Setting the scene

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**Key points**

- This book is made up of a set of essays.
- About half of the authors have aphasia. The others don’t.
- The authors write from many different points of view. They are counsellors, carers, teachers, therapists, linguists and people studying disability issues.
- We asked people to write about things they think are important but which don’t usually get written about.
- We also wanted people to reflect: to think about their work and their lives in the context of aphasia.
- The book allows people to write in ways that are unusual or different.
- We wanted to give people with aphasia an opportunity to write about it, from the inside. Often, they don’t get the chance to do this.
- We hope the book will appeal to lots of different people, including some people who are personally affected by aphasia. There are some good ideas here. Some chapters are easier to read than others.
- Others who might read the book include therapists and rehabilitation workers, and people interested in disability, language and writing.
- The authors have written about a number of different things with relation to aphasia: poetry, the Internet, identity or sense of self, community, the difficulties faced by people with aphasia, relationships in therapy, and getting involved.
Aphasia inside out

- Although these topics are all different, there are a number of themes that run through the chapters:
  1. Barriers, or things that get in the way, for people with aphasia.
  2. The effect of aphasia on one’s sense of self or identity.
  3. New ways of thinking and doing things.
  4. Celebrating aphasia.
- We think it’s important that people know more about aphasia, particularly those in the disability movement. We hope Aphasia Inside Out helps this to happen.

This book contains a selection of reflective essays about aphasia (a communication impairment that commonly follows stroke affecting one’s ability to use and understand spoken and written language). Half of the contributors to the book have personal experience of aphasia. Authors with and without aphasia write from the perspective of different backgrounds and disciplines including disability studies, linguistics, counselling, teaching, psychotherapy and aphasia therapy.

Aphasia Inside Out provides a platform for a group of people who hitherto have had little access to the mainstream literature concerning the relationship between disability and society. They have been silent, but this is not because they have nothing to say. Nor do they lack personal or professional expertise in discussions of disability and difference. So what is it that silences their voice?

It could be suggested that their silence is due to the nature of their impairment: aphasia brings with it a difficulty in pinning down and translating thoughts into words, trouble following densely written texts, and prevents engagement in the rapid cut and thrust of debate. But to focus on the impairment would be to overlook the role others (including disabled people) play, in either supporting or sidelining the contributions of those with communication impairments such as aphasia.

People with aphasia rarely get the opportunity to put forward their ideas, even within the ‘my story’ genre of lay accounts. In this volume we value the reflections of authors who have an inside knowledge of aphasia. We hope that this book will contribute to theory, philosophy and practice concerning aphasia. As such it should be stimulating and challenging to those who are affected by or concerned with aphasia, either personally or in their work.

The premise of the book is to provide an opportunity for writers to explore aspects of aphasia that are usually passed over by prevailing academic discourses. Accordingly the topics addressed in these essays are diverse and often unconventional: poetry, community, time, engagement, the Internet, confidence, counselling, identity, creativity and so on. The intention behind inviting these contributions was to offer the authors...
liberation from the tightly scientific or pragmatic focus of their respective
disciplines, to encourage reflection and subjectivity, to foster different,
collaborative and non-traditional styles of writing, and, most importantly,
to provide a platform for the work of those who arguably have the most
profound understanding of communication impairment.

For readers from the field of disability studies, *Aphasia Inside Out*
presents some challenging insights on the nature of disabling barriers,
identity issues, and the presence and impact of the impairment itself. For
lay readers, including some with aphasia, many chapters offer shared
experience, affirmation and ideas about recovery. Those concerned with
therapy and rehabilitation will find new ideas about practice, roles and
relationships. The book calls for reflection and self-pan. One and offers
some practical and creative ideas. Linguists and philosophers will gain
insights into the relationship between language and identity, and those
interested in creative writing will find the diverse styles of the chapters,
and the ways in which they have been constructed, intriguing.

