



City Research Online

City, University of London Institutional Repository

Citation: Hilari, K. (2011). Communication disability across the lifespan: the importance of documenting and sharing knowledge about wider impacts. In: Hilari, K. and Botting, N. (Eds.), The impact of communication disability across the lifespan. (pp. 1-5). London: J&R Press.

This is the published version of the paper.

This version of the publication may differ from the final published version.

Permanent repository link: <http://openaccess.city.ac.uk/5024/>

Link to published version:

Copyright and reuse: City Research Online aims to make research outputs of City, University of London available to a wider audience. Copyright and Moral Rights remain with the author(s) and/or copyright holders. URLs from City Research Online may be freely distributed and linked to.

City Research Online:

<http://openaccess.city.ac.uk/>

publications@city.ac.uk

1 Communication Disability Across the Lifespan

The Importance of Documenting and Sharing Knowledge about Wider Impacts

Nicola Botting and Katerina Hilari
City University London, UK

Communication disorders are wide-ranging and extend across the entire lifespan. Yet research into speech and language impairment is relatively young, with the literature focusing primarily on the nature of the impairment and interventions to address it. As we discover more about speech-language disorder, the more important it becomes to investigate and report the impact of communication disorders on people's lives. Understanding this impact is the only way for clinicians to make their interventions relevant to their clients' lives and to incorporate their clients' perspective into clinical decision-making.

The World Health Organization (WHO) has developed the *International Classification of Functioning, Disability and Health (ICF; WHO, 2001)*, which addresses the notion of impact in a number of different areas. A key area is that entitled 'activity and participation'. Within this category, among other possible impacts the ICF lists communication, and others that are affected by communication such as learning, interpersonal interactions and relationships, community, social, and civic life and domestic life.

This impact on life caused by communication impairment is the focus of the current text. We use 'impact' to encompass the ideas of quality of life (QoL) – a term which has gained ground in recent literature, particularly for adult populations, but without some of the conceptual difficulties associated with this specific phrase. In 1995, Cummins reported that there were over 500 different definitions of the term 'QoL'. Thus, we feel that 'impact' better describes the wide range of different underlying causes, associations and effects of communication disability. In adult populations alone, a variety of different challenges arise from differing sources. From the effects of laryngectomy (Lee, Chapter 15) and voice disorders (Oates, Chapter 14), through motor speech

disorder (Miller & Hartelius, Chapter 11) and acquired language impairment from traumatic brain injury (McDonald & Togher, Chapter 13) and stroke (Hilari, Chapter 9), to learning disabilities (Bunning & Buell, Chapter 12) and dementia (Bayles, Mahendra and Hopper, Chapter 10), communication is often one of the most impacting skills affected. It results in difficulties with employment; changes in family dynamics and relations; loss of friends; and a decline in social activities, emotional wellbeing and QoL. For adults there is a sense of loss for the skills and lifestyle that the individuals once enjoyed. Clients often feel isolated and under-resourced, as these chapters superbly indicate.

In contrast, in the developmental communication literature, the term 'QoL' is seldom used (notable exceptions are Markham, van Laar, Gibbard & Dean, 2009), but there has been much interest in the emotional and social challenges that associate with language and communication problems. In these developing populations, the challenges may be both similar and different. For example, children growing up with communication needs have never experienced life any differently, which brings the advantage of not 'losing' something, but also the disadvantage of having had more limited opportunity to build up strong communication experience, knowledge and support systems. In actual fact, little or no research has been conducted exploring the overlap of impact between these two groups. Within childhood disorders, it is also less clear the extent to which wider effects of communication disability are part of the neurological aetiology, or a psychosocial outcome of living with poor communicative skills. Developmental communication difficulties can also take many forms, from speech (Dodd, Chapter 4) and stuttering (Onslow & Langevin, Chapter 6), through young people with primary and persistent language impairments (Law, Chapter 2), and autism (Pasco & Slonims, Chapter 3), to those children with concomitant deafness (Herman & Morgan, Chapter 7) or learning disability (Harding, Chapter 5). For young people with communication needs, the overlap between disorders is also much less distinct, with many children receiving several diagnoses or experiencing concurrent difficulties. Rather than representing a medical truth, we need to view developmental diagnostic categories (even the quite wide ones presented in this volume) as dynamic and fluid constructs which best serve to describe and support individuals at a particular point in time.

