Annmaree Watharow

IMPROVING THE EXPERIENCE OF HEALTH CARE FOR PEOPLE LIVING WITH SENSORY DISABILITY

Knowing What is Going On

Disability Studies

Collection Editors
DAMIAN MELLIFONT
&
JENNIFER SMITH-MERRY

LIVED PLACES PUBLISHING

IMPROVING THE EXPERIENCE OF HEALTHCARE FOR PEOPLE LIVING WITH SENSORY DISABILITY

Annmaree Watharow PhD, MD

IMPROVING THE EXPERIENCE OF HEALTHCARE FOR PEOPLE LIVING WITH SENSORY DISABILITY

Knowing what is going on

The Disability Studies Collection

Collection editors
Damian Mellifont & Jennifer Smith-Merry

First published in 2023 by Lived Places Publishing

British Library Cataloguing in Publication Data
A CIP record for this book is available from the British Library

ISBN: 9781915271426 (pbk)
ISBN: 9781915271440 (ePDF)
ISBN: 9781915271433 (ePUB)

Cover design by Fiachra McCarthy
Book design by Rachel Trolove of Twin Trail Design
Typeset by Newgen Publishing UK

Lived Places Publishing
Long Island
New York 11789

www.livedplacespublishing.com

Acknowledgement of country

I acknowledge and pay my deepest respects to the Gadigal people of the Eora Nation, the traditional custodians of the land that I live and work on. I am writing from my home, on land the richness of which has inspired, supported, and housed my life experiences, my ongoing career, and my storytelling. In this, I recognise the continued connection of First Nation's people to the land on which I live, and the broader Australia, and I pay respects to the Elders past, present, and future. I acknowledge that it always was and always will be Aboriginal land.

Acknowledgements

Thank you to the loveliest editor, Rebecca Bush. Without you this would be a true masterpiece of word-salad and content mishmash.

People like myself, who live with communication disability, are often dependent on creative and talented human support. This book would not exist without the following:

Susannah McNally

Suzanne Wilding-Hart

Grace McKenzie

Ronnith Morris

Georgia Fagan

Roslyn Barnes

Sue Joseph

Sarah Wayland

Delia Falconer

Ly Ly Lim

To Tony, Hannah-Rose, Oliver, Georgia, and Eddie, the family that is "simply the best, better than all the rest."

Thank you to the work, help, and guidance from:

David Parker

Jennifer Smith-Merry

Damian Mellifont

Abstract

Going to hospital can be a profoundly negative experience for people who live with sensory loss/es. And it is not the illnesses or injuries that threaten health and wellbeing, but experiencing, or rather not experiencing, care and communication. This book will examine firstly how important communication is for all patients. Sensory loss/es are common and increasing rapidly in prevalence as the population ages. These are invisible disabilities and those who live with them are found everywhere, yet are often unseen, uncounted, and unsupported. People living with sensory loss/es are subject to greater health threats than those without and this means they/we land in hospital more frequently, stay for longer, and suffer misadventure and neglect. The COVID-19 pandemic has exacerbated pre-existing inequities and created new layers of difficulty in hospital care and communication. I demonstrate these with verbatim testimonies from my own experience and those of research participants who tell their stories in their own ways, in their own time, and with whatever storytelling assistive devices, supports, and interpreters they need. To change the status quo requires three broad actions: harness the patients' own capabilities; revolutionise the way professionals care and communicate; and transformation of the present ableist health and societal institutions. One single imperative is common for all students and professionals reading this book, communication is your responsibility: ASK, Acquire Specific Knowledge of each individual with disability, with sensory loss/es. What do they need? And then provide these.

Keywords

Deafblindness, dual sensory impairment, dual sensory loss, sensory loss, deaf, blind, low vision, lived experience, patient experiences, disability, communication

Contents

Content warning xiii

Learning objectives xv

Introduction 1

Chapter 1 Miscommunication and pain 25

Chapter 2 The undeniable importance of communication 41

Chapter 3 Who are we? 59

Chapter 4 Health threats 85

Chapter 5 The triple burden of COVID-19 105

Chapter 6 What really happens in hospitals 133

Chapter 7 Security. Knowledge. Power 155

Chapter 8 The expert-knowers speak 169

Chapter 9 Respect. Communication. Care 195

Chapter 10 Strategies for systemic transformation 215

Recommended further reading 239

Suggested learning activities 241

References 243

Content warning

This book contains references to and descriptions of medical abuse and neglect, elder abuse, and acts of ableism. References are frequent and throughout, but Chapters 5 and 6 in particular contain first-person descriptions of acts of violence and harm.

