Working with Deaf People – a Handbook for Healthcare Professionals

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GLOSSARY

ABI	Auditory brainstem implant, one of the treatment options for clients with NF2
A + E	Accident and Emergency department in a hospital
ASL	American Sign Language
BDA	British Deaf Association
BSL	British Sign Language
CHARGE	A genetic condition which causes deafblindness as well as heart and development problems
CRS	Congenital rubella syndrome, a cause of deafblindness
DDA	Disability Discrimination Act, legislation in the UK
deaf	Could be used generically to describe all people with any level or perception of deafness or could be used by those who are profoundly deaf. Could be used by deaf people who use speech and/or sign language

Deaf	Used by deaf people who use sign language as their first or preferred language
Deaf community	Group of people who are culturally Deaf, who use sign language as their first or preferred language, often have a positive identity and pride attached to deafness
Deaf culture	See Deaf community
Deaf World	See Deaf community
Deafened	Used by people who have lost their hearing. Often refers to a profound level of deafness. Deafened people align themselves with the Hearing World and usually use speech rather than sign language
ENT	Hospital clinic which involves the Ear, Nose and Throat
Ependymoma	Cerebral tumour associated with NF2
Glioma	General term used for tumours of the nervous system, but can also refer to tumours arising from non-nervous cells but still in the nervous system. Often associated with NF2
GP	Family doctor
Hard of hearing	Someone with hearing loss who uses spoken language to communicate and usually has a mild-moderate loss. May be used by people with elderly-onset hearing loss

Hearing World	Mainstream hearing society. Used when comparisons are being made to the Deaf World
Meningioma	A tumour which can occur in the brain or spinal chord, often associated with NF2
NF2	Neurofibromatosis Type 2, a genetic condition that causes deafness due to tumours on the auditory nerve
NHS	National Health Service in the UK
NRCPD	National Registers of Communication Professionals Working with Deaf and Deafblind People; a group that interpreters in England, Wales and Northern Ireland should be registered with
NSL	National Sign Language (e.g. British Sign Language), with different grammar and sentence construction to spoken language
RNID	Royal National Institute for Deaf and Hard of Hearing People, UK charity
RP	Retinitis pigmentosa, visual impairment associated with Usher syndrome
Schwannoma	Benign tumour of the nerve cells, usually found in people with NF2
SSE	Sign Supported English, direct translation of spoken English

SSSL	Sign Supported Spoken Language, direct translation of spoken language
Vestibular	As in 'vestibular Schwannoma' – benign tumour on the nerve in the brain which carries information about balance and movement from the inner ear to the brain
WFD	World Federation of the Deaf

FOREWORD

This book arose out of the activities of a working party on the 'Psychosocial aspects of genetic hearing impairment', which was part of the European Union's GENDEAF project. The main aim of the group was to provide an interface between the 'hard science' of molecular and clinical geneticists on one hand and interested professionals, non-governmental organisations and the general public, on the other.

The main findings of the working party have been published in two books, '*The Impact of Genetic Hearing Impairment*' and '*The Effects of Genetic Hearing Impairment in the Family*', edited by myself and Lesley Jones (Stephens and Jones 2005, 2006). The first of these books was essentially a literature review which highlighted how little was actually known about the psychosocial aspects of genetic hearing loss and deafness. In the second, we published a number of studies which attempted to address this deficit. In addition, it also included further studies on the communication of genetic findings with members of the Deaf community, as well as with a number of different ethnic groups. However, it also highlighted the amount of further work which was needed on these topics.

The present book represents an attempt to draw together the information published in this field in a way relevant to those working with people with a range of hearing limitations. This has the aim of facilitating the lives of those with such genetic disorders by improving the understanding by professionals, in a range of medical and related disciplines, who work with them.

