at risk of being stigmatised because of their deafness, which in turn leads to social exclusion and/or being bullied by others (Dixon, Smith, & Jenks, 2004; Weiner & Miller, 2006).

Some participants also linked the difficulties that they experienced in the transition from childhood to adulthood to their adult mental well-being. For many, this was around leaving the relatively safe environment of school and entering a mainstream society. Valentine and Skelton (2007) noted the vulnerability of d/Deaf people when entering adulthood because they are often ill-prepared and have a lack of understanding of the hearing world. Participants in this study emphasised the link between feeling ill prepared coupled with being given false expectations that they would fit in with and cope in the hearing world.

Having a sense of identity(ies) is one the key developments in a young person's life (Kroger, 2007). Deaf people who see themselves as being part of the Deaf community and are sign language users usually identify themselves as having a Deaf identity, whereas other people might view themselves as bicultural or as a hearing person. Some people in this study have shifted from a hearing identity to a Deaf identity. The discovery of sign language and meeting other Deaf people often helps deaf people to find their Deaf identity. Psychological well-being was found to be linked with a consistent view of self across roles (Sheldon, Ryan, Rawsthorne, & Ilardi, 1997). However some participants in this study reported to be feeling torn between the Deaf and the hearing community and described trying to fit in. Leigh (2009) identified that family, role models, and school have a role in influencing the identity development of d/Deaf young people. Bat-Chava (1994) reported that those Deaf people who identify strongly with other Deaf people have more positive self-esteem than those who do not.

Young people are often hugely affected by their social environment and views and expectations of others (Leigh, 2009). The perceptions of d/Deaf people as being unable to do some things that hearing people can do is as a result of the medical view of deafness, which reinforces what deaf people cannot do, i.e., ability to hear and to speak. "..., the repercussions related to perceptions that hearing difference automatically equates communication disorders or implied "can't do" perspectives when that is not necessarily the case, can have far-reaching consequences for the

saliency of deaf or hard-of-hearing identities” (Leigh, 2009, p. 108). Having strong social capital, such as a social support network, and positive view of self can be an aid to influence a ‘can do’ attitude. Having a self-belief and someone to believe in you can serve to promote a positive well-being, as a former president of Gallaudet University in Washington, D.C. stated “Deaf people can do anything except hear”. This implies that being deaf in itself should not stop someone from achieving the goals they set out to. Identification with Deaf culture can encourage a ‘can do’ attitude (De Clerck, 2007).

The vast majority of participants were certain that there was a clear link between events that they had experienced in childhood and their adult well-being. Furthermore these events, impacts and effects were attributed to their experiences of being a d/Deaf child and how others responded to their deafness. This, in turn, has impacted on their adult life. It was striking that considerable anger and emotion was still expressed about events and experiences which had happened, in some cases, more than 30 years ago. It is of note however that there were descriptions of life events in childhood (other than those associated with being deaf) that also impacted on later well-being.

In terms of maintaining well-being, the focus groups also discussed the barriers, and protective factors to maintaining mental well-being. Communication barriers do have impact on access requirements of d/Deaf people (Alexander, Ladd & Powell, 2012; Connolly, Rose, & Austen, 2006; McKee, Barnett, Block, & Pearson, 2011). Steinberg et al. (1998) found that communication difficulties for d/Deaf people were seen as a major cause of mental health difficulties. In this study, communication was seen by participants as a barrier to maintaining mental well-being in addition to being able to access to appropriate services. The latter difficulty was also noted by Steinberg et al. (1998) who found that over half of the participants were unable to locate mental health services.

Participants were able to identify a number of strategies that can be useful, for example, choosing not to be isolated among hearing people. The importance of accessing available support was also seen as a useful strategy in the promotion and maintenance of well-being. Participants found having social support whether from friends or family members valuable to mental well-being. Griggs (1998) noted the importance of Deaf people prioritising opportunities to communicate with deaf

friends. In a study by Werngren-Elgstrom, Brandt and Iwarsson (2006) with elderly Deaf people, the relationship between social activities within the Deaf club and subjective well-being were found to be significant. Participants in this study reported feeling at home and a sense of belonging at the Deaf club. Participants reported being involved in a way which goes beyond just being able to communicate as being valuable for promoting positive feelings of well-being.

It is not only having difficulties in overcoming barriers but the failure to maintain those factors that are protective that can lead to a risk of having negative mental well-being outcomes.

### **5.1. Limitations**

It is of note that participants in this study may not be representative of the Deaf community in general, for example at least half of the participants in this study were in employment and yet we know that the unemployment rate for deaf people is four times higher than in the general population (RNID, 2003). Some participants who took part in this study had attended schools with strong oralist policies and were punished for using sign language. Younger Deaf young people nowadays might have very different experiences as a result of a shift in policies within the educational arena. Furthermore, all of the participants in this study were able to use BSL, therefore may not be representative of those who are not fluent in BSL and where issues of isolation may be more or less pertinent. Additionally the stigma of mental health and issues around confidentiality may have prohibited some Deaf people from openly discussing their mental well-being in the focus groups.

## **6. Conclusion**

Previous studies have examined various factors that have negative effect on the mental well-being of Deaf people. Little consideration, has in the past, been given to what d/Deaf people themselves found valuable in relation to their mental well-being. This study has enabled us to have some insight into the particular childhood experiences that are linked to mental well-being for d/Deaf adults. The protective factors that are valuable to Deaf people's well-being, and the barriers which prevent d/Deaf people from achieving a positive well-being have been highlighted in this study. By taking these points into account we can go some way to

identifying the protective factors which could mitigate mental well-being difficulties for d/Deaf people in the future.

## References

- Alexander, A., Ladd, P., & Powell, S. (2012). Deafness might damage your health. *The Lancet*, 379(9820), 979-981.
- Bat-Chava, Y. (1993). Antecedents of self-esteem in deaf people: A meta-analytic review. *Rehabilitation Psychology*, 38(4), 221-234.
- Bat-Chava, Y. (1994). Group identification and self-esteem in deaf adults. *Personality and Social Psychology Bulletin*, 20, 494-502.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Connolly, C. M., Rose, J., & Austen, S. (2006). Identifying and Assessing Depression in Prelingually Deaf People: A Literature Review. *American Annals of the Deaf*, 151(1), 49-60.
- De Clerck, G. A. M. (2007). Meeting Global Deaf Peers, Visiting Ideal Deaf Places: Deaf Ways of Education Leading to Empowerment, an Exploratory Case Study. *American Annals of the Deaf*, 152(1), 5-19.
- Department of Health (2005). *Mental Health and Deafness – Towards Equity and Access: Best Practice Guidance*. London, England: HMSO.
- Dixon, R., Smith, P., & Jenks, C. (2004). Bullying and Difference: A Case Study of Peer Group Dynamics in One School. *Journal of School Violence*, 3(4), 41-58.
- Fellinger, J., Holzinger, D., & Pollard, R. Q. (2012). Mental health of deaf people. *The Lancet*, 379(9820), 1037-1044.
- Gregory, S., Bishop, J., & Sheldon, L. (1995). *Deaf Young People and their Families: Developing Understanding*. Cambridge, UK: Cambridge University Press.
- Griggs, M. (1998). *Deafness and Mental Health: Perceptions of Health within the Deaf Community* (Unpublished doctoral dissertation). University of Bristol, UK.

- Hindley, P., Hill, P. D., McGuigan, S., & Kitson, N. (1994). Psychiatric Disorder in Deaf and Hearing Impaired Children and Young People: A Prevalence Study. *Journal of Child Psychology and Psychiatry*, 35(5), 917-934.
- Hintermair, M. (2006). Parental Resources, Parental Stress, and Socioemotional Development of Deaf and Hard of Hearing Children. *Journal of Deaf Studies and Deaf Education*, 11(4), 493-513.
- Holte, M. C., & Dinis, M. C. (2001). Self-Esteem Enhancement in Deaf and Hearing Women: Success Stories. *American Annals of the Deaf*, 146(4), 348-354.
- Kroger, J. (2007). *Identity Development: Adolescence Through Adulthood (Second Edition)*. Thousand Oaks, California: Sage Publications.
- Ladd, P. (2003). *Understanding Deaf Culture: In Search of Deafhood*. Clevedon, England: Multilingual Matters Ltd.
- Leigh, I. W. (2009). *A Lens on Deaf Identities: Perspectives on Deafness*. New York, NY: Oxford University Press.
- Leigh, I. W., & Pollard, R. Q. (2003). Mental health and deaf adults. In M. Marschark & P. Spencer (Eds.). *Oxford handbook of deaf studies, language, and deaf education* (pp. 203-215). New York, NY: Oxford University Press.
- Listman, J., Rogers, K. D., & Hauser, P. (2011). Community Cultural Wealth and Deaf Adolescents' Resilience. In: D.H.Zand & K.J.Pierce (Eds.). *Resilience in Deaf Children: Adaptation Through Emerging Adulthood*. (pp. 279-297). New York: Springer.
- McKee, M. M., Barnett, S. L., Block, R. C., & Pearson, T. A. (2011). Impact of Communication on Preventive Services Among Deaf American Sign Language Users. *American Journal of Preventive Medicine*, 41(1), 75-79.
- Mitchell, R. E., & Karchmer, M. A. (2004). Chasing the Mythical Ten Percent: Parental Hearing Status of Deaf and Hard of Hearing Students in the United States. *Sign Languages Studies*, 4(2), 138-163.



- Murphy, E., Dingwall, R., Greatbatch, D., Parker, S., & Watson, P. (1998). Qualitative research methods in health technology assessment: A review of the literature. *Health Technology Assessment*, 2(16).
- Oliva, G. A. (2004). *Alone in the Mainstream: A Deaf Woman Remembers Public School*. Washington, D.C.: Gallaudet University Press.
- Padden, C. & Humphries, T. (1988). *Deaf in America: Voices from a Culture*. Cambridge, Massachusetts: Harvard University Press.
- RNID. (2003). Employment for all. Submission by RNID to the Work and Pensions Committee [consulted September 2010]. Retrieved from: <http://webarchive.nationalarchives.gov.uk/+http://www.cabinetoffice.gov.uk/media/cabinetoffice/strategy/assets/rnid3.pdf>
- Rogers, K. D., & Young, A. (In press). Is there an association between deaf children's mental health difficulties and their adult well-being? The state of evidence. In: L. Leeson, & M. Vermeerbergen (Eds), *Working with the Deaf Community: Education, Mental Health and Interpreting*. Dublin, Ireland: Interesource Group (Ireland) Limited.
- Rogers, S., Muir, K., & Evenson, C. R. (2003). Signs of Resilience: Assets that support deaf adults' success in bridging the deaf and hearing worlds. *American Annals of the Deaf*, 148(3), 222-232.
- Sheldon, K. M., Ryan, R. M., Rawsthorne, L. J., & Ilardi, B. (1997). Trait self and true self: Cross-role variation in the Big-Five personality traits and its relations with psychological authenticity and subjective well-being. *Journal of Personality and Social Psychology*, 73, 1380-1393.
- Sheppard, K. & Badger, T. (2010). The lived experience of depression among culturally Deaf adults. *Journal of Psychiatric and Mental Health Nursing*, 17(9), 783-789.
- Silverman, D. (2011). *Interpreting Qualitative Data* (4<sup>th</sup> ed.). London, England: Sage.
- Skelton, T., & Valentine, G. (2003). 'It feels like being Deaf is normal': an exploration into the complexities of defining D/deafness and young D/deaf

people's identities. *The Canadian Geographer / Le Geographe canadien*, 47(4), 451-466.

Steinberg, A. G., Sullivan, V. J., & Loew, R. C. (1998). Cultural and Linguistic Barriers to Mental Health service Access: The Deaf Consumer's Perspective. *American Journal of Psychiatry*, 155(7), 982-984.

Suh, E. M. (2002). Culture, Identity Consistency, and Subjective Well-Being. *Journal of Personality and Social Psychology*, 83(6), 1378-1391.

Weiner, M. T., & Miller, M. (2006). Deaf Children and Bullying: Directions for Future Research. *American Annals of the Deaf*, 151(1), 61-70.

Werngren-Elgstrom, M., Brandt, A., & Iwarsson, S. (2006). Everyday activities and social contacts among older deaf sign language users: Relationships to health and well-being. *Occupational Therapy International*, 13(4), 207-223.

Young, A., Carr, G., Hunt, R., McCracken, W., Skipp, A., & Tattersall, H. (2006). Informed Choices and Deaf Children: Underpinning Concepts and Enduring Challenges. *Journal of Deaf Studies and Deaf Education*, 11(3), 322-336.

## CHAPTER NINE: DISCUSSION

### 1. Overview

Several key studies across the world have established that d/Deaf children/young people and adults have a higher incidence of mental health difficulties in comparison with hearing people (Fellinger et al., 2012; Hindley, 1993; Kvam et al., 2007; Schlesinger & Meadow, 1972; Sinkkonen, 1998). These studies are largely based on the results of assessments standardised on hearing rather than d/Deaf populations. Additionally data has usually been taken at a single point in time, rather than longitudinally. As a result, the relationship between mental ill health in childhood and mental well-being outcomes in adults is significantly under-researched and d/Deaf people's own perspectives on their mental well-being has been little explored. Consequently, whilst it is possible to evidence in general terms that d/Deaf people experience greater mental distress and have poorer well-being than hearing people, there remains substantial gaps in our understanding.

Prior to this study there were no mental well-being assessments available in British Sign Language in the UK and there has been insufficient exploration into the reliability of mental well-being assessments (in either BSL or English) with d/Deaf populations. Yet, it is known that early identification of mental well-being difficulties can assist in getting the necessary support in place and in preventing the deterioration of any mental health difficulties. Problems inevitably will arise if an assessment is not reliable and its validity questionable as this may mean that the identification is inaccurate or potential difficulties may be missed. Validity is not just in relation to the language of the assessment but also about its cultural meaningfulness. The Deaf community is an entity in its own right; it has its own culture, history, and language.

Understanding and promoting well-being is not only the early identification of problems, it is also about positive recognition of what might be important in someone's life from their cultural context and perspective. Consideration therefore needs to be given as to what is important in d/Deaf people's lives, what is 'valuable' to them in terms of ensuring a positive mental well-being. This contextualised understanding is required, so that appropriate screening tools can be developed to identify potential risk factors which could lead to mental well-being difficulties amongst d/Deaf people.

As discussed in Chapter 1 one of the original aims was to undertake a follow-up study of participants whose mental health as children was first assessed in 1988 (Hindley 1993) and to investigate their adult mental well-being. This would necessitate the development of a valid mental well-being assessment for use with d/Deaf people in BSL and English and to make comparisons between the original data and outcome data from the traced participants. Despite multiple recruitment methods, insufficient participants from the original cohort were traced. Therefore the research addressed the evidence deficits in a different way (outlined in papers A to E). Collectively this work involved over 250 d/Deaf adults who had not participated in Hindley's original (1993) study. This final chapter brings together the entire thesis to provide an overview of the findings, and makes recommendations for future research.

## **2. Contribution to the knowledge of d/Deaf people and mental well-being as result of this study**

This study has succeeded in producing outputs for each of the aims and objectives established at the outset. The results are contained in the papers A, B, C, D, and E, of which three have been published, one is currently under review and one is ready to submit for publication. Each paper individually and collectively has made a contribution to knowledge about mental well-being in d/Deaf populations as set out below. Academic contributions to the knowledge of d/Deaf people's mental well-being as the result of this PhD have been made at different levels; theoretical, methodological, and empirical. For example, the methodological knowledge includes a greater understanding of what constitutes a robust translation procedure for sign language assessments and the effectiveness of using remote data collection with d/Deaf populations. The work has also made a significant contribution to clinical practice (see section on 'policies and practice implications').

### **2.1. Academic contributions: methodological and empirical**

#### **2.1.1. *Literature review on the association between childhood and adulthood mental well-being outcomes in d/Deaf populations [Paper A]***

There had previously been little discussion about the relationship between mental well-being in childhood and adults in d/Deaf populations. A detailed literature review (paper A) was conducted which focussed on critically analysing the

available evidence with regard to the association between childhood factors and later mental well-being outcomes for d/Deaf people. Association refers to both evidence of causal mechanisms and correlations, as well as less rigorous observations of potential influences.

It is known that, in hearing populations, mental health problems in childhood can be linked to mental health difficulties in adulthood (Steinhausen, Meier, & Angst, 1998; Dunn & Goodyer, 2006). Mental health difficulties in childhood in hearing populations have also been shown to contribute to poorer outcomes in adulthood, including lower educational attainments and unemployment. Some key social, familial and environmental factors in childhood have been found to predict later mental health outcomes in adulthood (Buchanan et al., 2002; Fergusson et al., 2000; Fergusson & Woodward, 2002). In d/Deaf populations, factors such as reading age (Griggs, 1998), being intellectually gifted (Vernon & LaFalce-Landers, 1993) and inconsistent communication (Wallis, Musselman, & MacKay, 2004) in childhood have been examined and a link with later poorer mental health outcomes was found. However, no literature was found which examined directly the connection between mental health difficulties in childhood and outcomes for adults in d/Deaf populations. There are no prospective or retrospective longitudinal studies of large cohorts of d/Deaf people similar to the studies in hearing populations which address issues of mental health and well-being outcomes (e.g. Dekker, Ferdinand, van Lang, Bongers, van der Ende & Verhulst, 2007).

It could be assumed that the findings from hearing populations might be similar for d/Deaf children, as some may have experienced similar key life events such as death of a family member, the separation of their parents, or family dysfunction. However, there may be additional factors that research within the general population has not taken into account. It is known that d/Deaf children are more vulnerable to abuse and neglect (Kennedy, 2000; Kvam, 2004; Sullivan & Knutson, 1998) (although the definition of neglect might be debatable as it should probably include communication needs), and may experience communication difficulties therefore they may not be able to disclose what is happening to them. In addition, d/Deaf children have experiences which are, in the main, different from those of hearing children; for example, communication difficulties with principal care givers and peers (Gregory et al., 1995), feeling isolated (Oliva, 2004) and limited interaction with others (Lederberg, 1993). From studies with hearing

populations, the timely recognition of mental health difficulties and early intervention is significant for the prevention of later negative outcomes. We also know that there are more opportunities for mental health difficulties to be identified at earlier stages in hearing populations than there are for d/Deaf people largely because d/Deaf people's access to services at primary, secondary and tertiary care levels are well recognised as being poor (Alexander et al., 2012; Department of Health, 2005; Steinberg et al., 1998). Furthermore, there is a lack of appropriate mental health assessment tools which are linguistically and culturally valid to the d/Deaf population (Cromwell, 2005; Hindley et al., 1993; Leigh, Corbett, Gutman & Morere, 1996).