Learning objectives

By the end of this book, my hope is that you will be able to:

Understand

- The prevalence of disabilities and sensory loss/es
- The complexity of disabilities and sensory loss/es
- The health threats
- The predominately negative hospital experiences of those living with sensory loss/es
- How COVID-19 and disasters impact people living with disabilities and sensory loss/es

Ask

- How you can help
- What communication modes work for each individual
- What devices, aids, and supports are needed for each individual

Identify

- Communication problems and solutions
- The need for better, more responsive communication

Provide

- Support

- Interpreters
- Devices
- Aids
- Individual specific tools
- Appropriate and good care and communication

Practice

- Being inclusive
- "Walking the talk"
- Upskilling
- Supporting systemic change
- Doing your job in its entirety
- Owning your responsibilities
- Kindness
- Patience

Recognise

- That it is your responsibility to communicate effectively with your patients/clients/customers/constituents

Introduction

Disability is common, with just under 20% of the Australian population identifying with one or more disabilities (SDAC, 2019). Aboriginal and Torres Strait Islander Australians, our First Peoples, experience disability at almost twice the rate of other Australians (Avery, 2018). A lot of this disability is invisible. Sensory disability is common—and commonly invisible—and increases markedly with age. Multiple disability is common too, with rates ranging from 20% to 75% depending on age and type of disability (World Federation of the Deafblind, 2018; SDAC, 2019). So, it cannot be understated: people living with disability (PLWD) are everywhere, but too often not seen.

Going to hospital and needing healthcare is common, but more so for people living with and managing disability. Hospitals are places where people are diagnosed with impairments, manage consequences and complications of impairments, bring disabilities with them (when they go for non-disability related conditions), and also where PLWD acquire new impairments. Hospitals are places where we rightly expect care and communication, shared decision-making and informed consent, and safety and respect. But PLWD don't always receive these, be it when they go to hospital or visit wider healthcare institutions. One in five PLWD have problems communicating with health professionals (Australian Bureau of Statistics (ABS, 2019)). These issues of care and communication impact all of us directly and indirectly, whether it be ourselves, our parents, or grandparents;

or through our taxes, as we pay for the consequences of substandard care experiences in readmissions, prolonged stays, delayed health help-seeking in future crises, and poorer health outcomes.

My lived experience

Doctors are often seen as shiny, golden people: they have to dazzle at school to get into medical degrees, and they have to maintain their sparkle among so much other glitter over courses and careers.

Few medical students and doctors live with disability/ies, so our medical profession doesn't reflect the wider community. If you're a doctor with a disability (like I am) you quickly learn to be normal and act normal, even if you are not. Especially if you are not!

I have experience of living with disabilities. I was born with hearing loss to two parents who were shocked but committed to an oralism approach to learning, where I would be speech-therapied and hearing-aided into language and therefore able to pass as "normal".

My first conscious experience of being denied participation because I was deaf occurred in year ten at school. I was competing for a place in the *It's Academic* team. I should have been a shoo-in but I was "gently" extracted from try-outs, with Mrs Z explaining that I wouldn't be able to compete. Imagine if I didn't hear a question correctly or didn't hear it all. Imagine how I would feel if I let the whole team and the whole school down. Instead, she decided that I should be the team manager—a prestigious position, and better even than competing.

The lesson: people could lie to me and to themselves if it alleviated their guilt. Of course, the team made it to the finals, then lost on a question I knew. It was not just Mrs Z's low expectations, it was that I should be bound by these expectations.

The next time was in Year 12, during a parent-teacher interview with Miss L. My parents asked if she knew I wanted to study Medicine. "You don't need to worry" she said, "Annmaree will never get in". But I did.