This book is aimed at professionals, students, parents and academics who wish to discover more about the wide impact on life that communication impairments have. It was put together to address the lack of current texts

focusing on the *impact* of communication difficulties rather than the nature of the disorders themselves.

Structure of the book

The volume is split into two halves: chapters dedicated to developmental disorders, and those discussing adult issues. Of course, the children and young people discussed grow up, and adult outcomes for those impairments are included in the first half (with the exception of adults with learning disabilities). We have asked authors to give relatively brief outlines of the disorders and populations themselves – there are numerous books outlining the nature of these, and in this volume they only serve as a background to further reading or clinical experience. Furthermore, although many of the impact themes are common in different chapters, we did not impose a set format for each client group in order that experts in the field could present and discuss the areas of impact most relevant to that particular communication difficulty. We have also decided not to include an index, since many of the themes of impact appear repeatedly throughout and across each chapter, and many different terms may be used to discuss the same aspect of impact. Instead, the table of contents gives each chapter's themes in more detail than usual. We felt that this was the most effective route for readers to identify the information they required.

The voice of people with communication disabilities

One aspect of reporting which is conspicuous in its absence from the literature is text written from the client's perspective or by those experiencing communication difficulties. This is not wholly surprising in that the medium of most dissemination is verbal and this makes personal narratives from people with communication impairments difficult to present in a straightforward way. We believe that this volume is the first academic text to offer people with communication disabilities the opportunity to share their experiences. Two chapters offer unique personal insights into the lives of young people with communication difficulties (Joffe, Beverly & Scott, Chapter 8) and the impact of aphasia on adults (Cruice, Cocks, Lancashire, Midgley, Morgan, Morgan & Morgan, Chapter 16). The first of these chapters is accompanied by expressive artwork by two of the young people to help convey their experiences.

Clinical implications

It is vitally important that, as well as problem-solving around the communication impairment itself, researchers and clinicians identify key areas of impact and work to manage and alleviate the challenges that arise. Educational needs is a key theme arising in the chapters on young people. McLeod and McKinnon (2010) conducted a large-scale cohort study (n=4845) examining support for groups of young people with educational needs. Importantly, of the nine areas of educational need identified, communication impairment was the strongest predictor of the teacher requesting additional classroom support.

For adults with communication disabilities, often physical or medical needs are the focus of attention. In their review of controlled trials with this population, Xiong, Bunning, Horton and Hartley (in press) report that 53% of outcome measures relate to the ICF category of 'bodily functions', compared with 36% addressing 'activity and participation'. For the clients discussed throughout this book, the impact of communication disability may require resources not only for educational, medical and health-related issues, but also support for the more subtle social and emotional needs that they experience. This is essential, as such needs (e.g. low mood and depression) can affect the client response to rehabilitation and their long-term outcomes. Although a substantial body of evidence is emerging on the complex impact of communication impairment in people's lives, much less attention has been devoted in the literature on what interventions best address this impact. The chapters in this book all include sections on the clinical implications, which aim to bring together this evidence for practising clinicians. They also identify gaps in our knowledge which highlight what future research should focus on.

It is important to note, whilst reading this volume, that many people with communication disorders or language needs would not describe themselves as disabled and would also identify positive impacts of the communication disorders on their lives. For example, people with aphasia sometimes mention having more time to spend with family and having a better perspective of what really matters in life; many young people with language impairment experience little or no impact on their everyday lives. Nevertheless, we hope the chapters on all the populations featured here are balanced and insightful, and give a useful window into the types of impact that different or limited communication needs can create.

References

- Cummins, R.A. (1995) Assessing quality of life. In R.I. Brown (Ed.) *Quality of Life for Handicapped People*. London: Chapman & Hall.
- Markham, C., van Laar, D., Gibbard, D. and Dean, T. (2009) Children with speech, language and communication needs: Their perceptions of their quality of life. *International Journal of Language and Communication Disorders*, 44, 748–768.
- McLeod, S. and McKinnon, D.H. (2010) Support required for primary and secondary students with communication disorders and/or other learning needs. *Child Language Teaching and Therapy*, 26(2), 123–143.
- World Health Organization (WHO) (2001) *International Classification of Functioning, Disability and Health (ICF)*. Geneva: World Health Organization.
- Xiong, T., Bunning, K., Horton, S. and Hartley, S. (in press) Assessing and comparing the outcome measures for the rehabilitation of adults with communication disorders in randomised controlled trials: An International Classification of Functioning, Disability and Health approach. *Disability and Rehabilitation*, DOI:10.3109/09638288.2011.568666