*Aphasia Inside Out* is grounded in the social model of disability. This
model represents disability as a product of externally imposed dis-
advantages and social restrictions, rather than as an inevitable result of
the impairment itself (Oliver and Barnes 1998). A number of the chapters
are concerned with identifying and discussing some of the more subtle
disabling barriers faced by people with aphasia.

Our book raises and addresses the controversial issue of *disabled identity*
in relation to communication impairments (Reeve 2002). This is a con-
tested topic, and the source of much conflict within the field of disability
studies, partly because it distracts attention away from external barriers
(Watson 2002). We focus on this issue in this book because aphasia
profoundly affects language and therefore has implications for self-
expression and conceptions of the self. Talking about aphasia means
talking about language and changing identities. Some authors address the
issue of identity by writing about transformation and affirmation, a kind
of reconfiguring of the self (Reeve 2002). They propose creative personal
responses to language impairment, and bring a personal dimension to
the struggle for social inclusion.

In a number of chapters rehabilitation professionals, sometimes in
collaboration with people who have aphasia, scrutinize their practice and
reconsider their roles and their relationships. The tone of these chapters is
tentative and enquiring, rather than dogmatic, as befits a cautious process
of reconfiguration and realignment. Readers will find that some authors
are more comfortable than others when stepping outside professional
discourses.

The ‘inside’ of inside out can be taken to mean inside the person, or
inside the impairment of aphasia. This focus on ‘inside’ may not, at first
glance, seem to be in keeping with a social model. We feel, however, that a
grounded social model needs to consider disability from within the perspectives of disabled people. Many essays in this book are therefore concerned with the relationship between impairment and disability. We focus on understanding and acknowledging the experience of the disability as well as identifying and dismantling disabling barriers. This relationship between impairment and disability is relatively unexplored both in disability studies and aphasia therapy. We therefore hope to offer new opportunities for investigation and theory building.

Why ‘inside out’?

The term ‘inside out’ concerns the external expression of internal feelings, beliefs and musings. Our authors, writing both from inside and outside the experience of aphasia, were encouraged to explore new lines of thinking as they reflected on the life implications of language difference and language loss. Jaspinder Khosa describes his nuanced and different identities in relation to the different languages he speaks and how his aphasia altered his linguistic and cultural identities. Maria Black and Chris Ireland dialogue with one another about mismatches between language and thinking, and how these mismatches increased for each of them. In Chris’s case these increased when she had a stroke resulting in aphasia and for Maria, when she shifted from languages that she was well grounded in, to new ones.

Another meaning of ‘inside out’ has to do with feelings of social exclusion resulting from aphasia. Those with aphasia are left out, non-members, ostracized, marginalized. Aura Kagan discusses this by stressing the need for multiple ‘communities’ (with a small ‘c’) to be restored as part of the everyday lives of those with aphasia. Alan Hewitt and Sally Byng explore forms of partnership, and in tracing their own professional and personal experience argue for the importance of ‘engagement’ in achieving an authentic sense of self-fulfilment. Susie Parr, Kevin Paterson and Carole Pound explore the many ways that disabled people are excluded because of the time requirements of everyday life. And Roberta Elman, Susie Parr and Becky Moss describe the many barriers that those with impairments meet when accessing the Internet. They go on to offer some suggestions for how these barriers might be reduced.

A third way that ‘inside out’ figures in this volume is reflected in a set of essays concerning how to support those with aphasia as they develop internal ways of managing new or changing identities. The business of helping people ‘adjust’ or ‘cope’ is often taken as an impairment-based approach with a focus on changing the disabled person rather than on social or physical barriers. The authors in this book suggest that these fixed role definitions and views of counselling and therapy be reworked.
They recommend that disabled people take a more active role in therapy processes and that the focus of the therapy be widened to include life circumstances and external barriers, as well as inner change. These two shifts, towards empowerment and the dismantling of disabling barriers, reframes counselling to be more in keeping with a social model of disability.