The three present authors have been major contributors to studies in this field. Anna Middleton has been concerned particularly with genetic understanding, communication and elucidating the views of different communities from the hard of hearing to the Deaf. Kerstin Möller has worked on many different aspects of the problems of people with deafblindness as well as with the World Health Organization's 'International Classification of Functioning, Disabilities and Health (ICF)'. Wanda Neary has written extensively on neurofibromatosis 2 (NF2), a genetic disorder resulting in total deafness as well as a number of other neurological impairments.

In this book they clearly summarise the most important elements of their knowledge in a way understandable to people with genetic hearing impairments and to the professionals who they may encounter when seeking help.

Professor Dafydd Stephens
Honorary Professor of Audiological Medicine
School of Medicine, Cardiff University, UK

PRE-PUBLICATION PEER REVIEWS

'This is a brilliant book that every health professional should read as part of their ongoing training. It is amazingly readable and gives insight into what it is like to be deaf, or deafblind. I've worked for 17 years with Deaf people and for the first time health professionals have a book that gives them sensible practical advice on working with deaf, Deaf and deafblind people.'.

Steve Powell
CEO, SignHealth, UK

'This book presents some excellent material in a wide and complex field, written with such clarity that it will be useful to almost any reader whatever their background. It will be of particular value to professionals whose work brings them into contact with people who have hearing loss, enhancing the effectiveness of their work through ensuring that they can relate well to their clients/patients. However, it will also be of interest to readers who themselves live with hearing loss, helping them understand the perspectives of the professionals they encounter.'

Dr Lorraine Gailey
CEO, Hearing Concern LINK, UK

'This is a must-read book for all health professionals. As health provision becomes increasingly the responsibility of individual patients making choices about their own care and treatment, professionals working in health not only need medical expertise but also skills in communication and information giving. For deaf and hard of hearing patients, this requires skills not often used by the average health professional; this book guides you through the maze of how to understand and communicate with a wide range of deaf and hard of hearing patients.

Well worth keeping for those times when you may be confronted by a patient that requires different communication tactics that you have never used before, and also for patients from other countries as you learn some of the useful tips of interacting with patients that communicate differently.'

Paul Redfern
Consultant: Disability & Diversity, UK

'Healthcare providers in a majority hearing/sighted society, the majority of who are themselves hearing and sighted, are likely to be unfamiliar with best practice when communicating with deaf or deafblind people, unless they are working in a speciality such as audiology. This book is a handy distillation of practical improvements that can be made in a consultation setting, many of which can be achieved by increasing one's self-awareness of the perspective of the person attending. The editor, Anna Middleton, has a professional background as a genetic

counsellor and therefore a good understanding, both clinically and from a research perspective, of how clinical genetics is a particularly sensitive area of medicine for many d/Deaf people. As a result, this book may be of particular interest to clinical geneticists and genetic counsellors.'

Rachel Belk
Registered Genetic Counsellor
St Mary's Hospital, Manchester, UK

'This is an extremely useful manual for health professionals who interact with deaf and deafblind people in a clinical setting. There are sections outlining different types of hearing loss and deafness, various methods of communications and types of communicators preferred by deaf people, as well as the historical context of genetics and eugenics with respect to deafness. For those who have little experience of meeting deaf people, the case studies emphasise common pitfalls in communication, and I will be recommending the book to trainees who are new to the field.'

Dr Maria Bitner-Glindzicz
Reader in Clinical and Molecular Genetics,
UCL Institute of Child Health, and
Great Ormond Street Hospital, London, UK

'This is a new, unusual and very exciting book aimed at all health professionals. The book can serve both professionals in training but also as a guideline into a

world unknown for many of us. The book is clearly structured and has a holistic approach including many components of ICF. I have worked with patients with deafblindness and NF2 for over 23 years, and I realise now that this is the first book which has addressed the basic knowledge of how to interact with people who are Deaf or Deafblind. I sincerely recommend this book.'