It was the overall intention of this study to address the association between childhood and adulthood mental well-being outcomes in d/Deaf populations by undertaking a longitudinal study using participants from Hindley's (1993) cohort. It was assumed that, because of the closeness of the Deaf community and the nature of Deaf culture, tracing the original cohort would be achievable. However this was not the case. This may however be possible in the future with a new cohort, particularly given the increased use of social media and the fact that d/Deaf children/young people are 'growing up digital' with easy access to virtual communities and networked communication. This is likely to make tracing individuals and groups far easier in the future. In the same way as prospective studies are undertaken amongst hearing populations, prospective longitudinal studies of mental well-being amongst d/Deaf people are needed. Without such studies it will not be possible to further develop an evidence-based understanding of the relationship between factors in childhood which affect d/Deaf children/young people and their later mental well-being.

Key conclusions/contribution:

- (i) There is inadequate evidence to support a detailed understanding of the risks and preventative factors which might link mental health difficulties in childhood with mental well-being outcomes for d/Deaf adults.
- (ii) Although it is possible to extrapolate likely factors which are casual or associated from the longitudinal evidence for hearing populations, the mechanisms of their likely effects are not understood with regard to d/Deaf populations.

- (iii) Retrospective follow up studies with d/Deaf populations face significant difficulties which threaten their viability.
- (iv) Prospective longitudinal studies concerning mental well-being are urgently required.

### ***2.1.2. Translating the mental health assessments into BSL [Paper B]***

Prior to the commencement of this thesis there were no mental well-being assessments that had been translated and validated in BSL that could be used directly with Deaf people. As a direct result of this study, the first four self-reporting mental health assessments have been produced in BSL and have been validated and are now ready for practitioners to use. This is important because it means that common mental health problems such as anxiety and depression can be identified and appropriate treatment and care provided. Without such measures, in the past, d/Deaf populations were considerably disadvantaged because of the lack of any appropriate means of assessment. The most common mental health difficulties experienced by all people are depression and anxiety and it is known that they have a higher prevalence amongst d/Deaf people. For this reason the mental health assessments that focus on these areas were selected for translation. PHQ-9 for example, focuses on depression and the GAD-7 focuses on anxiety. They were, therefore, an obvious target for this work and timely given that the study coincided with the nationwide roll out of the IAPT programme.

Whilst acknowledging that previous publications have considered issues of translation, this study gives an in-depth account of the issues related to translating standardised mental health assessments into BSL and an article (paper B) which highlights challenges in translation has been published. Paper B confirms some of the previous observations (e.g., Graybill et al., 2010; Montoya et al., 2004) but additionally identifies some hitherto unpublished issues. Examples of such challenges include the influence of modality, the use of visually motivated signs without giving leading examples and words in Deaf social contexts. Taking the aforementioned issues into consideration, will assist others who are considering translating other standardised assessment tools into BSL and will go some way towards ensuring the quality of such translations in the future. The publication also extends the literature in the general psychological community about the translation and validation of standardised assessments. It provides an evidence base for

their successful realisation in languages which have no written form through the use of a digital media as an interface for their delivery.

Key conclusions/contribution:

- (i) Barriers to early identification of and timely intervention in common mental health difficulties affecting d/Deaf people will not be overcome without linguistically and culturally appropriate standardised assessment instruments.
- (ii) The study of the processes of translation and cultural matching required for their production has extended the pre-existing literature on translation and standardised assessments in signed languages on an international basis.

### ***2.1.3. Pilot study of the CORE-OM (BSL and English) with d/Deaf populations [Paper C]***

Although this study was focussed on one instrument (the CORE-OM) it also provided the opportunity to explore and compare reliability between English and a Sign Language version of the same assessment when used with d/Deaf populations. This is an issue which has previously received little attention in the literature. This study has enabled such a comparison to be made. Reliability was compared using the Cronbach's alpha values with 95% confidence intervals for the BSL and English version completed by d/Deaf people and also with a non-clinical population in Evan et al.'s (2002) study. One of the creators of CORE-OM, Chris Evans, was involved in the translation process and provided guidance throughout this study. Both versions (BSL and English) of the CORE-OM were piloted with d/Deaf people and both were found to be reliable, although the reliability of two of the domains in the English version were found to be questionable (see paper C). This is important for professionals working with d/Deaf people as they need to be cautious about using the English version with d/Deaf populations even in cases where the client states a preference for taking the assessment in English. The BSL version of CORE-OM has been approved and is available for clinical use.

An online data collection approach was used in the pilot studies because the Deaf community is highly geographically dispersed and this is an effective way for reaching large numbers of this population. Additional benefits of this method of collecting data are that it allows for self-selected participants and maintains their



anonymity. It also saves travelling time and is economical in use. It does however potentially create a recruitment bias because it necessitates that participants have access to and are able to use a computer in order to participate. This has the potential to create barriers for those who are less familiar or comfortable with online environments. The impact of the computer interface on response is also unknown. Nonetheless, the methods used for this study have shown that it is possible to recruit a sufficient number of participants using online data collection. The details relating to this method have been submitted for publication (paper C). This includes an analysis of the additional questions raised about participation, sampling bias and impact that the means of data collection may have on the quality of data.

Key conclusions/contributions:

- (i) Online remote access data collection for piloting standardised assessments and testing their reliability is an efficient and effective approach to data collection in the Deaf community.
- (ii) Further studies are required to understand the impact of the computer interface on response and potential bias in sampling that might be produced.
- (iii) The study which compared a sample of d/Deaf participants completing the English version and the BSL version of the same instrument demonstrated concerns about the validity of the English version when used with d/Deaf populations, even in circumstances where a d/Deaf person self-selects to complete the English version over and above the BSL version.

#### **2.1.4. *Validation of four mental health assessments [Paper D]***

The three mental health assessments in this study are also those which are used to form part of the core set of assessments in the national IAPT (Increasing Access to Psychological Therapies) programme (IAPT, 2012a). This programme is being made accessible to Deaf people (Flynn, 2012), but cannot operate successfully without reliable and validated versions of the assessments in BSL. I have produced these versions, piloted them and published the results [Paper D]. As a consequence of this study the BSL versions now form part of the official Minimum Data Set within national IAPT. Validations of the BSL versions of four mental health assessments (PHQ-9, GAD-7, WSAS, and CORE-OM) have been

made, and the reliability was found to be good. The convergent validities for each of these BSL assessments were checked by the correlations with the relevant items in the CORE-OM, and it was found that there were positive correlations for each item. The construct validity for the BSL versions of the GAD-7 (anxiety) and WSAS (functioning) were found to be similar to those established in the hearing population. That is, in the hearing population the component for anxiety and functioning showed one underlying component for GAD-7 and WSAS respectively; this is also shown as one component in the BSL versions of GAD-7 and WSAS. However, the construct validity for the BSL version of PHQ-9 (depression) showed two components for depression, whereas the hearing population reported only one component. This finding indicates that further work is needed to understand the concept of depression; how its cultural meaning and expression may differ for Deaf people. This leads us to believe that the concept of certain aspects of mental well-being (i.e. depression) in the Deaf population might not be the same as found in the hearing population as two items in the BSL version of PHQ-9 (small component) do not fit with the rest of the items in the main component of the depression. The two items are both related to motivation. This may inform us that the way in which Deaf people conceptualise motivation in relation to depression might be different from the hearing population. For example, within the hearing population, if a person said that they were not motivated to do things then this might be perceived by others as a sign of depression. However, for Deaf people, (notwithstanding that they may be depressed) they may be unmotivated for other reasons other than depression. An example of this was identified within the focus groups with Deaf people when they described avoiding certain situations (e.g. being among non-signing people) to protect their mental well-being. Therefore it may be the case that an individual has little motivation to do things in specific situations. There is a need for further exploration of this area.

Of the 113 participants who completed assessments, 23 participants' scores led to concerns about their mental well-being and their GPs being contacted. Without having reliable and validated assessments, the difficulties experienced by those 23 participants might not have been detected. Although it is important to note that d/Deaf people experience difficulties in communicating with their GPs (Alexander et al., 2012; McKee et al., 2011), the information that we provided to GPs included sign posting to specialist mental health services for d/Deaf people where support to meet their language and cultural needs is available. In this way, our referral

also supported the GP's by enhancing their knowledge about appropriate services that are available for d/Deaf people. In a study of Deaf people's preferences, Feldman and Gum (2007) found, that older Deaf people preferred support from their GP for support in relation to their mental health needs whereas younger Deaf adults reported a wider range mental health professionals whom they would choose to access support rather than their GP. Feldman and Gum (2007) also reported that the opportunity to access professionals who are Deaf and can communicate with Deaf people directly (i.e. being able to sign) were preferred by most of the Deaf adults who took part in their study. Participants of the study had highlighted the importance of sign posting the appropriate services for Deaf people and had expressed concern that d/Deaf people might have continued not to get the support they need to address their mental health difficulties. It was therefore essential that GP's were given appropriate information to signpost their patients.

Although I have successfully translated the four standardised mental health assessments into BSL, this does not mean that all standardised assessments can be translated into BSL. For some assessments, in order to ensure that they are culturally and linguistically meaningful for the target population, a new assessment tool may need to be developed. One of the advantages of translating standardised assessments into another language is that comparisons between cultural groups can be made easily. The risk is that it might not include the domain(s) that are of relevance to users of the target language.

Key conclusions/contributions:

- (i) Mental health assessments in BSL have been produced as a result of this study and are in use on a nation-wide basis.
- (ii) Deaf and hearing populations might not share the same underlying components of certain aspects of mental health in a standardised assessment, e.g. depression.
- (iii) Future studies are required to explore the specific components of, e.g., depression in Deaf population using qualitative approach.

#### ***2.1.5. Deaf people's perspectives on mental well-being [Paper E]***

This study has explored Deaf people's perspectives on mental well-being and linkages were made by them between adult mental well-being and factors in their childhood (paper E). It is of note that they did not report the same factors identified

by hearing populations (see Paper A), possibly because they may have felt that the factors related to being d/Deaf were more important. Fellingner and Holzinger (2011) found a link between d/Deaf people having difficulties in communicating with their family and subsequent mental health difficulties; this issue was also raised by participants in the focus groups. Deaf people in this study however also identified a range of other factors such as; managing in school, bullying, transition issues, identity, and whether or not the individual had developed a 'can do' attitude.

Equally important as understanding the factors that influence the mental well-being of d/Deaf children is the identification of strategies, and what is important or of 'value' to d/Deaf people, as knowing this could be helpful in promoting positive mental well-being for individuals as they grow up and become adults. Deaf participants were able to cite a number of examples which contribute to maintaining mental well-being, such as: thinking positively, having support, a sense of belonging and involvement. Participants also reported some factors which are particularly related to the Deaf people such as membership of the community, integration, fulfilment of needs and shared emotional connections with other Deaf people. These points were also identified by McMillan and Chavis (1986), as an integral part of the definition of the sense of community. Therefore, having a sense of belonging in a community is important to one's mental well-being. The findings from the focus groups confirmed the results of a previous study with Deaf people who were experiencing depression in respect to the importance of a sense of belonging to the Deaf community and in relation to self worth (Sheppard & Badger, 2010). However it is possible that the participants in Sheppard and Badger's (2010) study were depressed and that this in turn had impacted on the importance of their sense of belonging. Nonetheless in this study not all participants were depressed yet they also identified a sense of belonging as a protective factor to maintaining positive well-being.

This study has enabled the consideration of d/Deaf people's perspective on mental well-being and the association between the childhood experiences of growing up Deaf with their adult experiences of wellness and mental health challenges. This is important in working towards a definition of mental well-being which is grounded in concepts generated by d/Deaf people, which are meaningful to them and which support the identification of community/cultural specific factors which might not be

covered in standardised assessments developed with hearing people. A good understanding of such factors will enable both professionals and parents of d/Deaf children or young people to positively promote the mental well-being of children and future generation of d/Deaf adults. This study has contributed to that goal.

Key conclusions/contributions:

- (i) Greater understanding of d/Deaf people's perspectives in relation to mental well-being.
- (ii) The study showed the importance of equality and the negative effect of others' ignorance in relation to mental well-being in minority groups.

## **2.2. Theoretical contributions**

The main theoretical contribution of this work lies in developing better ways to investigate and understand d/Deaf people's mental well-being. The exploration of the reliability of a standard psychological assessment of well-being (the CORE-OM) when used with d/Deaf people has provided specific evidence to support claims that its results may be misleading and inaccurate if administered in written language. It has demonstrated that offering a choice of languages (BSL or English) to use for its completion does not necessarily ensure a more sensitive result. This has led to the identification of new research questions about how responses may be influenced by the computer interface, rather than the language (see section 2.1.3). The translation and testing of a suite of standard assessments in BSL has reinforced the findings of other researchers, particularly in the USA, concerning specific challenges of translation into a visual gestural language, in addition to those which occur between two written languages. The paper from this component of the thesis (Paper B) is the most comprehensive reference work in relation to translating psychological assessments and signed languages that has been published to date. It is of particular note that when Deaf and hearing populations undertook the mental health assessment focusing on depression, their results did not show the same underlying components. This may indicate that Deaf people have a different concept of a certain aspect of depression; a proposition discussed in Paper D. Future work is required to explore this theoretical consideration further, but the thesis has provided a specific result on which such future studies can be built.

The thesis and the results reported in Paper E (the focus groups) have contributed to the disparate pre-existing evidence that there are specific factors associated with growing up deaf and being or becoming Deaf which influence well-being. Some of these have been recorded before, such as the greater vulnerability to abuse and problematic communication experiences in childhood. The study reported in Paper E set out to discover whether Deaf people make the connections between experiences in childhood and well-being in adulthood themselves, and how they understand those pathways from their perspective. There is very little evidence which has explored Deaf people's understanding, and the findings contribute to this small body of work. It lays the foundations for future studies which will examine what shapes those self-perceptions of pathways and well-being and whether the perceived connections are justified. Understanding how well-being is understood to be produced, rather than what it might be, is an important aspect of working with individuals' psychological distress. The studies in this thesis do not fully answer this question, but contribute to and expand upon knowledge about it.

### **3. Policy and practice implications**

HM Government (2011b) emphasised the importance of timely and effective assessments for the early identification of mental health difficulties in order that individuals can access the support that is needed. As a result of this study, BSL assessments have now been made available for use in practice, for example within Improving Access to Psychological Therapies (IAPT) services. BSL Healthy Minds services (BSL-IAPT) has been set up to ensure that Deaf people have access to appropriate IAPT service, that therapists working with Deaf people are fluent in BSL and are knowledgeable about Deaf culture and the issues facing Deaf people. To date, there are currently only two health authorities in England where BSL-IAPT service is available. Following this study, three mental health assessments (PHQ-9, GAD-7, and WSAS) have been implemented in the BSL-IAPT service. This is of particular significance as it will mean that the IAPT Minimum Data Set, using reliable assessments, from the Deaf clinical population will be available therefore giving future research opportunities (an application for NIHR funding has been made to this effect and reached the second round of consideration).

Not only can the BSL assessments be used as screening for signs of potential difficulties but they can also be used as part of evidence required to establish the effectiveness of service provision. For example using the assessments for each therapeutic session, will allow practitioners to compare initial scores to later scores and therefore to measure the effectiveness of their intervention. Having the assessments in BSL is a significant step forward for Deaf people, although it is acknowledged that widespread distribution is not yet in place. However, we need to move forward with some caution as Deaf people have a diverse range of language skills and therefore this does not mean that the tools are suitable for all Deaf people in the UK, for example some Deaf people may have learning disabilities and this should be taken into account. Some work in relation to BSL assessment of Deaf children/young people, is currently being undertaken by Deaf CAMHS in York (I am a co-investigator) in order to translate and validate the Strengths and Difficulties Questionnaire into BSL (Moore, Moore, Wright, Ogden, & Rogers, 2013).

The “No Health Without Mental Health” report (HM Government, 2011a) acknowledged the communication barriers faced by d/Deaf people and stated that commissioners need to ensure that mental health services are accessible to this group. Although BSL is recognised as an official language, it does not have the legal protection necessary to reduce the inequality that Deaf people face and it would serve them better to be acknowledged as a linguistic minority group. Prilleltensky, Dokecki, Frieden, and Ota Wang (2007) recognised that it can be challenging for someone who experiences inequality to achieve positive well-being. The legal protection of BSL could force policy makers to consider Deaf people’s language and culture, which, in turn, could promote their mental well-being. Despite the fact that there are now four mental health assessments available in BSL, it does not necessarily follow that services will be fully accessible for Deaf people. There are still issues at various levels, for example; the information related to mental well-being may not be provided in an accessible format, service provision that does not take into account the persons deafness, the lack of availability of appropriate support groups, and the need for more training of Deaf people at a professional level. Additionally, the educational attainments of d/Deaf people are usually lower in comparison to their hearing counterparts (as described in Chapter 2) and for this reason it may be more difficult to recruit

suitably qualified and experienced Deaf professionals to work within the field of mental health.

Changes in the National Health Service following the Health and Social Care Act 2012 mean that the provision of health services will become the responsibility of clinical commissioning groups. In effect, GPs and other clinicians will decide what will be spent on mental health services. Whilst the aim is to reduce the number of hospital admissions and long term care and to provide more cost effective services, there are a number of unanswered questions in relation to the provision of services for d/Deaf people. Whilst the Health and Social Care Act 2012 outlines the duty to promote the involvement of service users in the decision process related to their care, questions that need to be asked are: will d/Deaf patients have opportunities to be involved in the decision process and will they have the same choices as the hearing population? Some Deaf participants in this study have reported being unable to communicate with their GPs (as previously reported in other literature e.g. Alexander et al., 2012; McKee et al., 2011) and there is a general lack of awareness regarding the issues faced by d/Deaf people, these factors might affect the quality of mental health care needed by d/Deaf populations.

The UK Government acknowledges the need to send out key messages in order to maintain positive well-being. This has resulted in the establishment of the new economics foundation (nef) which has developed “Five Ways to Wellbeing” (Aked & Thompson, 2011). The five key messages outlined are: connect (e.g. build social relationships), be active (e.g. exercising), take notice (e.g. be mentally “present”), keep learning (e.g. try something new), and give (e.g. make a positive contribution to the lives of others). The barriers that Deaf people may experience may render it difficult for them to achieve these outcomes and the protective factors that are of value to them need to be included and identified within governmental policies.