Tom Penman and Turid de Mare talk about different professional ways of approaching group work. They advocate that therapists, whatever their ilk, become facilitators rather than leaders of groups and that members of aphasia therapy groups have responsibility for what transpires. Harry Clarke, a counsellor with aphasia, also argues for a less dominant role for therapists of people with aphasia – they should talk less and listen more! Sue Boazman reflects on her own experiences first as a manager, then as a person recovering from aphasia and now as a counsellor. She invites us to consider recovery from aphasia as a series of ups and downs in confidence and sense of control based on the interrelationships of impairments and life circumstances.

Another way that ‘inside out’ is used in this book relates to supporting people with aphasia in expressing themselves. This struggle to get the inside thoughts out can be viewed from an impairment perspective as a difficulty the person has with language, or from a disability perspective as a poverty of ways that those interacting with people with aphasia have in supporting their expression. Monica Clarke in a lively depiction of her conversations with her husband, John, who had severe aphasia, shows how successful communication can be achieved, given creativity, flexibility, persistence and the right resources. And Leanne Togher gives insight into traditional ways of thinking by aphasia therapists, arguing for a more conversationally based approach in which client and therapist share meaningful experiences – ones that they can talk about later. Finally, the chapter by Chris Ireland and Carole Pound offers a powerful way of making language expression available to those with aphasia – through celebrating language differences and seeing them in terms of poetic licence and legitimate expression rather than as ‘language errors’.

**Aphasia and access**

A major issue that arose in the course of putting this book together concerned access. We first conceived of the book as a way to create a publication venue for those with aphasia, who have little access to expressing to others their personal and professional concerns. This lack of access is particularly true in a publishing world that emphasizes professional discourse written in an academic style. Those with the authority to generate
and edit a volume such as this one generally approach established authors who are familiar with such discourses and, of course, at ease with language. Part of the editing process involves discussion and debate with the contributors, drawing on these shared resources.

In editing *Aphasia Inside Out* we were not always able to draw from those familiar with writing and publishing. This led to a need for us to provide support for some of our authors, giving verbal shape to their reflections for the purposes of publication. In that way we were able to draw on the expertise of the insiders who live the challenge of language impairment, and to have them join a discourse that has not only excluded them but has also been conducted in a language that seems foreign.

We also became aware when debating possible audiences for the book that speech/language therapists and other professionals working in the field of aphasia have had little access to the literature in the disability studies. Similarly those in disability studies have little exposure to professional writings in the field of aphasia. This is not unusual. Members of one discipline seldom explore outside their area because of time and informational barriers. Typically, those inside a discipline write for their peers, using technical jargon, presupposing common backgrounds and excluding the uninitiated.

Cross-disciplinary barriers have been exacerbated by the disability lobby’s critique of rehabilitation specialists. Those in the disability movement have complained about professionals’ unreflective exercising of power and their undue focus on impairments at the expense of meeting the social challenges of exclusion. Some have called this the ‘tyranny of professional discourses’ (Gillman *et al.* 1997).

While sharing many of the concerns voiced by the disability movement, we have sought in this book to encourage rehabilitation professionals to consider the implications of the social model.

Another major issue associated with access has to do with those with aphasia engaging with the disabled people’s movement. The disabled people’s movement does not represent the entire range of people with impairments (Shakespeare 1993). This is certainly the case for people with aphasia who have had virtually no voice and no presence in this context.

This is a particularly challenging aspect of access, since aphasia is an impairment that affects language: the most powerful weapon in the armoury of the disabled people’s movement. Aphasia compromises a person’s ability to talk and write, and read and understand. Sharing and expressing ideas, and listening to others are critical functions in the process of mobilizing and politicizing a minority and bringing about change. When language is compromised by an impairment such as aphasia, negotiation, campaigning, education, debate and argument become difficult, if not impossible. For these reasons, people who struggle
to communicate are often sidelined by a movement which should be representing them, championing their cause and sharing authority. We feel this need not be the case and our authors offer an example of how these access issues can be surmounted.