Prof Claes Möller
Head of Department of Audiology and Medical
Disability Research
University Hospital Örebro, Sweden

PREFACE

Anna Middleton

Use of the book

This book offers practical guidance for any health professional working with clients who have deafness or hearing loss. Such clients include those who are deaf, hard of hearing, hearing impaired, deafened, culturally Deaf, deafblind or have deafness due to neurofibromatosis type 2 (NF2).

> The work considers general communication issues relevant to both deaf sign language users and hard of hearing speech users. Specific attention is also given to the particular difficulties that sign language users face when interacting with health services.

The World Federation of the Deaf estimates there could be 70 million people with deafness across the world (WFD 2009). In the UK alone there are thought to be approximately 9 million people affected by hearing loss or deafness, which equates to 1 in 7 of the population (RNID 2008). This means that health professionals working regularly with the public will more

than likely meet clients with some level of hearing loss on a daily basis.

This book is intended for use as a general reference manual to help health professionals converse effectively, for example, when a deafblind client attends an Accident and Emergency department, a Deaf client who uses sign language attends a GP surgery or a person with NF2 attends an ENT clinic. Practical advice is offered on how to prepare for the consultation, what issues need to be considered with respect to language and communication, and what cultural attitudes (relevant in a Deaf sense) may impact on the consultation.

> The intention is to provide practical information and a code of 'best practice' to help health professionals unfamiliar with deafness and hearing loss to interact effectively with others who have a variety of needs linked to deafness.

The book builds on work already published by the authors elsewhere (Middleton 2006, Neary, Stephens et al. 2006, Möller 2008). Whilst there is specific reference to working in the UK and also in Sweden, we hope that the reader will be able to apply the recommendations to their own work setting, whatever country they are from.

In September 2008 a national workshop was organised by the editor in Cardiff, UK entitled: 'Deafness and

genetics: what do deaf people want?' (Middleton, Emery et al. 2008). This offered a forum for deaf and hard of hearing people from the UK to meet and mix with genetics professionals, other health professionals and academics working in the deafness field. Discussion took place around various issues surrounding clinical service provision for individuals with hearing loss and deafness in the UK. One of the outcomes of this meeting was to validate a set of recommendations for health professionals that are given in this book.

This text is relevant to all health professionals, irrespective of their discipline or specialist area of work. It is also used as a platform for providing specific information relevant to health professionals working in Clinical Genetics departments.

Currently, genetic counselling is a service that is rarely accessed by deaf and hard of hearing clients and therefore there is a general unfamiliarity amongst geneticists and genetic counsellors about how to communicate effectively with this client group. There are specific historical sensitivities surrounding eugenics and deafness which make it particularly important that communication problems are addressed. This is relevant not only to health professionals working in Clinical Genetics but also to any other health professional who might make a referral for genetic counselling.

We do not include too much detail about diagnostic or prognostic clinical information in relation to deafness other than a brief overview, as the focus of this text is on communication. We have chosen to focus on three clinical areas only – non-syndromal deafness (i.e. deafness on its own), deafness as part of neurofibromatosis Type 2 and deafblindness. The reason these three conditions have been chosen is because they can be used as clear examples of some of the different ways that deafness can manifest and the different styles of communication that are necessary for health professionals to adopt. Many of the communication recommendations that we offer may be relevant for clients with other types of syndromal deafness.

The World Health Organization has adopted the International Classification of Functioning, Disability and Health (ICF) for classifying deafness. Here, there are two terms which are used:

- Hearing impairment refers to complete or partial loss of the ability to hear from one or both ears. The level of impairment can be mild, moderate, severe or profound
- Deafness refers to the complete loss of ability to hear from one or both ears

(World Health Organization 2001, 2006)

However, for ease of language and also to fit in with the terms deaf and hard of hearing people themselves use to

describe their own deafness or hearing loss, we use the term 'deaf' or 'deaf and hard of hearing' rather than 'hearing impaired' through the majority of this book. We acknowledge that this approach may not be considered 'technically accurate' in terms of the ICF classifications. However, particularly in the UK, deaf and hard of hearing people themselves (as opposed to academics and health professionals who aim to implement the ICF definitions) are generally moving away from using the term 'hearing impaired'.

