Down Syndrome across the Life Span

Edited by

MONICA CUSKELLY, ANNE JOBLING
University of Queensland
and
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First published 2002 by
Whurr Publishers Ltd
19b Compton Terrace, London N1 2UN, England
325 Chestnut Street, Philadelphia PA19106, USA

Reprinted 2002

British Library Cataloguing in Publication Data

A catalogue record for this book is available from the British Library.

ISBN 1 86156 230 6

Printed and bound in the UK by CPI Antony Rowe, Eastbourne
Transferred to digital print on demand, 2007

Contents

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Preface

The 7th World Congress on Down syndrome was held in Sydney, Australia, in March 2000. The Congress is held approximately every four years and brings together researchers, professionals, parents, and lately, adults with Down syndrome from around the world. Contributors from 11 countries participated in the conference, discussing a diverse set of issues and presenting information on a range of research projects, interventions and services that had been developed with the aim of enhancing the lives of individuals with Down syndrome and of their families. Participants in the Congress came from an even larger number of countries and provided a lively discussion of the material presented in the various sessions.

It can be difficult to strike the right balance when organizing a conference that will include parents, professionals, and researchers as both presenters and audience. Each has different needs, expectations and background experiences, and understandings. There is a commonality, however, in the desire to improve understanding, and thus the lives, of individuals with Down syndrome and their families. The same dilemma occupied the editors of this collection.

The chapters presented in this book were collected together in order to provide readers with an introduction to some of the major issues confronting practitioners at this time. Not all areas of importance to those interested in Down syndrome have been included. Nevertheless, it is to be hoped that readers find some new insights in the material included here. The editors invited contributions from some of the individuals and groups who presented at the conference and the resulting book contains chapters from writers from four Australian states as well as from Canada, England, Iran, Italy, Northern Ireland, and Scotland. The dilemma alluded to above was resolved, at least in part, by including both researchers and practitioners in the contributors to the book, some of whom are also family of individuals with Down syndrome.

The content of the chapters covers a broad range of topics but there is a slight preponderance of chapters that focus on issues relevant to adults with

Down syndrome. This makes the book a very timely publication, as there is a growing recognition that our understanding of the needs, experiences, and desires of adults with Down syndrome is rather limited. As noted above, some of the chapters have been prepared by groups of researchers - one of the aims of the conference was to gather together research groups from across the world and to have them present an overview of their work. This has resulted in some chapters that briefly describe a number of research projects, rather than providing a more detailed report, although in these instances an overarching focus is clearly apparent. The editors have written a short introduction to each section of the book, at times to draw out themes and elsewhere to consider the implications of the work presented in the following chapters.

The organizing committee of the conference wished to include those with Down syndrome in the Congress and, to this end, involved a number of individuals in presentations to the entire audience as well as developing a parallel programme for adults with Down syndrome. This programme comprised seminars and workshops, in some cases delivered by individuals with Down syndrome, in addition to a social programme. The 'place' of individuals with Down syndrome in families, schools, communities, and in research, and the presentation of information about the lives of those with Down syndrome is a recurring theme throughout these chapters.

The final words of this preface belong to some of the people with Down syndrome who attended the Congress. The first is a record of a conversation between Luke Campbell and his mother.

Q: What kind of thing do you remember from the Down syndrome Congress at Darling Harbour, Luke?

A: You learn health. About anger and fear. How to be good and bad. Enjoy everyday life. If you are bad, no presents. If you're good, you get presents.

Q: You had a workshop on decision-making. What did you understand about that?

A: Someone in your head tells you what is good things to do and bad things. You walk your own path.

Q: At night after the second day, when you had the workshop on decision-making, poetry and about independence and joining in community things, you said to me 'Life is hard'. Was there anything in particular made you think that?

A: I felt scared and frightened about life. I felt good at the end of the Congress. Good to know how your brain works.

Luke Campbell

The workshops for people with Down syndrome were great. They were about friendships, feelings, keeping safe and decision-making for independence.

Linda Katuna-Rich

We talked about healthy food and watched videos. We talked about friends and drinking, when it is good for you and when it was bad for you.

Anne Power

I attended some workshops, and I enjoyed the Harbour cruise very much. But the highlight was the Congress dinner with live entertainment. It was really fantastic.

Caroline Brunner

The people with Down syndrome went along as well. We all got together – a special kind of people – once in our lifetime – to have fun.