The third time was in my first year of medical school. I had been assigned a surgeon mentor, Professor P. He had a reductive view of his role with his mentees: simple to take them out to dinner every term. At the first dinner, I explained about my hearing loss. He was aghast. He rang Professor G., the Dean of Medicine, and demanded my removal.

The Dean called me to an appointment the following Monday, and I, in hysterics, made my father come up from Melbourne to support me. After alternately crying all weekend and packing up my things, we turned up for tea and cream biscuits at the Faculty of Medicine Dean's office. Professor G. said that perhaps Professor P. didn't understand that the community might benefit from a doctor with my experience. More tea, Annmaree?

Professor P. taught me to go deep undercover—I worked on being and looking and sounding normal. To this end, I had more speech therapy three times a week for five years to eliminate residual lisps and mispronunciations (thank you, thank you Jenny G.). I grew my hair and kept my hearing aids covered up; a practice I would not relinquish until my 46th birthday. Also, I

studiously avoided getting drunk so that I was always in control and my veneer of normality would not be breached.

If only the congenital deafness was all I had to contend with. During the last month of my last year of study, I was diagnosed with retinitis pigmentosa, a degenerative sight loss condition. I would go blind eventually, one day, and definitely. For now, the losses were at the periphery so only my night vision and ability to drive were impacted.

Professor G. was proven right; I practiced medicine differently. When I encountered complex cases of disadvantage, disability, and disparate access to healthcare and services, I went above, beyond, and behind to get support and help for these patients and their families. As a general practitioner (GP), I went to schools for case conferences to support children in getting what was needed for their learning, to educate staff so they understood better that the "bad kid" was just a "deaf kid" who needed different communication strategies. These were the days before the National Disability Insurance Scheme (NDIS) and even before doctors were reimbursed for complex disease management.

Of course, GPs also hear from many patients about their experiences in hospital. I collected stories of patients like myself, who didn't see or hear very well, or both, and how the disease that took them to hospital was trivial compared to the indignities of the (mis)treatment they endured. Hearing of three such cases in one month in 2016 moved me to act.

Mr H. suffers an adverse event after leaving hospital, the result of staff not accommodating his accessibility needs. Mr H. has sensory losses: he can't see or hear very well. He has misunderstood the

diabetes education, misread the small print instructions, and given himself a near-lethal dose of insulin. After all, 3, 13, and 30 units of insulin sound similar aloud, don't they?

Another patient, Miss F., comes to see me clutching a discharge letter from the hospital, requesting a dementia workup, aged-care assessment, and prescription for antipsychotics. She is "seeing" things that aren't there: a little girl in a red coat who has lost her mother. She may not be real, Miss F. thinks, but the little girl seems to need her mother desperately. A detailed and distressing vision. However, these phenomena are not uncommon in people with low vision; they are manifestations of Charles Bonnet syndrome. Miss F. isn't dementing, she doesn't need antipsychotics and she doesn't need a care home at this time. I call the specialist to discuss: our mutual patient is losing her sight, not her capacity.

Finally, as I am packing up my much-loved career, I see Mr S. He has severe hearing loss due to old age and occupational noise exposure. He has vision loss from extensive macular degeneration. He sees little and doesn't hear much. He has hearing aids but doesn't like wearing them. I suspect he feels stigmatised and finds it difficult to manipulate the small controls. He can never find "the damn things". He is admitted to the local public hospital (one of great standing) presenting with abdominal pain. After some hours of nil by mouth, he is put onto clear fluids and then a light diet. Trouble is, no one seems to have told Mr S., in a way he could understand, that this was the plan. And then, no one points out his food and drink when it arrives. His meals are left untouched. Mr S. becomes dehydrated and sicker and sicker. And no one notices. On the fourth day, he is semi-conscious

and in renal failure. Now, needing dialysis, he has the attention of the doctors and nurses. But no one addresses Mr S. in a way that he can understand during his whole hospital stay, from his admission to his needing permanent dialysis. I am horror-struck at this account of preventable misadventure. I feel terror too. I can see a future in which a neglectful, over-busy, task-oriented hospital is a place where I, too, come to harm.