It is not sufficient to assume that accessible services are enough. More needs to be done in relation to preventative work to ensure that there is provision available for d/Deaf children and their families and that there are appropriate resources to assist d/Deaf children to achieve positive language development and good social-emotional outcomes. Issues identified in this study by the participants within the



focus groups need to be included in training programmes for professionals working with d/Deaf children and their families. Involving d/Deaf people as professionals and role models to work with d/Deaf children and their families would also be beneficial. Listman, Rogers and Hauser (2011) suggested that the promotion of six “capitals”; aspirational, family, social, linguistic, resistant and navigational (as conceptualised by Yosso, 2005), could serve to foster optimistic mental well-being outcomes for d/Deaf children. Involving Deaf adults as role models in the lives of d/Deaf children for example, could help them to acquire the navigational capital (e.g. knowledge about how to navigate a system) necessary to overcome the potential difficulties and barriers that they might face as they grow up.

This study has set the direction for future research (see below) which can build upon current and existing knowledge of mental well-being in d/Deaf populations.

#### **4. Future research**

In order to strengthen the evidence base on the mental well-being of d/Deaf people it would also be beneficial to develop the following:

##### **4.1. Identify normal distributions for the Deaf population**

To undertake research which identifies normal distributions for Deaf population with respect to assessments of well-being. Although the BSL mental health assessments have been validated, it is necessary to establish normative data with both large numbers of Deaf people from the general population and the clinical population. This would lead to establishing recommend cut-off scores which may or may not be the same as those for hearing people. Clinical cut-offs are known to be culturally sensitive and vary between communities and populations (Thabet, Stretch, & Vostanis, 2000). Normative data for the Deaf population will assist in developing a greater understanding of the interpretation of data derived from the assessments.

##### **4.2. Early intervention and preventative measures**

From the studies in hearing populations, early intervention is crucial in reducing the impact of later mental health difficulties (HM Government, 2011b; Rao, Weissman, Martin & Hammond, 1993). Given that there has been no research to date on early intervention within d/Deaf populations, research into preventative

work is needed to find out its effectiveness for the promotion of the mental well-being of d/Deaf children.

#### **4.3. Longitudinal study**

Retrospective factors in childhood have been explored in this study by examining d/Deaf adults' perspectives relating to their own experience. However to confirm the prospective validity of these factors, it is necessary to undertake a longitudinal study to trace d/Deaf children's mental well-being over the time. Hence a longitudinal study with a new cohort of d/Deaf children from childhood to adulthood is required which parallels work that has been undertaken in hearing communities such as Dekker et al.'s (2007) study.

#### **4.4. Collecting data remotely**

There is a growth in the amount of research being conducted by collecting data remotely. It is necessary to understand any impact the computer interface may have on the quality and validity of the research in respect to collecting data from d/Deaf populations.

In order to promote positive psychosocial development and mental well-being outcomes for d/Deaf people across their lifespan, further research is needed working with d/Deaf people to achieve these goals. It is imperative that Deaf people themselves are actively involved in such research so that that their views and perspectives are fully taken into account. The present study has been carried out by a Deaf researcher supported by a NIHR doctoral fellowship awarded to future research leaders.

## References

- Ahmad, W., Darr, A., Jones, L., & Nisar, G. (1998). *Deafness and ethnicity: Services, policy and politics*. Bristol, England: The Policy Press.
- Aiken, L. R., & Groth-Marnat, G. (2006). *Psychological Testing and Assessment* (12th ed.). Boston, MA: Pearson Education Group, Inc.
- Aked, J., & Thompson, S. (2011). *Five Ways to Wellbeing: New applications, new ways of thinking*. London, England: nef.
- Alexander, A., Ladd, P., & Powell, S. (2012). Deafness might damage your health. *The Lancet*, 379(9820), 979-981. doi:10.1016/S0140-6736(11)61670-X
- American Psychiatric Association. (1980). *Diagnostic and statistical manual of mental disorders* (3rd ed.). Washington, DC: Author.
- Anastasi, A., & Urbina, S. (1997). *Psychological Testing* (7<sup>th</sup> ed.). Upper Saddle River, New Jersey: Prentice Hall.
- Anderson, D., & Reilly, J. (2002). The MacArthur Communicative Development Inventory: Normative Data for American Sign Language. *Journal of Deaf Studies and Deaf Education*, 7(2), 83-119. doi:10.1093/deafed/7.2.83
- Baker, K., Chan, E., Evans, C., Kyle, J., & O'Rourke, S. (2008). *BSL translation of CORE-OM*. (Personal communication, 22 December 2009)
- Baker-Shenk, C., & Cokely, D. (1980). *American Sign Language: A Teacher's Resource Text on Grammar and Culture*. Silver Spring, Maryland: T.J. Publishers.
- Bamford, J., Ankjell, H., Crockett, R., Marteau, T. McCracken, W., Parker, D., ... Young, A. (2004). *Evaluation of the newborn hearing screening programme (NHSP) in England: report of the evaluation of the first phase of implementation of the NHSP*. November.
- Barkham, M., Bewick, B., Mullin, T., Gilbody, S., Connell, J., Cahill, J., ... Evans, C. (2012). The CORE-10: A short measure of psychological distress for routine use in the psychological therapies. *Counselling and Psychotherapy Research: Linking research with practice*. Advance online publication. doi:10.1080/14733145.2012.729069.
- Barkham, M., Evans, C., Margison, F., McGrath, G. Mellor-Clark, J., Milne, D., & Connell, J. (1998). The rationale for developing and implementing core outcome batteries for routine use in service settings and psychotherapy outcome research. *Journal of Mental Health*, 7(1), 35-47. doi:10.1080/09638239818328

- Barkham, M., Margison, F., Leach, C., Lucock, M., Mellor-Clark, J., Evans, C., ... McGrath, G. (2001). Service profiling and outcomes benchmarking using the CORE-OM: Towards practice-based evidence in the psychological therapies. *Journal of Consulting and Clinical Psychology, 69*, 184–196. doi:10.1037//0022-006X.69.2.184
- Barkham, M., Mullin, T., Leach, C., Stiles, W. B., & Lucock, M. (2007). Stability of the CORE-OM and the BDI-I prior to therapy: Evidence from routine practice. *Psychology and Psychotherapy: Theory, Research and Practice, 80*(2), 269-278. doi:10.1348/147608306X148048
- Bat-Chava, Y. (1993). Antecedents of Self-Esteem in Deaf People: A Meta-Analytic Review. *Rehabilitation Psychology, 38*(4), 221-234. doi:10.1037/h0080303
- Bat-Chava, Y. (1994). Group identification and self-esteem of deaf adults. *Personality and Social Psychology Bulletin, 20*(5), 494-502. doi:10.1177/0146167294205006
- Bauman, H-D. L., & Murray, J. M. (2009). Reframing: From Hearing Loss to Deaf Gain. *Deaf Studies Digital Journal, 1*, 1-10. Retrieved from [http://dsdj.gallaudet.edu/index.php?issue=1&section\\_id=2&entry\\_id=19](http://dsdj.gallaudet.edu/index.php?issue=1&section_id=2&entry_id=19)
- Belzner, K. A., & Seal, B. C. (2009). Children with Cochlear Implants: A Review of Demographics and Communication Outcomes. *American Annals of the Deaf, 154*(3), 311-333. doi:10.1353/aad.0.0102
- Beresford, B. (1995). *Expert Opinions: A national survey of parents caring for a severely disabled child*. Bristol, UK: Community care into practice series, Policy Press.
- Beresford, B., Greco, V., Clarke, S. & Sutherland, H. (2008). *An Evaluation of Specialist Mental Health Services for Deaf Children and Young People*. York, UK: Social Policy Research Unit, University of York.
- Beresford, P., Nettle, M., & Perring, R. (2010). *Towards a social model of madness and distress? Exploring what service users say*. York, UK: Joseph Rowntree Foundation.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. doi:10.1191/1478088706qp063oa
- Brislin, R. W. (1970). Back-translation for cross-cultural research. *Journal of Cross-Cultural Psychology, 1*(3), 185-216. doi:10.1177/135910457000100301

- British Society for Mental Health and Deafness. (2010, July) *July 2010 – Latest News: Deaf people's mental well-being put at risk by lack of services*. Retrieved from <http://www.bsmhd.org.uk/news0710.htm>
- Brooks, M., & Davies, S. (2007). Pathways to participatory research in developing a tool to measure feelings. *British Journal of Learning Disabilities*, 36(2), 128-133. doi:10.1111/j.1468-3156.2007.00476.x
- Buchanan, A., Flouri, E., & Ten Brinke, J. (2002). Emotional and behavioural problems in childhood and distress in adult life: Risk and protective factors. *Australian and New Zealand Journal of Psychiatry*, 36, 521-527. doi:10.1046/j.1440-1614.2002.01048.x
- Buchanan, T. (2002). Online Assessment: Desirable or Dangerous? *Professional Psychology: Research and Practice*, 33(2), 148-154. doi:10.1037//0735-7028.33.2.148
- Bullinger, M., Schmidt, S., Peterson, C., & Ravens-Sieberer, U. (2006). Quality of life – Evaluation criteria for children with chronic conditions in medical care. *Journal of Public Health*, 14(6), 343-355. doi:10.1007/s10389-006-0066-0
- Cahill, J., Barkham, M., Stiles, W. B., Twigg, E., Hardy, G. E., Rees, A. & Evans, C. (2006). Convergent Validity of the CORE Measures with Measures of Depression for Clients in Cognitive Therapy for Depression. *Journal of Counseling Psychology*, 53(2), 253-259. doi:10.1037/0022-0167.53.2.253
- Calderon, R., & Greenberg, M. T. (2000). Challenges to Parents and Professionals in Promoting Socioemotional Development in Deaf Children. In P. E. Spencer, C. S. Erting & M. Marschark (Eds.), *The Deaf Child in the Family and at School* (pp. 167-185). Mahwah, NJ: Lawrence Erlbaum Associates, Publishers.
- Carlisle, S., & Hanlon, P. (2008). 'Well-being' as a focus for public health? A critique and defence. *Critical Public Health*, 18(3), 263-270. doi:10.1080/09581590802277358
- Coaley, K. (2009). *An Introduction to Psychological Assessment and Psychometrics*. London, England: Sage.
- Coates, D. (2010). Impact of Childhood Abuse: Biopsychosocial Pathways Through Which Adult Mental Health is Compromised. *Australian Social Work*, 63(4), 391-403. doi:10.1080/0312407X.2010.508533
- Connell, J., Barkham, M., Stiles, W. B., Twigg, E., Singleton, N., Evans, O., & Miles, J. N. V. (2007). Distribution of CORE-OM scores in a general population, clinical cut-off points and comparison with the CIS-R. *British Journal of Psychiatry*, 190, 69-74. doi:10.1192/bjp.bp.105.017657

- Connolly, C. M. (2004) *Deafness and mental health, Vol. 1.* (Unpublished Doctoral Thesis). University of Birmingham, United Kingdom.
- Connolly, C. M., Rose, J., & Austen, S. (2006). Identifying and Assessing Depression in Prelingually Deaf People: A Literature Review. *American Annals of the Deaf*, 151(1), 49-60. doi:10.1353/aad.2006.0013
- Conrad, R. (1979). *The Deaf Schoolchild: Language and Cognitive Function.* London, England: Harper and Row.
- Cook, J. A., Graham, K. K., & Razzano, L., (1993). Psychosocial Rehabilitation of Deaf Persons with Severe Mental Illness: A Multivariate Model of Residential Outcomes. *Rehabilitation Psychology*, 38(4), 261-274. doi:10.1037//0090-5550.38.4.261
- Coolican, H. (2004). *Research Methods and Statistics in Psychology* (4<sup>th</sup> ed.). London: Hodder Arnold.
- CORE Partnership (2007). Is initial overall CORE-OM score an indicator of likely outcome? *CORE Partnership Occasional Paper, No 1.* CORE IMS: Rugby.
- Cortina, J. M. (1993). What is coefficient alpha? An examination of theory and applications. *Journal of Applied Psychology*, 78(1), 98–104. doi:10.1037/0021-9010.78.1.98
- Cromwell, J. (2005). Deafness and the art of psychometric testing. *The psychologist*, 18(12), 738-740. Retrieved from [http://www.thepsychologist.org.uk/archive/archive\\_home.cfm/volumeID\\_18-editionID\\_130-ArticleID\\_962-getfile\\_getPDF/thepsychologist%5C1205crom.pdf](http://www.thepsychologist.org.uk/archive/archive_home.cfm/volumeID_18-editionID_130-ArticleID_962-getfile_getPDF/thepsychologist%5C1205crom.pdf)
- Cronbach L. J. (1951). Coefficient alpha and the internal structure of tests. *Psychometrika*, 16(3), 297–334. doi:10.1007/BF02310555
- Crowe, T. V. (2002). Translation of the Rosenberg Self-Esteem Scale into American Sign Language: A Principal Components Analysis. *Social Work Research*, 26(1), 57-63. doi:10.1093/swr/26.1.57
- De Clerck, G. A. M. (2007). Meeting Global Deaf Peers, Visiting Ideal Deaf Places: Deaf Ways of Education Leading to Empowerment, an Exploratory Case Study. *American Annals of the Deaf*, 152(1), 5-19. doi:10.1353/aad.2007.0009
- De Clerck, G. A. M. (2010). Deaf Epistemologies as a Critique and Alternative to the Practice of Science: An Anthropological Perspective. *American Annals of the Deaf*, 154(5), 435-446. doi:10.1353/aad.0.0121
- Dekker, M. C., Ferdinand, R. F., van Lang, N. D. J., Bongers, I. L., van der Ende, J., & Verhulst, F. C. (2007). Developmental trajectories of depressive symptoms from early childhood to late adolescence: gender differences and adult

- outcome. *Journal of Child Psychology and Psychiatry*, 48(7), 657-666.  
doi:10.1111/j.1469-7610.2007.01742.x
- Department for Children, Schools and Families and Department of Health (2010). *Keeping Children and Young People in Mind: The Government's full response to the independent review of CAMHS*. London, DH. Retrieved from [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@ps/documents/digitalasset/dh\\_110930.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_110930.pdf)
- Department of Health. (2002). *A Sign of the Times: Modernising Mental Health Services for people who are Deaf*. London, UK: HMSO.
- Department of Health. (2005). *Mental Health and Deafness – Towards Equity and Access: Best Practice Guidance*. London: HMSO.
- Department of Health. (2009). *IAPT Black and Minority Ethnic (BME): Positive Practice Guide*. London, England: Department of Health.
- Department of Health (2011). *IAPT Data Handbook version 2*. Retrieved from <http://www.iapt.nhs.uk/silo/files/iapt-data-handbook-v2.pdf>
- Diener, E. (1994). Assessing subjective well-being: Progress and Opportunities. *Social Indicators Research*, 31, 103-157. doi:10.1007/BF01207052
- Disability: Beyond the medical model. [Editorial]. (2009). *The Lancet*, 374(9704), 1793.
- Dixon, R., Smith, P., & Jenks, C. (2004). Bullying and Difference: A Case Study of Peer Group Dynamics in One School. *Journal of School Violence*, 3(4), 41-58. doi:10.1300/J202v03n04\_04
- Donker, T., Straten, A. V., Marks, I., & Cuijpers, P. (2011). Quick and easy self-rating of Generalized Anxiety Disorder: Validity of the Dutch web-based GAD-7, GAD-2 and GAD-SI. *Psychiatry Research*, 188(1), 58-64. doi:10.1016/j.psychres.2011.01.016
- Dum, M., Pickren, J, Sobell, L. C., & Sobell, M. B. (2008). Comparing the BDI-II and the PHQ-9 with outpatient substance abusers. *Addictive Behaviors*, 33(2), 381-387. doi:10.1016/j.addbeh.2007.09.017
- Dunn, V., & Goodyer, I. M. (2006). Longitudinal investigation into childhood- and adolescence- onset depression: psychiatric outcome in early adulthood. *British Journal of Psychiatry*, 188, 216-222. doi:10.1192/bjp.188.3.216
- Dye, M., & Kyle, J. (2000). *Deaf People in the Community: Demographics of the Deaf Community in the UK*. Bristol, UK: Deaf Studies Trust.