Kylie Scott

SECTION 1
VIEWS OF SELF

Introduction

The chapter by Jan Gothard contained in this section breaks new ground for a publication such as this, coming as it does from the pen of an historian. Contributors to books on Down syndrome are more usually written by psychologists, educators, speech and language therapists, or those from the medical profession. As an historian Jan Gothard has used an approach to 'data gathering' which has enabled an aspect of the experience of Down syndrome that is usually presumed to be inaccessible to be presented. In her chapter she explicates her own decision-making as she approached her task of collecting the stories of adults with Down syndrome. The final product of this exploration was a project that gave skills to the individuals with Down syndrome to express their own perspectives.

Other chapters in this book, most particularly that by Muirhead (Chapter 12), also challenge the negative stereotypes that commonly surround individuals with Down syndrome. Both Gothard and Muirhead have used less traditional ways of collecting information and both force an examination of more commonly used methods.

Gothard leaves unresolved one of the most interesting aspects of the journey she describes - that is her frustration at the failure of the participants of her study to confirm for her the discrimination she believes they experience in their day-to-day lives. This impasse further highlights the relatively unexplored area of the emotional and social experiences of individuals with Down syndrome. We might hope that Gothard's chapter will ignite interest in this area, as well as suggest some ways of collecting authentic information.

CHAPTER 1
Beyond the myths: representing people with Down syndrome

JAN GOTHARD

Background

This chapter stems from my dual capacity as an historian and as the parent of Madeleine, an eight-year-old girl with Down syndrome. It is also partly autobiographical; my interest in disability and my work in the area are precisely as old as my daughter. The particular focus of this chapter is the way in which people with Down syndrome are represented, by themselves, as well as by others. The chapter outlines work still incomplete and seeks to show how my approach to representing people with Down syndrome has been illuminated and enhanced by my own reflections on my work and by the writings of others. Dealing initially with an oral history project of interviewing people with Down syndrome and their families, the chapter goes on to chart the growth of my belief that there are other, more powerful ways of representing people with Down syndrome. It concludes by arguing that, as important as representing people with Down syndrome is, facilitating self-representation is more important. Disability is discursively constructed and representations of individuals with Down syndrome, particularly from older and historical sources, can be a powerful vehicle for fostering negative responses and creating damaging stereotypical attitudes. Equally, they can promote positive attitudes and approaches. From this point of view, the most powerful contemporary representations are undoubtedly those produced by people with Down syndrome themselves.

Before my daughter was born, her father and I had had only extremely limited contact with people with any kind of intellectual disability. As is the case for most people outside the area, our ideas about Down syndrome had been quietly shaped by images from literature and the media, and by ignorance. Too often these things go together. Fay Weldon's book *Darcy's Utopia*, provides a telling example of some of the material in circulation

which does so much to fashion our images and our ignorance about disabilities such as Down syndrome.

> I think about my friend Erin, as I often do. She has a Down's syndrome baby. We all knew it would be disastrous; we foretold that her husband would walk out, that her other children would suffer: we saw she was the only one of the family unit who couldn't bear not to see the fruit of her womb, however sour, ripen, drop and live. And that's how it turned out: the child, now twelve, is badly retarded, Erin is no more than its nurse; she manages without a husband, her other children are spiteful and embarrassed. Erin talks about the joy the mindless child brings her – well, so it may, but her love for it has been most destructive for others. Left to us, friends and family, we would have said no, Erin, sorry, not for you. This baby you insist on having keeps other babies out, ones which won't cause this distress to you and yours. Just not this one; Erin, try again.
>
> (Weldon, 1990: 140)

Once our daughter was born, my partner and I set out to find out more about Down syndrome and we were amazed at the legacy of historical ignorance we encountered. This related not simply to Down syndrome but to the whole field of disability. Fay Weldon might have been bad enough, but once we started delving into historical material, it quickly grew worse. Works such as Crookshank's *The Mongol in our Midst*, written in 1924, and Tredgold's 1908 classic *Mental Deficiency* (still in circulation and in its 10th edition in 1963), made us aware of how far ideas about people with intellectual disability had progressed but – thanks to Fay Weldon and others – we felt there was still ground to cover. We believed that

> the 'truth' of contemporary ideas about intellectual disability, while it produces better outcomes for people with intellectual disabilities than [earlier views], is still contingent on perception, interpretation and, above all, on the operation of the language through which humans think about the world.
>
> (Cocks and Allen, 1996: 283)

My partner channelled his intellectual energy into co-editing a history of intellectual disability in Western Australia, *Under Blue Skies* (Cocks, Fox, Brogan and Lee, 1996), while I drew on my experience as a practitioner of oral history. I knew my own life was nothing like the life Fay Weldon had suggested was in store for the parents of a child with Down syndrome and I wanted to understand more about other people's experiences. I wanted to know what life was like for individuals with Down syndrome. I wanted to confront some of the myths about Down syndrome and, perhaps idealistically, to be part of a process of debunking them. With the support of the Down Syndrome Association of Western Australia (DSAWA), I started work.