We use the term 'deaf' as a general descriptor to refer to people with any audiological level of deafness or hearing loss, any perception of deafness and who may use either or both signed language and spoken language. Other texts use the phrases 'deaf/hard of hearing', 'hearing impaired', 'deaf/deafened/hoh', 'D/deaf' or 'people with a hearing loss' as general descriptors and our term 'deaf' should be interpreted as including all of these groups.

Therefore, in this book, the word 'deaf' is used inclusively and covers people who refer to themselves as Deaf, hard of hearing or deafened.

However, we also use the term 'hard of hearing' when we want to refer exclusively to speech users.

The term 'hard of hearing' is also used in a generic manner to include people who call themselves 'deafened'.

We also use the collective term National Sign Language to refer to British Sign Language, American Sign Language and any other indigenous signed language used by deaf people. In contrast, the term Signed Supported Spoken Language (SSSL) refers to the literal translation of spoken language, such as Signed Supported English (SSE) in the UK. We recognise that different countries have their own equivalents to these terms.

Anti-discrimination legislation

There is legislation in different countries which aims to prevent discrimination against deaf people. In the UK, the Disability Discrimination Act (DDA) (1995) prevents deaf people from being discriminated against by any service providers, including the Health Service and hospitals (RNID 2004a). The Act expects deaf and hard of hearing people to be treated equally to their hearing counterparts. This means that every healthcare setting has a legal responsibility to ensure that communication issues are addressed and an appropriate clinical environment is provided for deaf and hard of hearing clients.

The Royal National Institute for Deaf People (RNID) in the UK has a charter called 'Louder than Words' which provides guidance for organisations to help them meet the requirements of the DDA (see www.rnid.org.uk). This offers organisations advice on how to improve their access for deaf people, from looking at door entry, reception

areas, lighting, seating, policies, recruitment practices and so on. The Charter is recognised by the deaf and hard of hearing communities as a kite-mark of best practice and enables and supports organisations in complying with the DDA. The British Deaf Association (BDA), which is also called the SignCommunity, also have a BSL Charter, which aims to promote the recognition of sign language (www.bda.org.uk).

An example of potential discrimination in the clinic setting is not knowing how to take a call via a telephone relay service that enables communication through an operator (e.g. Text Relay in the UK). Another is omitting to organise an interpreter for a medical consultation and expecting the deaf client simply to lip-read the doctor; this too would be in breach of the legislation. A final example could be that of a deaf client attending a consultation accompanied by a Hearing Dog for Deaf People, but where the dog was not allowed into the clinic.

Within the UK, the law states in the Disability Discrimination Act (1995) that organisations and service providers should be proactive in making their service 'deaf friendly' rather than reactive and only responding when they have their first deaf or hard of hearing client. This book aims to offer guidance to help health service planners comply with the anti-discrimination legislation.

Work by hearing people 'on' deaf people

The vast majority of research done on deafness throughout history has been by hearing people. Many researchers, academics and health professionals have the preconceived idea that the 'poor deaf person' needs help and support to overcome their 'disability'. Nowadays it is more usual for deaf and hard of hearing people themselves to lead, organise and create their own research on deafness. There has also been a more recent insistence from funders of research to involve the consumer group that the research is aimed at, in the delivery, construction and dissemination of the findings. The editor's own research on deafness has involved a multi-skilled research team, including health professionals, academics and lay people who are deaf or hard of hearing and who use speech and/or signed language.

We are very mindful of the context within which this is written and have created this work with an open mind and an open perspective. Whilst we all happen, by coincidence, to be hearing we have worked extensively with deaf, hard of hearing and deafblind families and individuals over a number of years. We have deaf, hard of hearing and deafblind friends and colleagues; we have endeavoured to ensure that this work is relevant, appropriate and most of all not inadvertently patronising.