- Edwards, R. (1998). A critical examination of the use of interpreters in the qualitative research process. *Journal of Ethnic and Migration Studies*, 24(1), 197-208. doi:10.1080/1369183X.1998.9976626
- El-Rufaie, O. E. F. A., & Absood, G. (1987). Validity study of the Hospital Anxiety and Depression Scale among a group of Saudi patients. *British Journal of Psychiatry*, 151(5), 687–688. doi:10.1192/bjp.151.5.687
- Elfström, M. L., Evans, C., Lundgren, J., Johansson, B., Hakeberg, M., & Carlsson, S. G. (2012). Validation of the Swedish version of the Clinical Outcomes in Routine Evaluation Outcome Measure (CORE-OM). *Clinical Psychology & Psychotherapy*. Advance online publication. doi:10.1002/cpp.1788
- Emery, S. D. (2008). *The Mental Health Needs of Deaf Black Minority Ethnic People*. Greater Glasgow and Clyde NHS Board Mental Health Partnership.
- Emery, S. D. (2011). *Citizenship and the Deaf Community*. Nijmegen, The Netherlands: Ishara Press.
- Epstein, J., Klinkenberg, W. D., Wiley, D., & McKinley, L. (2001). Insuring sample equivalence across internet and paper-and-pencil assessments. *Computers in Human Behavior*, 17(3), 339-346. doi:10.1016/S0747-5632(01)00002-4
- Evans, C. (2008). *Translating and “normalising” CORE system: CORE System Trust (CST) position statement*. Retrieved from [http://www.psychtc.org/CORE-OM/Translating\\_CORE-OM\\_CST\\_position\\_statement.pdf](http://www.psychtc.org/CORE-OM/Translating_CORE-OM_CST_position_statement.pdf)
- Evans, C., Connell, J., Barkham, M., Margison, F., McGrath, G., Mellor-Clark, J., & Audin, K. (2002). Towards a standardised brief outcome measure: psychometric properties and utility of the CORE-OM. *British Journal of Psychiatry*, 180(1), 51-60. doi:10.1192/bjp.180.1.51
- Evans, C., Mellor-Clark, J., Margison, F., Barkham, M., Audin, K., Connell, J., & McGrath, G. (2000). CORE: Clinical Outcomes in Routine Evaluation. *Journal of Mental Health*, 9(3), 247–255. doi:10.1080/jmh.9.3.247.255
- Evans, J. (2011). *Findings from the National Well-Being Debate*. Office for National Statistics. London, UK: Office for National Statistics.
- Equality Act 2010. London, UK: HMSO.
- Feldt, L. S., Woodruff, D. J. & Salih, F. A. (1987). Statistical Inference for Coefficient Alpha. *Applied Psychological Measurement*, 11(1), 93-103. doi:10.1177/014662168701100107
- Fellinger, J., & Holzinger, D. (2011). Enhancing Resilience to Mental Health Disorders in Deaf School Children. In D.H. Zand & K.J. Pierce (Eds.),



- Resilience in Deaf Children: Adaptation Through Emerging Adulthood* (pp. 169-206). New York: Springer.
- Fellinger, J., Holzinger, D., Beitel, C., Laucht, M., & Goldberg, D. P. (2009). The impact of language skills on mental health in teenagers with hearing impairments. *Acta Psychiatrica Scandinavica*, 120, 153-159. doi:10.1111/j.1600-0447.2009.01350.x
- Fellinger, J., Holzinger, D., Dobner, U., Gerich, J., Lehner, R., Lenz, G., & Goldberg, D. (2005a). An innovative and reliable way of measuring health-related quality of life and mental distress in the deaf community. *Social Psychiatry and Psychiatric Epidemiology*, 40(3), 245-250. doi:10.1007/s00127-005-0862-9
- Fellinger, J., Holzinger, D., Dobner, U., Gerich, J., Lehner, R., Lenz, G., & Goldberg, D. (2005b). Mental distress and quality of life in a deaf population. *Social Psychiatry and Psychiatric Epidemiology*, 40(9), 737-742. doi:10.1007/s00127-005-0936-8
- Fellinger, J., Holzinger, D., & Pollard, R. (2012). Mental health of deaf people. *The Lancet*, 379(9820), 1037-1044. doi:10.1016/S0140-6736(11)61143-4
- Fergusson, D. M., & Woodward, L. J. (1999). Maternal Age and Educational and Psychosocial Outcomes in Early Adulthood. *Journal of Child Psychology and Psychiatry*, 40(3), 479-489. doi:10.1111/1469-7610.00464
- Fergusson, D. M., & Woodward, L. J. (2002). Mental Health, Educational, and Social Role Outcomes of Adolescents With Depression. *Archives of General Psychiatry*, 59(3), 225-231. doi:10.1001/archpsyc.59.3.225
- Fergusson, D. M., Woodward, L. J., & Horwood, L. J. (2000). Risk factors and life processes associated with the onset of suicidal behaviour during adolescence and early adulthood. *Psychological Medicine*, 30(1), 23-39. doi:10.1017/S003329179900135X
- Fichter, M. M., Kohlboeck, G., Quadflieg, N., Wyschkon, A., & Esser, G. (2009). From childhood to adult age: 18-year longitudinal results and prediction of the course of mental disorders in the community. *Social Psychiatry and Psychiatric Epidemiology*, 44(9), 792-803. doi:10.1007/s00127-009-0501-y
- Flynn, H. (2012). Healthy Minds for Deaf people: Outlines a new IAPT service which aims to increase access to psychological therapies for users of British Sign Language. *Best Practice Health Counselling and Psychotherapy Journal*, 34-39. Retrieved from

<http://www.signhealth.org.uk/documents/Services/bslhealthyminds/Healthcare%20counselling%20article.pdf>

- Forsyth, B. H., Kudela, M. S., Levin, K., Lawrence, D., & Willis, G. B. (2007). Methods for Translating an English-Language Survey Questionnaire on Tobacco Use into Mandarin, Cantonese, Korean, and Vietnamese. *Field Methods*, 19(3), 264-283. doi:10.1177/1525822X07302105
- Fortnum, H., Stacey, P., Barton, G., & Summerfield, A. Q. (2007). National Evaluation of Support Options for Deaf and Hearing-impaired Children: Relevance to Education Services. *Deafness and Educational International*, 9(3), 120-130. doi:10.1002/dei.222
- Fujishiro, K. (2009). Is perceived racial privilege associated with health? Findings from the Behavioral Risk Factor Surveillance System. *Social Science and Medicine*, 68(5), 840–844. doi:10.1016/j.socscimed.2008.12.007
- Gampe, K., Biešcad, M., Balúnová–Labanicová, L., Timulák, L., & Evans, C. (2007). Slovenská adaptácia metódy CORE-OM (Clinical Outcomes in Routine Evaluation – Outcome Measure). [A Slovak adaptation of CORE-OM (Clinical Outcome in Routine Evaluation – Outcome Measure)]. *Ceská a slovenská psychiatrie. [Czech and Slovak Psychiatry]*, 103(1), 4–13. Retrieved from <http://www.cspsychiatr.cz/detail.php?stat=312>
- Garcia-Campayo, J., Zamorano, E., Ruiz, M. A., Pardo, A., Perez-Paramo, M., Lopez-Gomez, V., ... Rejas, J. (2010). Cultural adaption into Spanish of the generalized anxiety disorder-7 (GAD-7) scale as a screening tool. *Health and Quality of Life Outcomes*, 8, 8. doi:10.1186/1477-7525-8-8
- Gardner, M. J. & Altman, D. G. (1986). Confidence intervals rather than P values: estimation rather than hypothesis testing. *British Medical Journal*, 292(6522), 746-750. doi:10.1136/bmj.292.6522.746
- Gascon-Ramos, M., Young, A. M., Petrides, K. V. Stone, C., & Woolfe, T. (2010). *TEIQue British Sign Language Version - a pilot project*. Final report to the Nuffield Foundation, February 2010.
- George, D. & Mallery, P. (2003). *SPSS for windows step by steps: A simple guide and reference*. Boston, MA: Allyn and Bacon.
- Gerich, J., & Legner, R. (2006). Video Computer-Assisted Self-Administered Interviews for Deaf Respondents. *Fields Methods*, 18(3), 267-283. doi:10.1177/1525822X06287535

- Goertz, G., & Mahoney, J. (2012). Concepts and measurement: Ontology and epistemology. *Social Science Information*, 51(2), 205-216.  
doi:10.1177/0539018412437108
- Goldberg, D. P. (1972). *The detection of psychiatric illness by questionnaire: A technique for the identification and assessment of non-psychotic psychiatric illness*. (Mansley Monograph No. 21). Oxford University Press: London.
- Goldberg D. (1978). *Manual of the General Health Questionnaire*. Oxford: NFER-NELSON.
- Goldstein, R. B., Olfson, M., Martens, E. G., & Wolk, S. I. (2006). Subjective Unmet Need for Mental Health Services in Depressed Children Grown Up. *Administration and Policy in Mental Health and Mental Health Services Research*, 33(6), 666-673. doi:10.1007/s10488-006-0082-y
- Goodwin, R. D., Fergusson, D. M., & Horwood, L. J. (2004). Association between anxiety disorders and substance use disorders among young persons: Results of a 21-year longitudinal study. *Journal of Psychiatric Research*, 38, 295-304. doi:10.1016/j.jpsychires.2003.09.002
- Gosling, S. D., Vazire, S., Srivastava, S., and John, O. P. (2004). Should We Trust Web-Based Studies? A Comparative Analysis of Six Preconceptions About Internet Questionnaires. *American Psychologist*, 59(2), 93-104.  
doi:10.1037/0003-066X.59.2.93
- Graybill, P., Aggas, J., Dean, R. K., Demers, S., Finigan, E. G., & Pollard, R. Q. (2010). A Community-Participatory Approach to Adapting Survey Items for Deaf Individuals and American Sign Language. *Field Methods*, 22(4), 429-448. doi:10.1177/1525822X10379201
- Gregory, S., Bishop, J., & Sheldon, L. (1995). *Deaf Young People and their Families: Developing Understanding*. Cambridge: Cambridge University Press.
- Griggs, M. (1998). *Deafness and Mental Health: Perceptions of Health within the Deaf Community* (Unpublished doctoral dissertation). University of Bristol, UK.
- Grosjean, F. (1996). Living with Two Languages and Two Cultures. In I. Parasnis (Ed.), *Cultural and Language Diversity and the Deaf Experience* (pp. 20-37). Cambridge, UK: Cambridge University Press.
- Guest, C. M., Collis, G. M., & McNicholas, J. (2006). Hearing Dogs: A Longitudinal Study of Social and Psychological Effects on Deaf and Hard-of-Hearing Recipients. *Journal of Deaf Studies and Deaf Education*, 11(2), 252-261. doi:10.1093/deafed/enj028

- Gusfield, J. R. (1975). *The community: A critical response*. New York, NY: Harper Colophon.
- Hair, J. F., Black, W. C., Babin, B. J., Anderson, R. E., & Tatham, R. L. (2006). *Multivariate Data Analysis* (6<sup>th</sup> ed.). Upper Saddle River, NJ: Pearson Prentice Hall.
- Hambleton, R. K. (1994). Guidelines for adapting educational and psychological tests: A progress report. *European Journal of Psychological Assessment*, 10(3), 229-244.
- Hambleton, R. K., & Patsula, L. (1998). Adapting tests for use in multiple languages and cultures. *Social Indicators Research*, 45(1-3), 153-171. doi:10.1023/A:1006941729637
- Hansson, M., Chotai, J., Nordstom, A., & Bodlund, O. (2009). Comparison of two self-rating scales to detect depression: HADS and PHQ-9. *British Journal of General Practice*, 59(566), e283-e288. doi:10.3399/bjgp09X454070
- Harris, R., Holmes, H. M., & Mertens, D. M. (2009). Research Ethics in Sign Language Communities. *Sign Language Studies*, 9(2), 104-131. doi:10.1353/sls.0.0011
- Hauser, P. C., O'Hearn, A., McKee, M., Steider, A., & Thew, D. (2010). Deaf epistemology: Deafhood and Deafness. *American annals of the deaf*, 154(5), 486-492. doi:10.1353/aad.0.0120
- Health and Social Care Act 2012 (Chapter 7)
- Hepner, K. A., Hunter, S. B., Edelen, M. O., Zhou, A. J., & Watkins, K. (2009). A comparison of two depressive symptomatology measures in residential substance abuse treatment clients. *Journal of Substance Abuse and Treatment*, 37, 318–325. doi:10.1016/j.jsat.2009.03.005
- Hertzog, M. A. (2008). Considerations in determining sample size for pilot studies. *Research in Nursing and Health*, 31(2), 180-191. doi:10.1002/nur.20247
- Hewson, C. (2003). Conducting research on the internet. *The Psychologist*, 16(6), 290-293. Retrieved from [http://ethics.grad.ucl.ac.uk/forms/hews\\_psychol.pdf](http://ethics.grad.ucl.ac.uk/forms/hews_psychol.pdf)
- Hill, Z. (2004). Reducing attrition in panel studies in developing countries. *International Journal of Epidemiology*, 33(3), 493-498. doi:10.1093/ije/dyh060
- Hindley, P. (1993). *Signs of feeling: A Prevalence study of psychiatric disorder in deaf and partially hearing children and adolescents*. London, England: RNID.
- Hindley, P., Hill, P., & Bond, D. (1993). Interviewing the Deaf Children, the Interviewer Effect: a Research Note. *Journal of Child Psychology and Psychiatry*, 34(8), 1461-1467. doi:10.1111/j.1469-7610.1993.tb02103.x

- Hindley, P., Hill, P. D., McGuigan, S., & Kitson, N. (1994). Psychiatric Disorder in Deaf and Hearing Impaired Children and Young People: A Prevalence Study. *Journal of Child Psychology and Psychiatry*, 35(5), 917-934. doi:10.1111/j.1469-7610.1994.tb02302.x
- Hintermair, M. (2000). Hearing impairment, social networks, and coping: the need for families with hearing-impaired children to relate to other parents and to hearing-impaired adults. *American Annals of the Deaf*, 145(1), 41-53. doi:10.1353/aad.2012.0244
- Hintermair, M. (2006). Parental Resources, Parental Stress, and Socioemotional Development of Deaf and Hard of Hearing Children. *Journal of Deaf Studies and Deaf Education*, 11(4), 493-513. doi:10.1093/deafed/enl005
- HM Government. (2011a). *No health without mental health: A cross-government mental health outcomes strategy for people of all ages*. London: HM Government.
- HM Government. (2011b). *No health without mental health: Delivering better mental health outcomes for people of all ages*. London: HM Government.
- Hoare, P. N., & Machin, M. A. (2010). The impact of reemployment on access to the latent and manifest benefits of employment and mental health. *Journal of Occupational and Organizational Psychology*, 83(3), 759-770.
- Hodges, K. (1987). Assessing children with a clinical research interview: the child assessment schedule. In R. J. Prinz (Ed.), *Advances in behavioural assessment of families and children* (vol. 3, pp. 203-233). Greenwich, CT: Academic Press.
- Hogg, M. A., & Vaughan, G. M. (2002). *Social Psychology* (3<sup>rd</sup> ed.). Harlow, England: Prentice Hall.
- Holmes, T. H., & Rahe, R. H. (1967). The Social Readjustment Rating Scale. *Journal of Psychosomatic Research*, 11(2), 213-218. doi:10.1016/0022-3999(67)90010-4
- Holte, M. C., & Dinis, M. C. (2001). Self-Esteem Enhancement in Deaf and Hearing Women: Success Stories. *American Annals of the Deaf*, 146(4), 348-354. doi:10.1353/aad.2012.0128
- House of Commons Education and Skills Committee. (2006). *Special Educational Needs: Third Report of Session 2005–06* (Volume 2). London: The Stationery Office.
- Howitt, D., & Cramer, D. (2005). *Introduction to Research Methods in Psychology*. Harlow, England: Pearson, Prentice Hall.

- Huang, F. Y., Chung, H., Kroenke, K., Delucchi, K. L., & Spitzer, R. L. (2006). Using the Patient Health Questionnaire-9 to Measure Depression among Racially and Ethnically Diverse Primary Care Patients. *Journal of General Internal Medicine*, 21(6), 547-552. doi:10.1111/j.1525-1497.2006.00409.x
- Huppert, F. A. (2008). *Mental Capital and Wellbeing: Making the most of ourselves in the 21<sup>st</sup> century. State-of-science review. Psychological wellbeing: evidence regarding its causes and consequences*. SR-X2. London: Government Office for Science Foresight project.
- Huurre, T., Junkkari, H., & Aro, H. (2006). Long-term Psychosocial effects of parents divorce: A follow-up study from adolescence to adulthood. *European Archives of Psychiatry and Clinical Neuroscience*, 256(4), 256-263. doi:10.1007/s00406-006-0641-y
- Hyphantis, T., Kotsis, K., Voulgari, P. V., Tsifetaki, N., Creed, F., & Drosos, A. A. (2011). Diagnostic Accuracy, Internal Consistency, and Convergent Validity of the Greek Version of the Patient Health Questionnaire 9 in Diagnosing Depression in Rheumatologic Disorders. *Arthritis Care & Research*, 63(9), 1313-1321. doi:10.1002/acr.20505
- Improving Access to Psychological Therapies. (2012a). *British Sign Language*. Retrieved from <http://www.iapt.nhs.uk/equalities/british-sign-language-bsl/>
- Improving Access to Psychological Therapies. (2012b). *Translations*. Retrieved from <http://www.iapt.nhs.uk/equalities/translations/?keywords=gad>
- International Test Commission. (2010). *International Test Commission Guidelines for Translating and Adapting Tests*. Retrieved from <http://www.intestcom.org>
- International Wellbeing Group (2005). *Personal Wellbeing Index. Australian Centre on Quality of Life*. Deakin University, Melbourne. Retrieved from [http://www.deakin.edu.au/research/acqol/instruments/wellbeing\\_index.htm](http://www.deakin.edu.au/research/acqol/instruments/wellbeing_index.htm)
- Jackson, C. J., & Furnham, A. (2000). *Designing and Analysing Questionnaires and Surveys: A Manual for Health Professionals and Administrators*. London, UK: Whurr Publishers Ltd.
- Johnston T. (2004). W(h)ither the Deaf Community? Population, Genetics, and the Future of Australian Sign language. *American Annals of the Deaf*, 148(5), 358-375. doi:10.1353/aad.2004.0004
- Jones, L., & Pullen, G. (1989). Inside we are all equal: a European social policy survey of people who are deaf. In L. Barton (Ed.) *Disability and dependency* (pp. 127-137). London: Falmer Press.