The original intention was to produce a book based on oral interviews and complementary research. From this emerged a scheme for a professionally produced photographic exhibition, drawing on themes important in the lives of families and individuals with Down syndrome. Finally a website was created to enable these photographs and associated material to be accessed more widely. The interview-based book, meanwhile, is on hold.

In retrospect, the process seems quite clear cut but in fact the path leading from the intended outcome of an interview-based book, to a photographic exhibition and website, was by no means straightforward and was littered with realizations about the implications of the work being undertaken. These issues will be addressed in the remainder of this chapter.

Limitations of the oral history approach

The starting point for this project was a series of interviews with the parents of people with Down syndrome. My agenda was clear; it was quite explicitly a bid to counter the Fay Weldonesque image of people with Down syndrome as 'mindless', their parents as 'little more than nurses', their siblings as soured and embittered. Certainly I had no difficulty in that task. But the intention was also to focus on the experience of *having* Down syndrome: how people with Down syndrome felt; how they were treated; what their expectations were; what difficulties they had encountered, if any, which they could attribute to their disability. I approached these issues in the broader context of finding out how young adults with Down syndrome lived their lives. And what I found was how very like, in many ways, the lives of my interviewees were to those of their peers who did not have a disability. Social interaction, recreation, education and training, relationships, work and family were the main foci of their lives. There were areas in which there were clear differences, largely associated with independence (driving cars featured strongly here) and leaving home (all my interviewees so far were living at home with their parents). On the whole, however, my interviews have reinforced the realization Jan Walmsley noted in other researchers: 'being a person with a learning disability is most akin to being a human being' (Walmsley, 1995: 72). At least, that was how my informants related their lives.

The question of the impact of having Down syndrome (a major focus of interest for me) I approached both obliquely and more directly, but my questioning seldom evoked the responses I had been expecting. Some informants were evidently surprised at my approach and politely expressed the

view that the treatment they received and their relations with other people were 'normal'. Yet interviews also elicited this kind of story:

Interviewer: Can you tell me more about your sport?
Adam: I do swimming; I used to do netball . . . and badminton . . . and bowling . . . everything. My favourite is swimming. I was doing overarm, breaststroke, and . . . oh, and butterfly. Bowling is full of fun, and . . . I used to go bowling with a group of friends . . . It was fun.
Well, I used to play netball with a group, and . . . I didn't like it very much. I feel . . . left out, 'cause . . . they pushed me away. Well I felt . . . they were teasing me . . . talking behind my back . . . That really annoyed me . . . That's all.
Interviewer: So you stopped?
Adam: Yes.

When pressed further, however, Adam did not see this treatment as a possible function of his having Down syndrome. There are a number of issues to resolve here.

In the United Kingdom, Aull Davies and Jenkins (1997) have researched the 'significant incongruence' they had observed in a group of young adults with learning difficulties, between their 'categorical identity as someone with learning difficulties and their self-identity': in other words, their understandings of themselves did not take into account the fact that they had a disability. Aull Davies and Jenkins attribute this to the fact that the families of the 60 individuals in their group had evidently avoided any discussion with them relating to disability, one set of parents going so far as to black out all reference to Down syndrome in a press article relating to their son. This was certainly not the case with my interviewees.

Adam had represented the state on several occasions in swimming and athletics and had a fistful of medals as testimony to his sporting prowess in 'special' sporting competition; and the mother of another young woman assured me her daughter would tell me 'in no uncertain terms' what it was like to have Down syndrome. (She didn't.) All of these individuals in any case, through their families, were members of the DSAWA. That was how I had contacted them, and their membership meant that these young adults had generally mixed socially with others with Down syndrome and certainly took active advantage of the recreational offerings made available through the DSAWA and other similar groups for people with disabilities. They all under-