Then I go to hospital myself. The first nurse I encounter refuses to use a pen and paper to communicate with me. Things go south from there. A registrar tells my husband I am cognitively impaired (I fail the mini mental state exam brilliantly). My husband asks, "Did she have her hearing aids in?" From here I undertake a PhD in the hospital experiences of people living with sensory losses. I find abuse, neglect, negative touch, dehumanisation, and a lack of care and communication to be common. My study finds that the supports and aids needed for research are the same supports and aids needed for people with communication disability to know what is going on—to them, for them, and around them—when in hospital spaces. Without such accommodations, negative experiences and harm are likely.

Life with sensory losses is messy and complicated. My accessibility needs are entwined in almost every task of preparing for and writing this book; each page I write must be reviewed for typos, "word salads", and misbegotten punctuation marks. I cannot see these, nor can I hear the voices of virtual assistants. I cannot go to the library unguided, and I cannot converse on a phone without a relay service and voice interpreter. I cannot read an article without converting it into mammoth-sized font that is then dark-moded.

But I *can* do this (with assistance); that is, writing this book and creating greater understanding of what it is to be a patient with sensory loss/es. I have subjective experiential expertise in the realities and complexities of living with sensory loss/es. I have objective expertise, too. As a researcher I have heard the stories of Amanda, Annie, Ava, Barbara, Belinda, Ben, Emma, George, Jane, Lachlan, Linda, Rebecca, Rhonda, Rose, Sally, Tess, Tom, and William. So much is the same, and yet each story is different. Their experiences in words and signs inform and illustrate this book. I am and was a clinician too, so have practical experience in healthcare giving and looking after patients and their families. These deidentified patient histories inform and illustrate this book too. I have convened hundreds of chronic disease and disability management team meetings and written numerous reports supporting PLWD to obtain the care and services they need. I have been awed by how well the system can work and made distraught by its failures.

This book, then, contains the perspectives of a medical practitioner who knows what it is like to be harried, time-poor, and emergency-task-oriented, so that the communication needs of patients are overlooked or poorly understood; a medical practitioner who hears stories from GP clinic patients of what happened to them in hospital and how they did not know what was going on, sometimes or all the time; a person who lives with communication difficulties all day every day, and who goes to hospital dreading the failed communication encounters, which are often worse than the injury or disease that brought them there; a researcher whose thesis centred on what happens when people living with sensory loss/es go to hospital, finding that it is

mostly not good. I am also a family member and carer of relatives with sensory loss/es; I have to watch the distress of loved ones not knowing what is going on.

Above all, this book has been written so that you, the reader, will carry its knowledge with you in your healthcare, studies, and work; your communication encounters with family, friends, colleagues, patients, clients, and the public; and your future protections, policies, and practice development.

How to use this book

In this text, each chapter has standalone content to allow you to dip in and out or read sections immediately relevant. There are resources to supplement each section and case examples to illustrate content with real people, events, and emotions. This book is as accessible as we can make it, so you won't see graphs, Likert scales, or complicated diagrams, which are all inaccessible to those using screen readers. Instead, visual descriptions and lists are used in lieu of diagrams and tables.

Language and disability

While disability is an unavoidable part of the human spectrum of difference, it is linguistically layered and nuanced, collective and individual. The language shifts and changes. So, while this book uses several umbrella terms to aid descriptions and explanations, readers will be consistently reminded to ASK what individuals and communities prefer.

Disability has many definitions, with the United Nations detailing: "persons with disabilities include those who have

long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others" (United Nations, 2006). In 2018, the ABS conducted its triennial survey into Disability, Ageing, and Carers and issued a report in 2019 (SDAC, 2019). In this, they define disability as "any limitation, restriction or impairment which restricts everyday activities and has lasted or is likely to last for longer than six months" (SDAC, 2019). Using this definition, the survey found that just under 20% (17.7%) of Australians live with disability. This book will use a person-first identity: the phrase "person living with . . .". While some individuals, communities, and countries prefer other descriptors—such as "disabled person" or "person with disability"—it remains wisest and most respectful to ASK individuals which they prefer and communities what the common practice is for them.