Finally, this book is concerned with access for those with communication differences. The writing of Chris Ireland in this volume not only requires courage on the part of the author in challenging language standards and breaking rules, but on the part of publishers in opening up a strikingly different linguistic landscape. We seldom see texts that are not ‘cleaned up’ by spellcheckers and proofreaders. Writing, with the possible exception of poetry and creative writing, is not a medium that readily promotes language difference or communication access for all.

So, much of this book is concerned with gaining access. It offers a venue and support for the writing of people with aphasia. It provides accessible ideas to those in disability studies and aphasia therapy, calling for a common discourse. It suggests that a focus on the specific nature of the impairment, in a volume based in the social model, can make those with aphasia a more visible and powerful presence within the disability movement.

**Power and authority, discomfort and clarity**

The process of preparing this volume for publication has been challenging, bringing discomfort and concern along with clarity and communication. As editors we have the power to invite, select, commission and focus the collection, and to support the development of individual contributions. We are also in the position to exclude those with an interest in aphasia who are not known, are not able to write or who require what seems an unworkable level of support. As the process unfolds, while setting our sights on egalitarian, inclusionary practices, we are forced to exercise our power and our privilege.

Struggles with identity, culture, role and expertise also emerge from the stories of our contributors. While some essays rest on a more confident foundation, a level of discomfort is evident in their questioning of their position and expertise. In some instances this questioning forms the content of their contribution (Hewitt and Byng; Togher) whereas in others the discomfort emerges more subtly as they talk about different styles and dominant voices (Penman and de Mare; Black and Ireland; Ireland and Pound). Jasvinder Khosa writes about how conflicts between different cultural aspects of his identity developed during his childhood and have been consolidated by his experience of aphasia.

Difficulties with the process of collaborative writing are addressed
explicitly in some contributions (Ireland and Pound). Themes of power, authority, dominant and vanishing voices, constraining or emancipatory language have criss-crossed the production phases of this volume, prompting different moments of insight and discomfort for all. For example, in supporting people with aphasia to catch hold of opaque, cellophane wrapped ideas (Khosa), a communication supporter might justifiably offer structures, concepts and words to help the storyteller fix on a means of expression. Yet words both shape and constrain meaning, possibly adding a colour, an emphasis, a nuance that was not a part of the original thought.

People with aphasia require language and confidence to challenge and question those supporting them. When time and energy are limited, the temptation is to accept fast-track ‘solutions’ of suggested words and questions, to defer to those with professional or academic status and style of expression, and to underplay personal expression.

**Negotiating roles in writing and editing**

Negotiations between authors, co-authors and editors took different forms depending upon the individuals, their roles and the tasks at hand. The role of ‘communication supporter’ (for authors with and without aphasia) has covered diverse tasks including:

- interviewing, questioning to clarify, extend and articulate ideas, checking meaning and word selection;
- listening, bearing witness to personal accounts, supporting the narrative telling of stories;
- recording, note-taking, supporting memory for themes and thoughts;
- acting as reflector, sounding board, mirror for thoughts, words and nuances;
- producing first drafts, suggesting structures and ‘translations’, meeting to check interpretations and translations, highlighting unclear passages, expanding first ideas;
- word processing, proofreading, checking references for accuracy;
- motivating, encouraging, supporting people to reach for an extra level of clarity while being sensitive to the linguistic demands of yet another struggle for words.

As well as writing, contributors and editors were acting as conversation and narrative partners and administrative assistants, all of which raised different issues concerning authorship and privilege.

The authors and editors of this book have struggled to find the language to reveal the inside worlds of self-reflection and personal experience. We hope that the essays in the volume will lead to an on-going exploration of
communication styles, personal and professional identities, and different approaches to collaboration and engagement. While many of the themes of this book will be familiar, we suggest that the issue of the communicative competence and style – of people both with and without a language impairment – poses an additional obstacle to breaching the power divide. Communicating clearly while negotiating communication difference is an exciting new challenge.

References


Watson, N. (2002) Well I know this is going to sound very strange to you, but I don’t see myself as a disabled person: identity and disability, *Disability and Society*, 17(5): 509–27.