- Jones, S. (2004). Problematizing the Familiar: Deaf Students as Researchers of Deaf People. *Qualitative Social Work*, 3(1), 27-38.  
doi:10.1177/1473325004041130
- Kafka, G. J., & Kozma, A. (2004). The Construct Validity of Ryff's Scales of Psychological Well-Being (SPWB) and their Relationship to Measures of Subjective Well-Being. *Social Indicators Research*, 57(2), 171-190.  
doi:10.1023/A:1014451725204
- Kennedy, M. (2000). Disability and abuse. In K. Wilson and A. James (Eds.), *The Child Protection Handbook* (2<sup>nd</sup> ed.) (pp.147-171). Edinburgh, UK: Harcourt.
- Kettles, A. M., Creswell, J. W., & Zhang, W. (2011). Mixed methods research in mental health nursing. *Journal of Psychiatric and Mental Health Nursing*, 18(6), 535-542. doi:10.1111/j.1365-2850.2011.01701.x
- Kiefer, R. A. (2008). An Integrative Review of the Concept of Well-Being. *Holistic Nursing Practice*, 22(5), 244-252. doi:10.1097/HNP.0b013e318203d06a
- Klatter-Folmer, J., van Hout, R., Kolen, E., & Verhoeven, L. (2006). Language Development in Deaf Children's Interactions With Deaf and Hearing Adults: A Dutch Longitudinal Study. *Journal of Deaf Studies and Deaf Education*, 11(2), 238-251. doi:10.1093/deafed/enj032
- Kleinman, L., Leidy, N. K., Crawley, J., Bonomi, A., & Schoenfeld, P. (2001). A Comparative Trail of Paper-and-Pen versus Computer Administration of the Quality of Life in Reflux and Dyspepsia (QOLRAD) Questionnaire. *Medical Care*, 39(2), 181-189. Retrieved from <http://www.jstor.org/stable/3768040>
- Kluwin, T. N., & Morris, C. S. (2006). Lost in a Giant Database: The Potentials and Pitfalls of Secondary Analysis for Deaf Education. *American Annals of the Deaf*, 151(2), 121-128. doi:10.1353/aad.2006.0028
- Konner, M. (1991). *Childhood: A Multicultural View*. Boston, MA: Little, Brown and Company.
- Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: Validity of a Brief Depression Severity Measure. *Journal of General Internal Medicine*, 16(9), 606-613. doi:10.1046/j.1525-1497.2001.016009606.x
- Kroger, J. (2007). *Identity Development: Adolescence through adulthood* (2<sup>nd</sup> ed.). Thousand Oaks, California: Sage Publications.
- Kumpulainen, K., & Rasanen, E. (2002). Symptoms and Deviant Behavior Among Eight-Year-Olds as Predictors of Referral for Psychiatric Evaluation by Age 12. *Psychiatric Services*, 53(2), 201-206. doi:10.1176/appi.ps.53.2.201

- Kusters, A. (2010). Deaf Utopias? Reviewing the Sociocultural Literature on the World's "Martha's Vineyard Situations". *Journal of Deaf Studies and Deaf Education*, 15(1), 3-16. doi:10.1093/deafed/enp026
- Kvam, M. H. (2004). Sexual abuse of deaf children. A retrospective analysis of the prevalence and characteristics of childhood sexual abuse among deaf adults in Norway. *Child Abuse & Neglect*, 28, 241-251. doi:10.1016/j.chiabu.2003.09.017
- Kvam, M. H., Loeb, M., & Tambs, K. (2007). Mental Health in Deaf Adults: Symptoms of Anxiety and Depression Among Hearing and Deaf Individuals. *Journal of Deaf Studies and Deaf Education*, 12(1), 1-7. doi:10.1093/deafed/enl015
- Kyle, F. E., & Harris, M. (2010). Predictors of reading development in deaf children: a 3-year longitudinal study. *Journal of Experimental Child Psychology*, 107(3), 229-243. doi:10.1016/j.jecp.2010.04.011
- Ladd, P. (2003). *Understanding Deaf Culture: In Search of Deafhood*. Clevedon, England: Multilingual Matters Ltd.
- Lambert, M. J., Hansen, N. B., & Harmon, S. C. (2010). Outcome Questionnaire system (The OQ System): Development and practical applications in healthcare settings. In M. Barkham, G. E. Hardy & J. Mellor-Clark (Eds.), *Developing and delivering practice-based evidence: a guide for the psychological therapies* (pp. 139–154). Chichester, UK: John Wiley & Sons Ltd.
- Landau, R., & Litwin, H. (2001). Subjective well-being among the old-old: The role of health, personality and social support. *International Journal of Aging & Human Development*, 52(4), 265-280. doi:10.2190/RUMT-YCDX-X5HP-P2VH
- Lane, H. (1992). *The mask of benevolence: disability the Deaf community*. San Diego, CA: DawnSignPress.
- Lane, H., Pillard, R. C., & Hedberg, U. (2011). *The People of the Eye: Deaf Ethnicity and Ancestry*. New York, NY: Oxford University Press.
- Laranjeira, C. A. (2008). General health questionnaire—12 items: Adaptation study to the Portuguese population. *Epidemiologia e Psichiatria Sociale*, 17(2), 148–151. doi:10.1017/S1121189X00002840
- Lau, A. L. D., Cummins, R. A., & McPherson, W. (2005). An investigation into the cross-cultural equivalence of the Personal Wellbeing Index. *Social Indicators Research*, 72, 403-430. doi:10.1007/s11205-004-0561-z
- Lederberg, A. (1993). The Impact of Deafness on Mother-Child and Peer Relationships. In M. Marschark & M. D. Clark (Eds.), *Psychological*



- Perspective on Deafness* (pp. 93-119). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Leigh, G. (2008). Changing Parameters in Deafness and Deaf Education: Greater Opportunity but Continuing Diversity. In M. Marschark & P. C. Hauser (Eds.), *Deaf Cognition: Foundations and Outcomes* (pp. 24-51). Oxford, UK: Oxford University Press.
- Leigh, G., & Marschark, M. (2005). Ethics and Deafness: A Matter of Perspective? *Journal of Deaf Studies and Deaf Education*, 10(2), 109-110.  
doi:10.1093/deafed/eni023
- Leigh, I. W. (2009). *A Lens on Deaf Identities*. New York, NY: Oxford University Press.
- Leigh, I. W., Corbett, C. A., Gutman, V., & Morere, D. A. (1996). Providing psychological services to Deaf individuals: A response to new perceptions of diversity. *Professional Psychology: Research and Practice*, 27(4), 364-371.  
doi:10.1037/0735-7028.27.4.364
- Leigh, I. W., & Pollard, R. Q. (2003). Mental health and deaf adults. In M. Marschark & P. Spencer (Eds.), *Oxford handbook of deaf studies, language, and deaf education* (pp. 203-215). New York, NY: Oxford University Press.
- Lim, L., & Firkola, P. (2000). Methodological issues in cross-cultural management research: Problems, solutions, and proposals. *Asia Pacific Journal of Management*, 17(1), 133-154. doi:10.1023/A:1015493005484
- Lindsay, G. (2003). Inclusive education: a critical perspective. *British Journal of Special Education*, 30(1), 3-12. doi:10.1111/1467-8527.00275
- Listman, J., Rogers, K. D., & Hauser, P. (2011). Community Cultural Wealth and Deaf Adolescents' Resilience. In D. H. Zand & K. J. Pierce (Eds.), *Resilience in Deaf Children: Adaptation Through Emerging Adulthood* (pp. 279-297). New York, NY: Springer.
- Liu, S., Yeh, Z. T., Huang, H. C., Sun, F. J., Tjung, J. J., Hwang, L. C., ... Yeh, A. W. (2011). Validation of Patient Health Questionnaire for depression screening among primary care patients in Taiwan. *Comprehensive Psychiatry*, 52(1), 96-101. doi:10.1016/j.comppsy.2010.04.013
- Lotrakul, M., Sutida, S., & Saipanish, R. (2008). Reliability and validity of the Thai version of the PHQ-9. *BMC Psychiatry*, 8(1), 46. doi:10.1186/1471-244X-8-46
- Luft, P. (2011). Promoting Resilience in Deaf Adolescents. In D. H. Zand and K. J. Pierce (Eds.), *Resilience in Deaf Children: Adaptation Through Emerging Adulthood* (pp. 299-338). New York, NY: Springer.

- Malakouti, S. K., Fatollahi, P., Mirabzadeh, A., & Zandi, T. (2007). Reliability, validity and factor structure of the GHQ-28 used among elderly Iranians. *International Psychogeriatrics*, 19(4), 623-634.  
doi:10.1017/S1041610206004522
- Maller, S. J., & French, B. F. (2004). Universal Nonverbal Intelligence Test Factor Invariance across Deaf and Standardization Samples. *Educational and psychological Measurement*, 64(4), 647-660. doi:10.1177/0013164404263877
- Mallinson, S. (2002). Listening to respondents: a qualitative assessment of the Short-Form 36 Health Status Questionnaire. *Social Science & Medicine*, 54(1), 11-21.
- Marschark, M. (1993). *Psychological Development of Deaf Children*. New York, NY: Oxford University Press.
- Marschark, M. (2007). *Raising and Educating a Deaf Child: A Comprehensive Guide to the Choices, Controversies, and Decisions Faced by Parents and Educators*. New York, NY: Oxford University Press.
- Marschark, M., Lang, H. G., & Albertini, J. A. (2002). *Educating Deaf Students; from Research to Practice*. New York, NY: Oxford University Press.
- Marschark, M., Rhoten, C., & Fabich, M. (2007). On Ethics and Deafness: Research, Pedagogy and Politics. *Deafness and Educational International*, 9(1), 45-61. doi:10.1002/dei.211
- Mataix-Cols, D., Cowley, A. J., Hankins, M., Schneider, A., Bachofen, M., Kenwright, M., ... Marks, I. M. (2005). Reliability and validity of the Work and Social Adjustment Scale in phobic disorders. *Comprehensive Psychiatry*, 46(3), 223–228. doi:10.1016/j.comppsy.2004.08.007
- Mayberry, R. I. (2002). Cognitive development in deaf children: the interface of language and perception in neuropsychology. In S. J. Segalowitz & I. Rapin. (Eds.) *Handbook of Neuropsychology*, 2nd Edition, Volume 8, Part II (pp. 71-107). Amsterdam, the Netherlands: Elsevier.
- Mayer, C. (2007). What Really Matters in the Early Literacy Development of Deaf Children. *Journal of Deaf Studies and Deaf Education*, 12(4), 411-431.  
doi:10.1093/deafed/enm020
- McConnell, A. R., Strain, L. M., Brown, C. M., & Rydell, R. J. (2009). The simple life: On the benefits of low self-complexity. *Personality and Social Psychology Bulletin*, 35(7), 823-835. doi:10.1177/0146167209334785
- McDowell, I., & Newell, C. (1996). *Measuring Health: A guide to Rating Scales and Questionnaire* (2<sup>nd</sup> ed.). New York: Oxford University Press.

- McKee, M. M., Barnett, S. L., Block, R. C., & Pearson, T. A. (2011). Impact of Communication on Preventive Services Among Deaf American Sign Language Users. *American Journal of Preventive Medicine*, 41(1), 75-79.  
doi:10.1016/j.amepre.2011.03.004
- McMillan, D. W., & Chavis, D. M. (1986). Sense of Community: A Definition and Theory. *Journal of Community Psychology*, 14(1), 6-23. doi:10.1002/1520-6629(198601)14:1<6::AID-JCOP2290140103>3.0.CO;2-I
- Melchior, M., Moffitt, T. E., Milne, B. J., Poulton, R., & Caspi, A. (2007). Why do children from socioeconomically disadvantaged families suffer from poor health when they reach adulthood? A lifecourse study. *American Journal of Epidemiology*, 166, 966-974. doi:10.1093/aje/kwm155
- Michell, R. & Karchmer, M. (2004). Chasing the mythical ten percent: Parental hearing status of deaf and hard of hearing students in the United States. *Sign Languages Studies*, 4(2), 138-163. doi:10.1353/sls.2004.0005
- Milfont, T. L., Denny, S., Ameratunga, S., Robinson, E., & Merry S. (2008). Burnout and Wellbeing: Testing the Copenhagen Burnout Inventory in New Zealand Teachers. *Social Indicators Research*, 89(1), 169-177.  
doi:10.1007/s11205-007-9229-9
- Mishcon, J., Sensky, T., Lindsey, M., & Cook, S. (2000). *Report of the Independent Inquiry Team into the Care and Treatment of Daniel Joseph*. London, UK: Merton, Sutton and Wandsworth and Lambeth, Southwark and Lewisham Health Authorities.
- Mohay, H. (2000). Language in Sight: Mothers' strategies for making language visually accessible to deaf children. In P. E. Spencer, C. S. Erting & M. Marschark (Eds), *The Deaf Child in the Family and at School* (pp. 151-166). Mahwah, NJ: Lawrence Erlbaum Associates, Publishers.
- Mohay, H., Milton, L., Hindmarsh, G., & Ganley, K. (1998). Deaf Mothers as Communication Models for Hearing Families with Deaf Children. In A. Weisel (Ed.), *Issues Unresolved: New Perspectives on Language and Deaf Education* (pp. 76-87). Washington, DC: Gallaudet University Press.
- Montoya, L. A., Egnatovitch, R., Eckhardt, E., Goldstein, M., Goldstein, R. A., & Steinberg, A. G. (2004). Translation Challenges and Strategies: The ASL Translation of a Computer-Based, Psychiatric Diagnostic Interview. *Sign Language Studies*, 4(4), 314-344. doi:10.1353/sls.2004.0019

- Moore, K., Moore, D., Wright, B., Odgen, R., & Rogers, K. D. (2013). *From written to signed: Overcoming the challenges of translating from a spoken to a signed languages*. Manuscript submitted for publication.
- Morris, J. (2001) *That Kind of Life? Social Exclusion and Young Disabled People with High Levels of Support Needs*. London, Scope.
- Mundt, J. C., Marks, I. M., Shear, M. K., & Greist, J. H. (2002). The Work and Social Adjustment Scale: A simple accurate measure of impairment in functioning. *The British Journal of Psychiatry*, 180, 461-464.  
doi:10.1192/bjp.180.5.461
- Muniz, J. & Bartram, D. (2007). Improving International Tests and Testing. *European Psychologist*, 12(3), 206-219. doi:10.1027/1016-9040.12.3.206
- Munoz-Baell, I. M., & Ruiz, M. T. (2000). Empowering the deaf. Let the deaf be deaf. *Journal of Epidemiology and Community Health*, 54(1), 40-44.  
doi:10.1136/jech.54.1.40
- Murphy, E., Dingwall, R., Greatbatch, D., Parker, S., & Watson, P. (1998). Qualitative research methods in health technology assessment: A review of the literature. *Health Technology Assessment*, 2(16).
- NDCS. (2008). *Results from NDCS survey on educational attainment of deaf children* (May 2008). London, UK: National Deaf Children Society.
- NHS (2011). *Annual Report: NHS Newborn Hearing Screening Programme 2010-2011. Annual Report and 2009-2010 Data Report*. London, UK: NHS Newborn Hearing Screening Programme.
- Niclasen, J., Teasdale, T. W., Andersen, A-M. N., Skovgaard, A. M., Elberling, H., & Obel, C. (2012). Psychometric Properties of the Danish Strength and Difficulties Questionnaire: The SDQ Assessed for More than 70,000 Raters in Four Different Cohorts. *PLoS ONE* 7(2): e32025.  
doi:10.1371/journal.pone.0032025
- Nikolarazi, M., & Hadjikakou, K. (2006). The role of educational experiences in the development of deaf identity. *Journal of Deaf Studies and Deaf Education*, 11(4), 477–492. doi:10.1093/deafed/enl003
- Nolan, J. (2005). *Interpretation: Techniques and Exercises*. Clevedon, England: Multilingual Matters Ltd.
- Obasi, C. (2008). Seeing the Deaf in “Deafness”. *Journal of Deaf Studies and Deaf Education*, 13(4), 455-465. doi:10.1093/deafed/enn008

- Obinna, J. (2005). *Understanding Sexual Violence in the Deaf Community: A Preliminary Report on the Service Provider Perspective*. Minneapolis, MN: Council on Crime and Justice.
- Ofsted (2010). *The Special Educational Needs and Disability Review: a statement is not enough*. Manchester, UK: Ofsted.
- Oliva, G. A. (2004). *Alone in the Mainstream: A Deaf Woman Remembers Public School*. Washington, D.C.: Gallaudet University Press.
- Padden, C., & Humphries, T. (1988). *Deaf in America: Voices from a culture*. Cambridge, MA: Harvard University Press.
- Pajer, K. A. (1998). What happens to "bad" girls? A review of the adult outcomes of antisocial adolescent girls. *American Journal of Psychiatry*, 155(7), 862-870.
- Palmieri, G., Evans, C., Hansen, V., Brancaleoni, G., Ferrari, S., Porcelli, P., ... Rigatelli, M. (2009). Validation of the Italian version of the clinical outcomes in routine evaluation outcome measure (CORE-OM). *Clinical Psychology & Psychotherapy*, 16(5), 444-449. doi:10.1002/cpp.646
- Parasnis, I. (Ed.). (1996). *Cultural and Language Diversity and the Deaf Experience*. Cambridge: Cambridge University Press.
- Pernice, R. (1996). Methodological issues in unemployment research: Quantitative and/or qualitative approaches? *Journal of Occupational and Organizational Psychology*, 69(4), 339-349. doi:10.1111/j.2044-8325.1996.tb00620.x
- Peterson, C. C., & Siegal, M. (1999). Representing inner worlds: Theory of mind in autistic, deaf, and normal hearing children. *Psychological Science*, 10, 126-129. doi:10.1111/1467-9280.00119
- Petrides, K. V., & Furnham, A. (2003). Trait Emotional Intelligence: Behavioural Validation in Two Studies of Emotion Recognition and Reactivity to Mood Induction. *European Journal of Personality*, 17(1), 39-57. doi:10.1002/per.466
- Petrides, K. V., Perez-Gonzalez, J. C., & Furnham, A. (2007). On the criterion and incremental validity of trait emotional intelligence. *Cognition and Emotion*, 21(1), 26-55. doi:10.1080/02699930601038912
- Pett, M. A., Lackey, N. R., & Sullivan, J. J. (2003). *Making Sense of Factor Analysis: The use of factor analysis for instrument development in health care research*. Thousand Oaks, CA: SAGE Publications.
- Pollard, R. Q. (1992). Cross-Cultural Ethics in the Conduct of Deafness Research. *Rehabilitation Psychology*, 37(2), 87-101. doi:10.1037//0090-5550.37.2.87

- Pollard, R. Q. (2002). Ethical Conduct in Research involving Deaf People. In V. A. Gutman (Ed.), *Ethics in Mental Health and Deafness* (pp. 162-178). Washington, DC: Gallaudet University Press.
- Power, C., Stansfeld, S. A., Matthews, S., Manor, O., & Hope, S. (2002). Childhood and adulthood risk factors for socio-economic differentials in psychological distress: evidence from the 1958 British birth cohort. *Social Science and Medicine*, 55, 1989-2004. doi:10.1016/S0277-9536(01)00325-2
- Power, D. J., Power, M. R., & Rehling, B. (2007). German Deaf People Using Text Communication: Short Message Service, TTY, Relay Services, Fax, and E-Mail. *American Annals of the Deaf*, 152(3), 291-301. doi:10.1353/aad.2007.0030
- Preisler, G., Tvingstedt, A. L., & Ahlstrom, M. (2002). A psychosocial follow-up study of deaf preschool children using cochlear implants. *Child: Care, Health and Development*, 28(5), 403-418. doi:10.1046/j.1365-2214.2002.00291.x
- Prilleltensky, I., Dockecki, P., Frieden, G., & Ota Wang, V. (2007). Counseling for Wellness and Justice: Foundations and Ethical Dilemmas. In E. Aldarondo (Ed.), *Advancing social justice through clinical practice* (pp.19–42). Mahwah, NJ: Lawrence Erlbaum.
- R development core team. (2012). *R: A language and environment for statistical computing*. Vienna, Austria: R Foundation for Statistical Computing. Retrieved from <http://www.R-project.org/>
- Rao, U., Weissman, M. M., Martin, J. A., & Hammond, R. W. (1993). Childhood Depression and Risk of Suicide: A Preliminary Report of a Longitudinal Study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 32(1), 21-27. doi:10.1097/00004583-199301000-00004
- Reips, U-D. (2002). Standards for Internet-Based Experimenting. *Experimental Psychology*, 49(4), 243-256. doi:10.1026//1618-3169.49.4.243
- Ridgeway, M. S. (1998). *The Psychological Health and Well-being of Deaf People in the Community* (Unpublished doctoral dissertation). The University of Manchester, UK.
- RNID (2003). *Employment for all: assisting people with health problems and disabilities into work*. Submission by RNID to the Work and Pensions Committee. Retrieved from <http://webarchive.nationalarchives.gov.uk/+http://www.cabinetoffice.gov.uk/media/cabinetoffice/strategy/assets/rnid3.pdf>