Acknowledgements

There have been several people and also texts that have been very influential in guiding practice and influencing

research that was completed for this book. In 1995, Jamie Israel, a genetic counsellor from Gallaudet University, Washington DC, wrote the first manual for genetic counsellors on working with deaf people and families (Israel 1995). Despite its age, this work is still very current and offers a thorough account, together with practical advice on how to best serve deaf clients. We hope we have been able to build on this seminal text. Also recognition goes to Kathleen Arnos, Gallaudet University, who was one of the first people to publish work on how genetics services for deaf people should be structured (Arnos, Israel et al. 1991, 1992).

Particular recognition goes to Dafydd Stephens from the School of Medicine, Cardiff University, the leader of the GENDEAF European Union Thematic Network Project (2001–2005) subgroup on psychosocial aspects of genetics and deafness. Dafydd had the vision and expertise to bring together health professionals, researchers and academics interested in psychosocial issues and deafness. He was particularly influential in enabling this book to be written.

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Maria Bitner-Glindzicz, Claes Möller and Paul Redfern for reviewing the content of this book prior to publication.

The authors

The authors all belonged to the GENDEAF European Union Thematic Network Project (2001–2005), and it is through this that the idea for the book was developed.

Work done by the editor as part of a Health Services Research, Department of Health funded research project (2005–2009) entitled 'deaf individuals' understanding and perception of genetics and their needs from a genetic counselling service' has been very influential in guiding the content of this book. Many of the recommendations for deaf clients are based on research evidence gathered in the Department of Health project.

Anna Middleton is a Consultant Research Genetic Counsellor and Registered Genetic Counsellor working at the School of Medicine, Cardiff University. She has been working as a genetic counsellor since 1995 and completed her PhD in 1999; this involved gathering the attitudes of deaf and hard of hearing people towards prenatal testing for inherited deafness. Anna has written extensively on the attitudes that deaf and hard of hearing people have towards various issues surrounding genetics. The years 2005–2009 were spent running a national research project which involved interviewing Deaf people in sign language to gather their views about genetics, genetic counselling,

access to the health service and communication issues. This research also ascertained attitudes towards using health services, collected via a specially designed written questionnaire for deaf, deafened and hard of hearing people. Anna has worked clinically within the NHS as a general genetic counsellor at St James's Hospital in Leeds and as a specialist cancer genetic counsellor at Addenbrooke's Hospital in Cambridge. Between the years 2004 and 2010 Anna was Vice-Chair of the Genetic Counsellor Registration Board in the UK and in this role has written policy and guidelines for the UK genetic counselling profession. Anna has worked for Homerton College at the University of Cambridge as an associate lecturer on genetic counselling and has also taught on the two UK MSc Genetic Counselling courses in Manchester and Cardiff. Since 1999 she has also been the UK representative on the editorial board of the Journal of Genetic Counselling.

Wanda Neary is a Consultant Community Paediatrician (Paediatric Audiology), working in Warrington Community Services Unit. She has been involved in collaborative research with the Department of Otolaryngology Head and Neck Surgery, Manchester Royal Infirmary, the Department of Medical Genetics, St Mary's Hospital Manchester, and the Welsh Hearing Institute, Cardiff. Her special research interest from 1989 has been in the field of neurofibromatosis Type 2 (NF2).

Kerstin Möller has an MSc in Management of Health and Welfare Organisations, and a PhD in Disability Research.

She has conducted public investigations of services for people with deafblindness on behalf of the Swedish Ministry of Social Affairs and the Swedish National Agency for Education. She has done consultancy for the Nordic Staff Training Centre for Deafblind Services, the Swedish Resource Centre for Matters regarding Deafblindness and the Swedish Association of Rare Disorders. She teaches students, professionals and people with deafblindness and their next of kin in deafblindness know-how. She works as a supervisor at Research & Development in Sörmland and is associated to the Swedish Institute of Disability Research including HEAD and Audiological Research Centre at Örebro University Hospital.