Here are some definitions of some terms used in the book:

- **Ableism**: One of the main challenges PLWD face in daily life is the ubiquity of ableism. Ableism refers to the use of stereotypes, prejudicial attitudes, and discriminatory behaviour with the intent to oppress or inhibit the rights and well-being of people with disabilities (Andrews et al., 2021; Nario-Redmond, 2019). The ABCs of ableism as outlined by Nario-Redmond (2019) include: affective emotions or attitudinal reactions, behavioural actions or practices, and cognitive beliefs/stereotypes that go beyond general negativity.

- **Accessibility**: This comprises access to communication and information; aids to communication; and environmental information, mobility, and orientation.
- **Ally**: Someone who supports the inclusion of people living with disability.
- **Communication disability**: There are other types of communication disability, apart from hearing and or vision loss. Autism accounts for one-third of those living with communication disability (SDAC, 2019). Communication disability will be presented alongside the importance of good communication in Chapter 2. Communication disabilities may be temporary or permanent, isolated or recurring. In this text, those living with the communication-disabling sequelae of surgeries, diseases, and injuries will generally be included in the sensory loss/es group. This is particularly relevant in the latter sections of the book, which deal with solutions and suggestions to improve communication in healthcare settings.
- **Deafblindness**: In this book, deafblindness is used as one umbrella term referring to all those who live with co-occurring losses of hearing and sight, such that neither sense can compensate for the other. In the research literature, "deafblindness" is the commonest collective term for the group. Other terms used for this diverse group are dual sensory loss or dual sensory impairment. The UK sometimes uses the phrase multi-sensory impairment.
- **d/Deafblindness**: There is a distinct difference between lowercase and capitalised "deafblindness" (d/Deafblindness), in that Deafblindness refers explicitly to people who identify as part of an emergent culturally and linguistically diverse (CALD) group (Roy, 2019). Sometimes this has been referred

to as a "minority within a minority", denoting how deaf communities may have historically marginalised people living with Deafblindness.

- **d/Deafness**: There is a distinct difference between lowercase and capitalised "deafness" (d/Deafness), in that Deafness refers explicitly to people who identify as part of a CALD group. Deafness then falls into two intersectional minorities: a language minority and a disability minority.
- **Double/multiple disadvantage**: The accretion of disadvantage caused by two overlapping identities such as disability in combination with indigeneity, CALD, or lesbian, gay, bisexual, transgender, and intersex identities, for example. Many with a disability are multiply disadvantaged, belonging to more than two different marginalised groups.
- **Intersectionality**: "The interconnected nature of social categorisations such as race, class, and gender, regarded as creating overlapping and independent systems of discrimination or disadvantage. In short, intersectionality refers to the overlapping aspects of a person's life" (Oxford University Press, 2022).
- **Multiple disability**: Having more than one disability is common, and often second and third (or more) disabilities may be invisible and undiagnosed. The data we have on visible and diagnosed multiple disability is that 1,849,300 Australians live with disability (one or more impairments) (ABS, 2019). Of these, 771,100 live with two impairments. This means 42% of Australians with disability have two or more impairments, and 521,300 or 28% of Australians with disability have three or more impairments (ABS, 2019).
- **Nonverbal**: Denotes an individual who does not or is not able to use oral speech.

- **Ontological security**: This is the desired state of trust, reliability, and predictability of people, places, things, and information, which promotes the sense of knowing what is going on.
- **Restrictive practices**: Any actions which restrict the rights or freedom of movement of any person. These may include but are not limited to: "Seclusion, where a person is confined to a physical space and prevented from leaving. An example is locking a person in a room for a set period of time. They may also refer to the use of physical or chemical restraints, for example, holding a person down on the ground so they cannot move in a hospital, or using medication to sedate a person. Mechanical restraints may be used, for example, tying a person to a chair in a classroom, or disconnecting the power of an electric wheelchair, or taking a person's communication device away from them" (Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 26 May 2020).
- **Sensory loss/es**: This term is used in this book as a collective to discuss all people with single or dual sensory loss and includes other communication disorders. Again, we remind practitioners to always ASK individuals and communities which descriptor is preferred, and then proceed to use that in their communications and work. The many words used in the community to describe or identify their sensory loss/es will also be discussed further in Chapter 2. It is important to note that a great many who live with single or dual sensory loss/es do not identify or present to health and social care as such. Pre-eminent in this group are older citizens who may regard sensory loss as normal in the ageing process.