- RNID (2004). *A simple cure: a national report into deaf and hard of hearing people's experiences of the National Health Service*. London: Royal National Institute for the Deaf.
- Roberts, C. & Hindley, P. (1999). Practitioner Review: The Assessment and Treatment of Deaf Children with Psychiatric Disorders. *Journal of Child Psychology and Psychiatry*, 40(2), 151-157. doi:10.1111/1469-7610.00430
- Robson, C. (2002). *Real World Research: A resource for social-scientists and practitioner-researchers* (2<sup>nd</sup> ed.). Oxford, UK: Blackwell.
- Rogers, K. (2010, September). ICED 2010 Rejects Milan 1880 Congress Resolution: Long Live Sign Language. *British Deaf News*, 22-23.
- Rogers, K. D., Evans, C., Campbell, M., Young, A., & Lovell, K. (2013). *The reliability of British Sign Language and English versions of the CORE-OM with d/Deaf populations in the UK: a pilot study*. Manuscript submitted for publication.
- Rogers, K. D., & Young, A. M. (2011). Being a Deaf Role Model: Deaf People's Experience of Working with Families and Deaf Young People. *Deafness and Educational International*, 13(1), 2-16. doi:10.1179/1557069X10Y.0000000004
- Rogers, K. D., & Young, A. (In press). Is there an association between deaf children's mental health difficulties and their adult well-being? The state of evidence. In L. Leeson, & M. Vermeerbergen (Eds), *Working with the Deaf Community: Education, Mental Health and Interpreting*. Dublin, Ireland: Interresource Group (Ireland) Limited.
- Rogers, K. D., Young, A., Lovell, K., & Evans, C. (2013). The challenges of translating the Clinical Outcomes in Routine Evaluation - Outcome Measure (CORE-OM) into British Sign Language. *Journal of Deaf Studies and Deaf Education*. Advance online publication. doi:10.1093/deafed/ent002
- Rogers, K. D., Young, A., Lovell, K., Campbell, M., Scott, P. R., & Kendal, S. (2013). The British Sign Language Versions of the Patient Health Questionnaire, the Generalized Anxiety Disorder 7-Item Scale, and the Work and Social Adjustment Scale. *Journal of Deaf Studies and Deaf Education*, 18(1), 110-122. doi:10.1093/deafed/ens040
- Rogers, S., Muir, K., & Evenson, C. R. (2003). Signs of Resilience: Assets that support deaf adults' success in bridging the deaf and hearing worlds. *American Annals of the Deaf*, 148(3), 222-232. doi:10.1353/aad.2003.0023
- Røysamb, E., Harris, J. R., Magnus, P., Vittersø, J., & Tambs, K. (2002). Subjective well-being. Sex-specific effects of genetic and environmental factors.

- Personality and Individual Differences*, 32(2), 211-223. doi:10.1016/S0191-8869(01)00019-8
- Rutter, M. (2000). Resilience reconsidered: Conceptual consideration, empirical findings, and policy implications. In J.P. Shonkoff (Ed.), *Handbook of early intervention* (pp. 651-682). Cambridge: Cambridge University Press.
- Rutter, M., Tizard, J., & Whitmore, K. (Eds). (1970). *Education, health and behaviour*. London, UK: Longman.
- Ryff, C. D. (1989). 'Happiness is everything, or is it? Explorations on the meaning of psychological well-being'. *Journal of Personality and Social Psychology*, 57, 1069–1081. doi:10.1037//0022-3514.57.6.1069
- Ryff, C. D. (1995). Psychological Well-Being in Adult life. *Current Directions in Psychological Science*, 4(4), 99-104. doi:10.1111/1467-8721.ep10772395
- Sacks, O. (1989). *Seeing Voices*. London, England: Picador.
- Sales, C., Moleiro, C., Evans, C., & Alves, P. (2012). Versão Portuguesa do CORE-OM: Tradução, adaptação e estudo preliminar das suas propriedades psicométricas (The Portuguese version of CORE-OM: Translation, adaptation and preliminary data on its psychometric properties). *Interface*, 39(2), 54–59. Retrieved from <http://www.scielo.br/pdf/rpc/v39n2/03/pdf>
- Samady, W., Sadler, G. R., Nakaji, M., Malcarne, V. L., Trybus, R., & Athale, N. (2008). Translation of the Multidimensional Health Locus of Control Scales for Users of American Sign Language. *Public Health Nursing*, 25(5), 480-489. doi:10.1111/j.1525-1446.2008.00732.x
- Schlesinger, H. S., & Meadow, K. P. (1972). *Sound and Sign: Childhood Deafness and Mental Health*. Berkeley, CA: University of California Press.
- Scholte, W. F., Verduin, F., Kamperman, A. M., Rutayisire, T., Zwinderman, A. H., & Stronks, K. (2011). The Effect on Mental Health of a Large Scale Psychosocial Intervention for Survivors of Mass Violence: A Quasi-Experimental Study in Rwanda. *PLoS ONE* 6(8): e21819. doi:10.1371/journal.pone.0021819
- Schroedel, J. G., & Geyer, P. D. (2000). Long-term career attainments of deaf and hard of hearing college graduates: results from a 15-year follow-up survey. *American Annals of the Deaf*, 145(4), 303-314. doi:10.1353/aad/2012.0099
- Sell, H., & Nagpal, R. (1992). *Assessment of Subjective Well-Being: The Subjective Well-Being Inventory (SUBI)*. Regional Health Paper, SEARO, No. 24. World Health Organization, Regional Office for South-East Asia. New Delhi.
- Sheldon, K. M., Ryan, R. M., Rawsthorne, L. J., & Ilardi, B. (1997). Trait self and true self: Cross-role variation in the Big-Five personality traits and its relations



- with psychological authenticity and subjective well-being. *Journal of Personality and Social Psychology*, 73, 1380-1393. doi:10.1037//0022-3514.73.6.1380
- Sheppard, K. & Badger, T. (2010). The lived experience of depression among culturally Deaf adults. *Journal of Psychiatric and mental Health Nursing*, 17(9), 783-789. doi:10.1111/j.1365-2850.2010.01606.x
- Sijtsma K. (2008). On the Use, the Misuse, and the Very Limited Usefulness of Cronbach's Alpha. *Psychometrika*, 74(1), 107–120. doi:10.1007/s11336-008-9101-0
- Silva, P. A., Chalmers, D. & Stewart, I. (1986). Some audiological, education and behavioural characteristics of children with bilateral otitis media with effusion: A longitudinal study. *Journal of Learning Disabilities*, 19, 165-169. doi:10.1177/002221948601900307
- Silverman, D. (2011). *Interpreting Qualitative Data* (4<sup>th</sup> ed.). London, England: Sage.
- Singleton, N., Bumpstead, R., O'Brien, M., Lee, A., & Meltzer, H. (2001). *Psychiatric Morbidity Among Adults Living In Private Households 2000*. London, UK: The Stationery Office.
- Sinkkonen, J. (1998). Mental health problems and communication of children with hearing loss in Finnish special schools. In A. Weisel (Ed.), *Issues Unresolved: New Perspectives on Language and Deaf Education* (pp. 197-205). Washington, D.C.: Gallaudet University Press.
- Skelton, T., & Valentine, G. (2003). 'It feels like being Deaf is normal': an exploration into the complexities of defining D/deafness and young D/deaf people's identities. *The Canadian Geographer / Le Geographe canadien*, 47(4), 451-466. doi:10.1111/j.0008-3658.2003.00035.x
- Skevington, S., Lotfy, M., & O'Connell, K. (2004). World Health Organisation WHOQOL-BREF quality of life assessment: psychometric properties and results of international field trial. A report from the WHOQOL group. *Quality of Life Research*, 13(2), 299–310.
- Skovgaard, A. M., Olsen, E. M., Houmann, T., Christiansen, E., Samberg, V., Lichtenberg, A., & Jorgensen, T. (2005). The Copenhagen County child cohort: Design of a longitudinal study of child mental health. *Scandinavian Journal of Public Health*, 33, 197-202. doi:10.1080/14034940510005662

- Slobin, D. I. (2008). Breaking the Molds: Signed Languages and the Nature of Human Language. *Sign Language Studies*, 8(2), 114-130.  
doi:10.1353/sls.2008.0004
- Smith, A. (2003). *Written Ministerial Statement on British Sign Language*. London, England: Hansard. Retrieved from  
<http://www.publications.parliament.uk/pa/cm200203/cmhansrd/vo030318/wmstext/30318m02.htm>
- Social Exclusion Unit. (2004). *Mental Health and Social Exclusion: Social Exclusion Unit Report Summary*. London: Social Exclusion Unit.
- Solano-Flores, G., Backhoff, E., & Contreras-Nino, L. A. (2009). Theory of Test Translation Error. *International Journal of Testing*, 9(2), 78-91.  
doi:10.1080/15305050902880835
- Sonnentag, S., & Fritz, C. (2007). The Recovery Experience Questionnaire: Development and validation of a measure for assessing recuperation and unwinding from work. *Journal of Occupation Health Psychology*, 12(3), 204-221.  
doi:10.1037/1076-8998.12.3.204
- Spencer, P. E., & Meadow-Orlans, K. P. (1996). Play, language, and maternal responsiveness: A longitudinal study of deaf and hearing impaired infants. *Child Development*, 67(6), 3176-3191.
- Spitzer, R. L., Kroenke, K., & Williams, J. B. W. (1999). Validation and utility of a self-report version of PRIME-MD: The PHQ Primary Care Study. *The Journal of the American Medical Association*, 282, 1737-1744.  
doi:10.1001/jama.282.18.1737
- Spitzer, R. L., Kroenke, K., Williams, J. B. W., & Lowe, B. (2006). A brief measure for assessing generalized anxiety disorder: The GAD-7. *Archives of Internal Medicine*, 166, 1092-1097. doi:10.1001/archinte.166.10.1092
- Steinberg, A. G., Lipton, D. S., Eckhardt, E. A., Goldstein, M., & Sullivan, V. J. (1998). The Diagnostic Interview Schedule for Deaf Patients on Interactive Video: A Preliminary Investigation. *American Journal of Psychiatry*, 155(11), 1603-1604.
- Steinberg, A. G., Sullivan, V. J., & Loew, R. C. (1998). Cultural and Linguistic Barriers to Mental Health service Access: The Deaf Consumer's Perspective. *American Journal of Psychiatry*, 155(7), 982-984.
- Steinhausen, H. C., Meier, M., & Angst, J. (1998). The Zurich long-term outcome study of child and adolescent psychiatric disorders in males. *Psychological Medicine*, 28, 375-383. doi:10.1017/S0033291797005989

- Stinson, M. S. (1994). Research on Deaf Individuals by Hearing Persons: One Deaf Researcher's Perspective. *Journal of the American Deafness and Rehabilitation Association*, 27(3), 17-21.
- Stinson, M. S., & Whitmire, K. A. (2000). Adolescents Who Are Deaf or Hard of Hearing: A Communication Perspective on Educational Placement. *Topics in Language Disorders*, 20(2), 58-72. doi:10.1097/00011363-200020020-00006
- Suh, E. M. (2002). Culture, Identity Consistency, and Subjective Well-Being. *Journal of Personality and Social Psychology*, 83(6), 1378-1391. doi:10.1037//0022-3514.83.6.1378
- Sullivan, P., Brookhouser, P., & Scanlan, M. (2000). Maltreatment of deaf and hard of hearing children. In P. Hindley & N. Kitson (Eds.), *Mental Health and Deafness* (pp.148-184). London, UK: Whurr.
- Sullivan, P. M., & Knutson, J. F. (1998). Maltreatment and behavioral characteristics of youth who are deaf and hard-of-hearing. *Sexuality and Disability*, 16(4), 295-319. doi: 10.1023/A:1023019912548
- Sullivan, P. M. & Knutson, J. F. (2000). Maltreatment and Disabilities: A population-based epidemiological study. *Child Abuse & Neglect*, 24(10), 1257-1273. doi:10.1016/S0145-2134(00)00190-3
- Sutherland, H., & Rogers, K. (2013). *The Hidden Gain: A New Lens of Research with d/Deaf Children and Adults*. Manuscript submitted for publication.
- Sutton-Spence, R., & Woll, B. (1999). *The Linguistics of British Sign Language: An Introduction*. Cambridge, UK: Cambridge University Press.
- Takala, M., Kuusela, J., & Takala, E. (2000). A Good Future for Deaf Children: A Five-Year Sign Language Intervention Project. *American Annals of the Deaf*, 145(4), 366–374. doi:10.1353/aad.2012.0078
- Temple, B., & Young, A. (2004). Qualitative research and translation dilemmas. *Qualitative Research*, 4(2), 161-178. doi:10.1177/1468794104044430
- Thabet, A. A., Stretch, D., & Vostanis, P. (2000) Child Mental Health Problems in Arab Children: Application of the Strengths and Difficulties Questionnaire. *International Journal of Social Psychiatry*, 46(4), 266-280. doi:10.1177/002076400004600404
- Tiliouine, H. (2009). Health and subjective wellbeing in Algeria: A developing country in transition. *Applied Research in Quality of Life*, 4(2), 223-238. doi:10.1007/s11482-009-9073-y
- Titov, N., Dear, B. F., McMillan, M., Anderson, T., Zou, J., & Sutherland, M. (2011). Psychometric Comparison of the PHQ-9 and BDI-II for Measuring

- Response during Treatment of Depression. *Cognitive Behaviour Therapy*, 40(2), 126-136. doi:10.1080/16506073.2010.550059
- Todd, C. & Bradley, C. (1994). Evaluating the design and development of psychological scales. In C. Bradley (Ed.), *Handbook of psychology and diabetes: A guide to psychological measurement in diabetes research and practice* (pp. 15-42). Chur, Switzerland: Harwood Academic.
- Tonan, K., Sonoda, A., & Ono, Y. (1995). Production of the Japanese edition of the Subjective Well-Being Inventory: Its reliability and validity. *Japanese Journal of Health Psychology*, 8(2), 12-19.
- Traxler, C. B. (2000). The Stanford Achievement Test, 9<sup>th</sup> edition: National norming and performance standards for deaf and hard of hearing students. *Journal of Deaf Studies and Deaf Education*, 5(4), 337–348. doi:10.1093/deafed/5.4.337
- Trzesniewski, K. H., Donnellan, M. B., Moffitt, T.E, Robins, R. W., Poulton, R., & Caspi, A . (2006). Low self-esteem during adolescence predicts poor health, criminal behavior, and limited economic prospects during adulthood. *Developmental Psychology*, 42, 381-390. doi:10.1037/0012-1649.42.2.381
- Tuulio-Henriksson, A., Poikolainen, K., Aalto-Setälä, T., & Lonnqvist, J. (1997). Psychological defense styles in late adolescence and young adulthood: a follow-up study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 36(8), 1148-1153. doi:10.1097/00004583-199708000-00025
- Uher, R., & Goodman, R. (2010). The Everyday Feeling Questionnaire: The structure and validation of a measure of general psychological well-being and distress. *Social Psychiatry and Psychiatric Epidemiology*, 45(3), 413-423. doi:10.1007/s00127-009-0074-9
- UNESCO (1994). *The Salamanca Statement and Framework for Action on Special Needs Education*. Paris, France: UNESCO.
- Valentine, G., & Skelton, T. (2003). Living on the edge: the marginalisation and 'resistance' of D/deaf youth. *Environment and Planning A*, 35, 301-321. doi:10.1068/a3572
- Valentine, G. & Skelton, T. (2008). Changing spaces: the role of the internet in shaping Deaf geographies. *Social & Cultural Geography*, 9(5), 469-485. doi:10.1080/14649360802175691
- Valentine, G., & Skelton, T. (2009). 'An umbilical cord to the world': The role of the Internet in D/deaf people's information and communication practices.

- Information, Communication & Society*, 12(1), 44-65.  
doi:10.1080/13691180802158573
- Van der Kamp, L. J. Th., & Bijleveld, C. C. J. H. (1998). In C. C. J. H. Bijleveld, L. J. Th. van der Kamp, A. Mooijaart, W. A. van der Kloot, R. van der Leeden, & E. van Der Burg, *Longitudinal data analysis: Designs, models, and methods* (pp.1-45). Thousand Oaks, CA: Sage Publications.
- Van der Werf, M., Thewissen, V., Dominguez, M. D., Lieb, R., Wittchen, H., & van Os, J. (2011). Adolescent development of psychosis as an outcome of hearing impairment: a 10-year longitudinal study. *Psychological Medicine*, 41, 477-485.  
doi:10.1017/S0033291710000978
- Van Eldik, T. (2005). Mental Health Problems of Dutch Youth with Hearing Loss as Shown on the Youth Self Report. *American Annals of the Deaf*, 150(1), 11-16.  
doi:10.1353/aad.2005.0024
- Vermeerbergen, M., & Leeson, L. (2011) European signed languages – towards a typological snapshot. In B. Kortmann & J. Van der Auwera (Eds.), *The languages and linguistics of Europe: A comprehensive guide* (pp. 269-290). Berlin, Germany: Mouton de Gruyter.
- Vernon, M. (2005). Fifty Years of Research on the Intelligence of Deaf and Hard-of-Hearing Children: A Review of Literature and Discussion of Implications. *Journal of Deaf Studies and Deaf Education*, 10(3), 225–231.  
doi:10.1093/deafed/eni024
- Vernon, M., & LaFalce-Landers, E. (1993). A Longitudinal Study of Intellectually Gifted Deaf and Hard of Hearing People: Educational, Psychological, and Career Outcomes. *American Annals of the Deaf*, 138(5), 427-434.  
doi:10.1353/aad.2012.0335
- Wallhagen, M. I., Strawbridge, W. J., Shema, S. J., Kurata, J., & Kaplan, G. A. (2001). Comparative impact of hearing and vision impairment on subsequent functioning. *Journal of the American Geriatrics Society*, 49(8), 1086-1092.  
doi:10.1046/j.1532-5415.2001.49213.x
- Wallis, D., Musselman, C., & MacKay, S. (2004). Hearing Mothers and Their Deaf Children: The Relationship between Early, Ongoing Mode Match and Subsequent Mental Health Functioning in Adolescence. *Journal of Deaf Studies and Deaf Education*, 9(1), 2-14. doi:10.1093/deafed/enh014
- Warnock Committee (1978). *Special Educational Needs: the Warnock Report*. Retrieved from <http://www.educationengland.org.uk/documents/warnock/>

- Warnock. M. (2005). *Special Educational needs: a new look*. London, UK: Philosophy of Education Society of Great Britain.
- Watkins, S., Pitman, P., & Walden. B. (1998). The Deaf Mentor Experimental Project for Young Children Who Are Deaf and Their Families. *American Annals of the Deaf*, 143 (1), 29–34. doi:10.1353/aad.2012.0098
- Weiner, M. T., & Miller, M. (2006). Deaf Children and Bullying: Directions for Future Research. *American Annals of the Deaf*, 151(1), 61-70. doi:10.1353/aad.2006.0021
- Werngren-Elgstrom, M., Brandt, A., & Iwarsson, S. (2006). Everyday activities and social contacts among older deaf sign language users: Relationships to health and well-being. *Occupational Therapy International*, 13(4), 207-223. doi:10.1002/oti.218
- Whittington, J. E., & Huppert, F. A. (1998). Neuroticism, Psychiatric Symptoms and Life Events. *Personality and Individual Differences*, 24(1), 97-107. doi:10.1016/S0191-8869(97)00151-7
- Wild, D., Grove, A., Martin, M., Eremenco, S., McElroy, S., Verjee-Lorenz, A., & Erikson, P. (2005). Principles of good practice for the translation and cultural adaptation process for Patient-Reported Outcomes (PRO) measures: report of the ISPOR task force for translation and cultural adaptation. *Value in Health*, 8(2), 94–104. doi:10.1111/j.1524-4733.2005.04054.x
- Wilkinson, S. (2003). Focus groups. In J. A. Smith. *Qualitative Psychology: A Practical Guide to Research Methods* (pp. 184-204). London, UK: Sage Publications.
- Willig, C. (2001). *Introducing Qualitative Research in Psychology: Adventures in theory and method*. Maidenhead, UK: Open University Press.
- Wilson, J. A. B., & Wells, M. G. (2009). Telehealth and the Deaf: A Comparison Study. *Journal of Deaf Studies and Deaf Education*, 14(3), 386-402. doi:10.1093/deafed/enp008
- Woll, B., & Ladd, P. (2003). Deaf communities. In M. Marschark & P. E. Spencer (Eds.), *Oxford Handbook of Deaf Studies, Language and Education* (pp. 151-163). Oxford, UK: Oxford University Press.
- Woodward, J. (1972). Implications for Sociolinguistics Research among the Deaf. *Sign Language Studies*, 1, 1–7.
- Woolfe, T., Want, S. C., & Siegal, M. (2002). Signposts to development: Theory of mind in deaf children. *Child Development*, 73(3), 768-778. doi:10.1111/1467-8624.00437

- Yoshinaga-Itano, C. (2003). From Screening to Early Identification and Intervention: Discovering Predictors to Successful Outcomes for Children With Significant Hearing Loss. *Journal of Deaf Studies and Deaf Education*, 8(1), 11-30. doi:10.1093/deafed/8.1.11
- Yosso, T. J. (2005). Whose culture has capital? A critical race theory discussion of community cultural wealth. *Race Ethnicity and Education*, 8(1), 69-91. doi:10.1080/1361332052000341006
- Young, A. (2003). *Parenting and Deaf Children: A Psycho-Social Literature Based Framework*. London, UK: NDCS.
- Young, A. (2006). The experience of deafness: psychological effects. In V. E. Newton & P. J. Valley (Eds.), *Infection and Hearing Impairment* (pp. 279-286). Chichester, England: John Wiley & Sons, Ltd.
- Young, A., & Ackerman, J. (2001). Reflections on validity and epistemology in a study of working relations between deaf and hearing professionals. *Qualitative Health Research*, 11(2), 179-189. doi:10.1177/104973201129119037
- Young, A., Carr, G., Hunt, R., McCracken, W., Skipp, A., & Tattersall, H. (2006). Informed Choices and Deaf Children: Underpinning Concepts and Enduring Challenges. *Journal of Deaf Studies and Deaf Education*, 11(3), 322-336. doi:10.1093/deafed/enj041
- Young, A., Green, L., & Rogers, K. (2008). Resilience and deaf children: a literature review. *Deafness and Educational International*, 10(1), 40-55. doi:10.1002/dei.234
- Young, A. & Hindley, P. (2004). *The social functioning of deaf adults. Pilot work for a multi generational cohort study*. Report presented to the Hearing Research Trust.
- Young, A., & Hunt, R. (2011). *Research with d/Deaf People*. NIHR School for Social Care Research.
- Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, 67(6), 361–370. doi:10.1111/j.1600-0447.1983.tb09716.x

## **Appendix 1**

### **A critique of the Hindley (1993) study**

The study carried out by Hindley (1993) was well organised and used several assessments in an attempt to detect the prevalence of psychiatric disorder in d/Deaf young people. Hindley used standardised assessment as well as assessments developed by Hindley himself including some items that were considered relevant to d/Deaf young people (for example, “He is always alone – he never mixes even with other deaf children”, “Does he refuse to communicate with you even though both of you can?”)

#### *Interviewer effect*

In his pilot study Hindley did consider the effect of the interviewer on the results of the CAS scores (Hindley, Hill, & Bond, 1993). However all interviews were not carried out in the same language (one was in PSE and two were in British Sign Language) and they were not all carried out by an experienced psychiatrist (some were conducted by a Deaf counsellor who was trained to use the CAS). It would be interesting to see what the results would have been if the CAS interviews had been carried out by a psychiatrist who had no knowledge of d/Deaf people, via a British Sign Language/English interpreter, and whether the results of this would differ if a qualified Deaf psychiatrist had carried out the interviews in BSL, as both interviewer and interviewee would then share the same language and culture and the interviewer might be more able to accurately detect signs.

#### *‘Parents’ report in the pilot study*

For those d/Deaf children at boarding school both the PCL and Rutter A(2) forms were completed. Although, Hindley (1993) attempted to get as many parents as possible to complete the forms, because of the small number of responses from parents, they decided to use houseparents’ reports too. Differences noted between parents’ and houseparents’ scores in the pilot study were that parents reported fewer disturbances in d/Deaf children than did houseparents. Hindley (1993) thought that this was because parents only saw their children at weekends and during school holidays. Using houseparents to fill in a form that was designed for parents might have affected the actual results as the responses may have differed from parents themselves. The way in which houseparents perceive the



d/Deaf child may have been different to how parents would see their own child, particularly because houseparents would have been responsible for a number of d/Deaf children within a school.

### *Assessments used*


The scale used for the Parents and Teachers' Checklist was a four-point scale: never, less than every month, every month to once a week, more than once a week. On another part of the form a different range was used; never, less than every 3 months, every 3 months to every month, and more than once a month.

The CAS (Hodges, 1987) was developed for 7-12 years old, but it was used with 11-16 year old d/Deaf young people because Hindley thought that some of them had social and emotional developmental delay. However, the way assessment was developed and the content of the items in the tool are relevant to the 7-12 year old age group. To use the measure in this way (i.e. for an older different age group) might not be valid because of the different life experiences at that age, regardless of the social and emotional development of the group in question.

## Appendix 2

### Materials for pilot study of the CORE-OM with d/Deaf populations

#### (a) Information Sheet

The University of Manchester		<b>Project no.</b> 10/1040/NMSW
	<b>What is this research project about?</b>	
	<p>This study is looking at how well-being assessments in British Sign Language can be used with the d/Deaf populations. Well-being will be measured using the Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM), which was created for the hearing population. This study aims to find out whether both the BSL version and the English version of CORE-OM can be used with the d/Deaf populations or not. The CORE-OM has been translated into British Sign Language; however the English version has not been modified.</p>	
	<p>The results from Deaf people taking part in this study will help me to find out whether the BSL version and/or the English version of CORE-OM are useful or not. As the CORE-OM was created for the hearing population, it is possible that some of the questions are designed to get answers from a hearing perspective on well-being. Therefore, some of the answers from the Deaf community might not match what the questions in the CORE-OM are looking for. This study will try to spot potential difficulties when Deaf people answer questions on well-being from a Deaf perspective. These will be taken into consideration and corrected for when we go back to check the BSL version of some of the questions.</p>	
	<p>The results from both the BSL version and English version of CORE-OM will help us to know whether we can be confident that the assessment can be trusted for use in the main study, a follow up to a 1988 study looking at the well-being outcomes of deaf young people.</p>	
<b>Well-being assessment for the d/Deaf populations</b> <b>INFORMATION SHEET</b>	<b>If I agree to take part, what is involved?</b>	
	<p>If you agree to take part, you will be asked to choose either the BSL version or English version of the CORE-OM assessment and complete it. This will measure your perspective on your own well-being as well as asking you to provide some brief background information about yourself. The assessment will take about 10-15 minutes to complete. This questionnaire can be done online.</p>	
	<p>There are no known risks involved in this study. You will be asked to sign a consent form.</p>	
	<b>Will I be paid to take part?</b>	
	<p>You will receive a £15 voucher for taking part in the study and all necessary materials will be provided for you, so taking part will not cost you anything.</p>	
	<b>Will my information be kept confidential?</b>	
	<p>The information about you and your answers on the wellbeing assessment will not be passed on to anyone else or published without protecting your identity. All personal information will be destroyed after the research project is complete. Your data will be given a code to protect your identity, and any information that identifies you will not be included as part of the database.</p>	
	<p>All data will be stored anonymously; e.g. a code number will be assigned to your questionnaire and your name and contact details will be stored separately from your questionnaire.</p>	

Well-being assessment for deaf population  
INFORMATION SHEET**What happens if I decide not to take part?**

You do not have to take part in this research study. If you decide not to take part, this will not affect you in any way.

If you do decide to take part, and then change your mind later, you are free to withdraw at any time without giving a reason.

**If I decide to take part, what do I do now?**

Please fill in the consent form and sign it. This will state that you have agreed to take part.

**If I want more information, who should I contact?**

This information sheet is available in both BSL and English. The BSL version is available on the website: <http://www.manchester.ac.uk/deafwellbeing>. If you would like a CD copy of the BSL version, please let me know.

If you would like more information about this study, you can contact me, Katie Rogers, by email at [katherine.rogers@manchester.ac.uk](mailto:katherine.rogers@manchester.ac.uk) or by post at: School of Nursing, Midwifery and Social Work, The University of Manchester, 4.312 University Place, Oxford Road, Manchester, M13 9PL. You can also text me on 07856 696533 or call me on 0161 306 0260 (minicom).



If you would like to, you can contact one of my supervisors, Professor Alys Young and/or Professor Karina Lovell. Professor Alys Young can be reached at [alys.young@manchester.ac.uk](mailto:alys.young@manchester.ac.uk) or by post at the School of Nursing, Midwifery and Social Work, The University of Manchester, 4.327 University Place, Oxford Road, Manchester, M13 9PL. Professor Karina Lovell can be reached at [karina.lovell@manchester.ac.uk](mailto:karina.lovell@manchester.ac.uk) or by post at the School of Nursing, Midwifery and Social Work, The University of Manchester, 6.322a University Place, Oxford Road, Manchester, M13 9PL.

**This project has been approved by the School of Nursing, Midwifery and Social Work Research Ethics Committee**

This project is funded by the National Institute for Health Research and is part of Katherine Rogers' Doctoral Research Fellowship.

**NHS**  
**National Institute for  
Health Research**

**(b) Consent form**

Have you read the Information Sheet?	<b>YES/NO</b>
Have you received enough information about the study?	<b>YES/NO</b>
Do you consent for the information that you give to be kept and used for future studies?	<b>YES/NO</b>
Do you understand that you do not have to take part in the study and that if you do take part, you are free to withdraw:- <ul style="list-style-type: none"><li>• at any time</li><li>• without having to give a reason for withdrawing</li><li>• and without you experiencing any disadvantages</li></ul>	<b>YES/NO</b>
Do you agree to take part in this study?	<b>YES/NO</b>

**(c) Background information**

Your gender:

Male ☐ Female ☐

Your age:

18-24 ☐ 25-34 ☐ 35-49 ☐ 50-64 ☐ 65+ ☐

Your hearing status:

Deaf ☐ Hard of hearing ☐

What is your preferred language?

British Sign Language ☐ Sign Supported English ☐ Spoken English ☐

How old were you when you started using British Sign Language?

From birth ☐ 1-3 yrs old ☐ 4-7 yrs old ☐ 8-11 yrs old ☐ 12-16 yrs old ☐  
17-24 yrs old ☐ 25+ yrs old ☐ I have never learnt BSL ☐

Are you the only deaf person in your family?

Yes ☐ No ☐ If not, please tick who else is deaf:

Both of my parents are deaf ☐

One of my parents is deaf ☐

I have sibling(s) who are deaf ☐

Other: \_\_\_\_\_

Do you consider yourself to be part of the Deaf community?

Yes ☐

No ☐

Do you have any other disability? If so, please state what.

No ☐

Yes ☐ Disability: \_\_\_\_\_

Have you ever had any difficulties relating to your mental well-being?

Yes ☐

No ☐

If Yes, please tick:

I have current difficulties relating to my mental well-being ☐

I had difficulties relating to my mental well-being up to 5 years ago ☐

I had difficulties relating to my mental well-being over 5 years ago ☐

Your ethnic background:

White: British ☐

White: Irish ☐

White: Any other white background ☐ (please state) \_\_\_\_\_

Black or Black British: African ☐

Black or Black British: Other black background ☐ (please state) \_\_\_\_\_

Asian or Asian British: Indian ☐

Asian or Asian British: Bangladeshi ☐

Asian or Asian British: Pakistani ☐

Asian or Asian British: Other Asian ☐ (please state) \_\_\_\_\_

Mixed: White and Black African ☐

Mixed: Any Other Mixed Background ☐ (please state) \_\_\_\_\_

Chinese or other Ethnic Groups: Chinese ☐

Other Ethnic Groups: any other ☐ (please state) \_\_\_\_\_



## Appendix 3

### Materials for the pilot study in relation to the validation of the BSL assessments with the Deaf population

#### (a) Information sheet for Deaf people

The University  
of Manchester



#### THE TRANSLATION OF THE PATIENT HEALTH QUESTIONNAIRE (PHQ-9), THE GENERALIZED ANXIETY DISORDER 7-ITEM (GAD7) AND THE WORK AND SOCIAL ADJUSTMENT SCALE (WSAS) INTO BRITISH SIGN LANGUAGE.

##### PARTICIPANT INFORMATION SHEET

###### What is this research project about?

This study is about mental well-being assessments that are commonly used in counselling and other mental health services. They are called the GAD-7, PHQ-9 and WSAS assessments. These measures of well-being were all created for hearing people, but it would be helpful if they could be used with Deaf people too. They have now all been translated into BSL, but we need to test out the translated versions with Deaf people to find out if they are useful or not. Because these assessments were originally created for hearing people, it is possible that some of the questions are designed to get answers from a hearing person's point of view. Therefore, even if the translation is good, some of the answers from the Deaf community might not match what the questions are designed to find out. This study will try to spot things that might be difficult when Deaf people answer questions on well-being. We will think about these things and correct them when we go back to check the BSL versions of some of the questions.

The results of the BSL versions of the assessments will help us to know whether we can be confident in trusting the assessments or not. Having a good BSL assessment could help to identify people's mental health difficulties in the earliest stages, which means they could get appropriate support from mental health care services sooner.

###### If I agree to take part, what is involved?

If you agree to take part, you will be asked to do the BSL version of the assessments online. This will measure your view of your own well-being, as well as asking you to give some brief background information about yourself. The assessment will take about 15-20 minutes to do. You will be asked to sign a consent form online.

It is possible that some people might find some of the questions in the assessments upsetting.

###### Will taking part in this study lead to me getting support from mental health services?

This is an independent research project, and we do not provide mental health services. We are only looking at whether BSL versions of mental well-being assessments can be used with Deaf people. However, if you feel that you need someone to talk to about any issues that might have been raised for you, you can contact a mental health service for Deaf people, such as SignHealth.

However, if there are concerns about your and/or other people's safety after we have seen your response, we will contact your GP, to tell them that you have taken part in this study and that we are worried about your and/or other people's safety. We will not give them any other details, including the exact information from each of your answers. We will give them information about two different support services that might be suitable for you.

V3 15 07 2011

**Who should I contact if I need support related to my mental well-being?**

When you have finished this study, if you feel you would like to talk to someone about issues it has brought up for you, you can email [therapy@signhealth.org.uk](mailto:therapy@signhealth.org.uk) and they will put you in touch with someone who you can talk to confidentially.

**Will I be paid to take part?**

You will receive a £15 voucher for taking part in the study. Any materials that you need will be provided for you, so taking part will not cost you anything.

**Will my information be kept confidential?**

The information about you and your well-being assessment answers will not be passed on to anyone else nor published using your name. All personal information will be destroyed after the research project is finished. After the completion of the research project, the personal information will be stored in secure place for up to 5 years and will be destroyed afterwards.

All data will be kept anonymously – this means that your questionnaire will be given a code number and your name and contact details will be kept separately from your questionnaire.

**What happens if I decide not to take part?**

You do not have to take part in this research study. If you decide not to take part, this will not affect you in any way. If you are getting support from mental health services at the moment, you will still get support even if you not want to be involved in this study.

If you do decide to take part, and then change your mind later, you can pull out at any time without saying why.

**If I decide to take part, what do I do now?**

Please fill in the consent form and sign it, to say that you have agreed to take part.

**If I want more information, who should I contact?**

This information sheet is available in both BSL and English. The BSL version is available on the website: <http://www.manchester.ac.uk/bsl-iapt-translation>. If you would like a CD copy of the BSL version, please let me know.

If you would like more information about this study, you can contact me, Paul Scott by email at [paul.scott-2@manchester.ac.uk](mailto:paul.scott-2@manchester.ac.uk) or by post at:

School of Nursing, Midwifery and Social Work, The University of Manchester, 4.312 University Place, Oxford Road, Manchester, M13 9PL. You can also call me on 0161 306 0260 (minicom).

If you would like to, you can contact one of the research team, Katherine Rogers and/or Professional Alys Young. Katherine Rogers can be emailed at [katherine.rogers@manchester.ac.uk](mailto:katherine.rogers@manchester.ac.uk) or contacted by post at: The School of Nursing, Midwifery and Social Work, The University of Manchester, 4.312 University Place, Oxford Road, Manchester, M13 9PL. Professor Alys Young can be emailed at [alys.young@manchester.ac.uk](mailto:alys.young@manchester.ac.uk) or contacted by post at: The School of Nursing, Midwifery and Social Work, The University of Manchester, 4.327 University Place, Oxford Road, Manchester, M13 9PL.

**This project is funded by the British Society for Mental Health and Deafness.**

V3 15 07 2011



## **(b) Information sheet for professionals**

### **TRANSLATION OF GAD-7, PHQ-9 AND WSAS INTO BRITISH SIGN LANGUAGE**

#### **INFORMATION SHEET FOR PROFESSIONALS**

##### **What is this research project about?**

This study aims to test the reliability and validity of a BSL version of the GAD-7, PHQ-9 and WSAS assessments. These have been translated into BSL but their properties require testing with Deaf people before they could be used in regular clinical practice. The results of the testing of these three assessments will also be compared to those from the BSL version of the CORE-OM questionnaire, which has previously been translated and checked for reliability in a different project.

The GAD-7, PHQ-9 and WSAS were originally created for hearing people. It is possible that some of the questions are designed to get answers from a hearing view of well-being. Therefore, some of the answers from the Deaf community might not match what the questions in these assessments are looking for. This study will try to spot things that might be difficult when Deaf people answer questions on well-being. We will think about these things and correct them when we go back to check the BSL versions of some of the questions.

The results of the BSL version of the assessments will help us to know whether we can be confident in trusting the assessments or not. Having a reliable and validated BSL assessment could help to identify people's mental health difficulties in the earliest stages, which means they could get appropriate support from mental health care services sooner. This also could assist professionals in evaluating their services for Deaf people.

##### **Who can take part?**

People who:

- Are deaf
- Use BSL
- Are aged 16 or above
- Are currently having support from mental health services, or have had this kind of support in the past 12 months

##### **Who cannot take part?**

People who:

- Are not deaf
- Have psychosis
- Have learning disabilities
- Are current inpatients on mental health wards
- Are unable to see signed information on a computer screen well enough to take part

##### **If I agree to assist this project, what is involved?**

If you work with Deaf people who might fit the above criteria, you can pass on information about this project to them. Do not pass their personal details to the research team. If they agree to take part, they will have to contact the researchers directly to indicate their consent and to pass on their contact details. Participants will

V2 15 07 2011



be asked to do the BSL version of the assessments online. This will measure their view of their own well-being, as well as asking them to give some brief background information about themselves. The assessments will take about 15-20 minutes to do. They will receive a £15 voucher for taking part in the study. As a professional who has passed on information about the project, you will not receive the results of any participant, nor be told who has taken part.

**If I want more information, who should I contact?**

This information sheet is available in both BSL and English. The BSL version is available online at: <http://www.manchester.ac.uk/bsl-iapt-translation>. If you would like a CD copy of the BSL version, please let me know.

If you would like more information about this study, you can contact me, Paul Scott by email at [paul.scott-2@manchester.ac.uk](mailto:paul.scott-2@manchester.ac.uk) or by post at:

The School of Nursing, Midwifery and Social Work, The University of Manchester, 4.312 University Place, Oxford Road, Manchester, M13 9PL. You can call me on 0161 306 0260 (minicom).

If you would like to, you can contact one of the research team, Katherine Rogers and/or Professional Alys Young. Katherine Rogers can be emailed at [katherine.rogers@manchester.ac.uk](mailto:katherine.rogers@manchester.ac.uk) or contacted by post at: The School of Nursing, Midwifery and Social Work, The University of Manchester, 4.312 University Place, Oxford Road, Manchester, M13 9PL. Professor Alys Young can be emailed at [alys.young@manchester.ac.uk](mailto:alys.young@manchester.ac.uk) or contacted by post at: The School of Nursing, Midwifery and Social Work, The University of Manchester, 4.327 University Place, Oxford Road, Manchester, M13 9PL.

**This project is funded by the British Society for Mental Health and Deafness.**



**(c) Consent form**

Have you read or watched the information sheet?	<b>YES/NO</b>
Have you received enough information about the study?	<b>YES/NO</b>
Do you give us permission to keep your anonymised data and use it for future studies?	<b>YES/NO</b>
<p>Do you understand that you do not need to take part in the study, and that if you do take part, you are free to withdraw:</p> <ul style="list-style-type: none"> <li>• At any time;</li> <li>• Without having to give a reason why you are withdrawing;</li> <li>• And without you experiencing any disadvantages.</li> </ul>	<b>YES/NO</b>
Do you understand that you do not have to take part just because you might be using mental health services?	<b>YES/NO</b>
Do you agree to take part in this study?	<b>YES/NO</b>
Do you agree for us to contact your GP if there are any concerns about your response?	<b>YES/NO</b>

## (d) Demographic questions

### BACKGROUND QUESTIONNAIRE

#### Demographic information:

1. **Date of birth:** (DD/MM/YYYY)

2. **Gender:** Male ☐ Female ☐

3. **Ethnicity:**

White: British ☐

White: Irish ☐

White: Any other white background ☐ (please state) \_\_\_\_\_

Black or Black British: African ☐

Black or Black British: Other Black background ☐ (please state) \_\_\_\_\_

Asian or Asian British: Indian ☐

Asian or Asian British: Bangladeshi ☐

Asian or Asian British: Pakistani ☐

Asian or Asian British: Other Asian background ☐ (please state) \_\_\_\_\_

Mixed: White and Black African ☐

Mixed: Any other mixed background ☐ (please state) \_\_\_\_\_

Chinese ☐

Other ethnic group ☐ (please state) \_\_\_\_\_

4. **Are you:**

Deaf ☐ Hard of hearing ☐ Hearing ☐

5. **Are you the only deaf person in your family?**

☐ Yes

☐ No

If not, please tick who else is deaf:

Both of my parents are deaf ☐

One of my parents is deaf ☐

I have sibling(s) who are deaf ☐

Other: \_\_\_\_\_

6. **Do you have any disability? If so, please state what.**

No ☐

Yes ☐

Disability: \_\_\_\_\_

7. **Communication:**

a. My preferred means of communication is: [tick one only]

i. BSL ☐

ii. SSE ☐

iii. Speech/lip-reading ☐

b. How do you usually communicate with Deaf people?

i. BSL ☐

ii. SSE ☐

iii. Speech/lip-reading ☐

c. How do you usually communicate with hearing people?

i. BSL ☐

ii. SSE ☐

iii. Speech/lip-reading ☐

d. How old were you when you started using British Sign Language?

From birth ☐ 1-3 yrs old ☐ 4-7 yrs old ☐ 8-11 yrs old ☐ 12-16 yrs old ☐

17-24 yrs old ☐ 25+ yrs old ☐ I have never learnt BSL ☐

8. **Relationship (or not) to the Deaf community and Deaf culture**

a. I am involved in the Deaf community:

Not involved at all ☐ Involved a little ☐ Often involved ☐ Very much involved ☐

b. I feel that I belong in the Deaf community:

Not at all ☐ A little bit ☐ Somewhat ☐ Quite so ☐ Very much so ☐

c. I feel I am culturally Deaf:

Not at all ☐ A little bit ☐ Somewhat ☐ Quite so ☐ Very much so ☐

9. **Mental Health**

Are you currently experiencing mental well-being difficulties?

No ☐

Yes ☐

Are you currently receiving professional support for your difficulties in mental well-being?

I have no support ☐

I have professional support ☐

What kind of service are you receiving professional support from?

Deaf mental health service ☐ hearing service ☐

If you have professional support, how useful are you finding it?

Not useful at all ☐ Not sure ☐ Fairly useful ☐ Very useful ☐

Can you please explain your reason: \_\_\_\_\_

Is the service accessible to you?

No ☐

Yes ☐

Please explain: \_\_\_\_\_

Have you experienced mental well-being difficulties in the past?

Yes ☐

No ☐

If Yes, please tick:

I am having current difficulties relating to my mental well-being ☐

I have had difficulties relating to my mental well-being in the past 5 years ☐

I had difficulties relating to my mental well-being over 5 years ago ☐

If yes, did you receive support relating to mental health/well-being difficulties?

• From hearing services ☐

- From Deaf services ☐
- No, I never received any support ☐

If you did receive support, how useful did you find it?

Not useful at all ☐ Not sure ☐ Fairly useful ☐ Very useful ☐

**Thank you for your time.**

## Appendix 5

### Materials for the study on d/Deaf people's perspectives of mental well-being

#### (a) Information sheet

The University  
of Manchester

MANCHESTER  
1824

#### DEAF WELL-BEING PROJECT

##### What is this research project about?

Past research has shown that deaf people tend to experience mental health difficulties more than hearing people. Most of the understanding of mental health issues in deaf populations usually comes from the results of assessments. Little is known about how deaf people perceive their own well-being. Is it the same or different from how they score on an assessment? Little is also known about how deaf people make sense of their current well-being, and what they consider to be the important things in childhood that have influenced their later mental health outcomes.

This study aims to learn how deaf people's views of their own life events and experiences influence their well-being. We want to understand what Deaf people value in relation to their mental well-being.

##### Am I eligible to take part in this study?

To take part, you will need to be deaf and over 18 years old.

##### If I agree to take part, what is involved?

If you agree to take part, you will be asked to undergo a well-being assessment by completing the Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM) assessment, which is available in BSL as well as English. This will measure your perspective on your own well-being. You will also be asked to complete another assessment, the Trait Emotional Intelligence Questionnaire. This provides information about your personality characteristics. You will also be asked to fill in a questionnaire about important life events and to detail information about yourself such as your education, employment history, family life, social life and health. Altogether, this will take about 30-40 minutes to complete and it can all be done online in either BSL or English. Before taking part, you will be asked to sign a consent form online.

You will then take part in the focus group, to talk about what is valuable to you in relation to your well-being and to find out what mental well-being means to you. This interview will take about 60 minutes and will be video/audio recorded as appropriate. The recordings will be treated as confidential.

##### Will I be paid to take part?

You will be given a £30 voucher for completing the online questionnaire as well as taking part in the interview. Taking part will not cost you anything, as all materials will be provided for you.

##### Will my information be kept confidential?

All information about you and your answers on the wellbeing assessment will not be passed on to anyone else (including the researchers who were involved in the original study), or published without protecting your identity. Your personal information will be destroyed after the whole research project is complete. Your data will be given a code to protect your identity, and the information that identifies you, e.g. your name, will not be included as part of the database.

**What happens if I decided not to take part?**

You do not have to take part in this study. If you decide not to take part, this will not affect you in any way. However, if you do decide to take part, then change your mind later, you are free to withdraw at any time without giving a reason.

**If I decide to take part, what do I do now?**

Please fill in the consent form and sign it. This states that you have agreed to take part.

**If I want more information, who should I contact?**

This information sheet is available in both BSL and English. The BSL version is available on this website: [www.manchester.ac.uk/deafwellbeing/studyfour](http://www.manchester.ac.uk/deafwellbeing/studyfour)



Katherine Rogers

If you would like to contact one of Katie Rogers' supervisors, Professor Alys Young or Professor Karina Lovell, you can do so. Professor Alys Young can be reached at [alys.young@manchester.ac.uk](mailto:alys.young@manchester.ac.uk) or by post at the School of Nursing, Midwifery and Social Work, The University of Manchester, 4.327 University Place, Oxford Road, Manchester, M13 9PL. Professor Karina Lovell can be reached at [karina.lovell@manchester.ac.uk](mailto:karina.lovell@manchester.ac.uk) or by post at the School of Nursing, Midwifery and Social Work, The University of Manchester, 6.322a University Place, Oxford Road, Manchester, M13 9PL.



**National Institute for  
Health Research**



## (b) Consent form

Have you read the information sheet?	YES/NO
Have you received enough information about this study?	YES/NO
Do you give us permission to keep your anonymised data and use it for future studies?	YES/NO
Do you understand that you do not need to take part in the study, and that if you do take part, you are free to withdraw:- <ul style="list-style-type: none"><li>• at any time;</li><li>• without having to give a reason for withdrawing;</li><li>• and without you experiencing any disadvantages?</li></ul>	YES/NO
Do you agree to take part in this study?	YES/NO
Do you agree to take part in the discussion group?	YES/NO
Do you agree to the focus group being video/audio recorded?	YES/NO
Do you agree to being contacted in the future for a possible follow up study?	YES/NO

## (c) Focus group topics

The University  
of Manchester



### Discussion group with deaf people

This discussion group has been created to collect information about your views on mental well-being. We are interested in your views on significant life events; both positive events and difficulties; as well as other things that you feel have influenced your mental well-being. You will also be asked about the challenges that you faced when you were a child, in comparison to those in your adult life.

This group will last for between 60-90 minutes. As it is hard to remember what was said, the conversation will be filmed and then translated into English and written down; we want to make sure that we capture all of the information in detail so that we can look at it again later and think about it. After the study is over, the recordings will be destroyed. The written transcript of the group discussion will not contain any names, and any other information that might identify you will be removed.

---

### Topics to be covered:

In this section we invite your thoughts about what mental well being means to you. We would like you to think about different points in your life when you think your well being has been good, and when you think it has not. Please consider how much you think your childhood has influenced your adult well being.

- Your thoughts and views on your mental well-being since your childhood
- What was the transition from school to adult life like for you?
- The key turning points for you in your life course?
- What are the really helpful things you feel your childhood gave you which have helped you as an adult?
- In your life, what have been the key stresses and pressures for you?
- In your life, what have been the key successes for you?
- Thinking about relationships with others, what are your relationships with other people, including family and friends, like?
- What are your views on mental health in general?

Thank you.

## Appendix 6

### Descriptive statistics of the scores on CORE-OM and TEIQue-SF from the focus groups' participants

For the report of mean and standard deviation, the missing items on the CORE-OM and TEIQue-SF were dealt with by replacing the mean score of the remaining items. Those data with at least 10% of missing items were not included in the analysis, i.e. for the all items of CORE-OM (N = 34) only allow up to 3 missing items to be replaced by the mean score of the rest items. There were 20 (with exception of CORE-OM risk domain which was 19) useable data included in the data analysis. It was not possible to carry out the reliability analysis for BSL and English versions owing to insufficient sample size (e.g. for all items CORE-OM, n = 5 valid cases for BSL version, and n = 13 valid cases for English version). Table 1 show the mean and standard deviation as well as internal reliability (with Cronbach's alpha value) for Global Trait TEIQue-SF, all items in CORE-OM, each domain of CORE-OM as well as non-risk items in CORE-OM.

	Global Trait TEIQue- SF	CORE-OM All items	CORE-OM Well-Being	CORE-OM Problems	CORE-OM Functioning	CORE- OM Risk	CORE-OM Non-risk items
Means (SDs)	5.15 (0.60)	0.71 (0.38)	0.79 (0.71)	0.80 (0.52)	0.91 (0.51)	0.11 (0.19)	0.86 (0.44)

Table 1. Mean and standard deviations of the TEIQue-SF score and the scores of CORE-OM including each of its domains.

Although the sample size for this study is small, the interpretation should be taken with caution. From the results of the mean score of the TEIQue-SF, which is 5.15, it show that it is a similar mean score for the men and women as outlined in the study of Cooper and Petrides (2010). The mean score for all items CORE-OM, each of four domains as well as non-risk items is less than 1 however the standard deviation is wide spread such as standard deviation for the well-being domain is 0.71, which indicates that some participants have more than 1 (indicating poorer well-being).

## Appendix 7

### Ethical approval letters

The University  
of Manchester



School of Nursing, Midwifery and Social Work  
The University of Manchester  
University Place  
Oxford Road  
Manchester M13 9PL  
+44(0)161 306 0260  
[www.manchester.ac.uk](http://www.manchester.ac.uk)

Our Ref: HS/MH

Ms K Rogers  
Research Fellow  
School of Nursing, Midwifery & Social Work  
Jean McFarlane Building  
University of Manchester  
Oxford Road  
Manchester  
M13 9PL

26 May 2010

*By email and internal post.*

Re: Mental Well-Being Outcomes for Deaf Young People: A 22 year follow up study of the mental well-being of a cohort of deaf young people previously screened for the likelihood of having a psychiatric disorder.

Proposal Number: 10/1040/NMSW

Dear Ms Rogers,

Thank you for the clarifications and amendments to the above study as requested by the Research Ethics Committee.

I am of the opinion that no major concerns or objections are evident of an ethical nature. Therefore on behalf of the Committee and taking Chair's Action, I am happy to grant full ethical approval.

During the progress of the study please inform the Committee of any changes or amendments that may be necessary.

On completion of the study would you please provide the Committee with a "Completion of Study Report".

In order to arrange University Insurance Cover please forward the completed Insurance Form (enclosed) along with your Research Proposal and a copy of this letter to the Purchasing Office at the address printed on the form.

Best wishes for your study.

Yours sincerely

Howard Shilton  
Chair: School Research Ethics Committee

Enc.

cc. A. Young  
K. Lovell





**National Research Ethics Service**  
NRES Committee Yorkshire & The Humber - Leeds West

First Floor  
Millside  
Mill Pond Lane  
Leeds  
LS6 4RA

Tel: 0113 3050122  
Fax:

27 July 2011

Professor Alys Young  
Professor of Social Work Education and Research  
University of Manchester  
Jean McFarlane Building  
Oxford Road  
Manchester  
M13 9PL

Dear Professor Young

**Study title:** Validation of British Sign Language versions of the Generalised Anxiety Disorder Assessment (GAD7), the Patient Health Questionnaire (PHQ-9) and the Work and Social Adjustment Scale (WSAS)  
**REC reference:** 11/YH/0180  
**Amendment number:** 1  
**Amendment date:** 18 July 2011

The above amendment was reviewed by the Sub-Committee in correspondence.

**Ethical opinion**

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

**Approved documents**

The documents reviewed and approved at the meeting were:

Document	Version	Date
receipt letter for voucher	1	15 July 2011
Advertisement	2	15 July 2011
Participant Consent Form	4	15 July 2011
Participant Information Sheet: for professionals	2	15 July 2011
Participant Information Sheet	3	15 July 2011
Protocol	4	15 July 2011
Notice of Substantial Amendment (non-CTIMPs)		18 July 2011

**Membership of the Committee**

This Research Ethics Committee is an advisory committee to the Yorkshire and The Humber Strategic Health Authority  
*The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England*

The members of the Committee who took part in the review are listed on the attached sheet.

**R&D approval**

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

11/YH/0180:

Please quote this number on all correspondence

Yours sincerely



*N* **Dr Rhona Bratt**  
**Chair**

E-mail: Elaine.hazell@nhs.net

*Enclosures:* *List of names and professions of members who took part in the review*

*Copy to:* *Ms Lynne MacRae, University of Manchester*  
*Ms Rachel Georgiou, ReGroup c/o Research and Development*