

YOUNG PEOPLE WITH COGNITIVE DISABILITY IN TRANSITION TO ADULthood

This book presents the lived experiences of young people with cognitive disability and their struggles as they transition to adulthood. Whether you are a young person yourself looking to transition to adulthood, a parent, or a professional supporting a young person, this book will help you understand the systemic failures that have caused abuse, exploitation, neglect, and violence. But it will also outline the inner and outer resources that have enabled young people to maintain their self-belief and overcome adversity. Despite the fact society is failing these young people, the young people in this book speak of belief and have hope for the future. Drawing upon the United Nations human rights framework, this book provides a narrative for empowerment and reform. It involves the input of co-researchers with disability and includes Easy English summaries in each chapter to ensure its accessibility to young people with cognitive disability.

KATHY ELLEM is a scholar, social worker, and disability advocate. Her interest in the disability sector has stemmed from her personal experience as a parent of a young man with cognitive disability. She values working inclusively with people with cognitive disability in research and social work practice.

PAUL HARPUR is a professor with the TC Beirne School of Law, the University of Queensland, an associate with the Harvard Law School Project on Disability, and ARC Future Fellow, Paralympian, Fulbright Scholar, and a Member of the Order of Australia 'for service to people with disability'.

FOTINI HARDY is a social worker, scholar and researcher. Hardy's interest in the disability sector stems from her experiences with the disability rights movement in the 1980s, sparking her ongoing commitment for a more just society that recognises the human rights of everyone.

MICHAEL ASHLEY STEIN is the co-founder and Executive Director of the Harvard Law School Project on Disability, and a Visiting Professor at Harvard Law School since 2005. He is considered one of the world's leading disability law and policy experts.

ANN FUDGE SCHORMANS is a critical disability scholar and researcher. Her teaching and research are informed by many years of social work practice, her experiences parenting two daughters with intellectual disability, and her engagements with people with intellectual disability in inclusive research and knowledge production.

YOUNG PEOPLE WITH COGNITIVE DISABILITY IN TRANSITION TO ADULTHOOD

Stories of Survival, Aspiration, and Systemic Failures

KATHY ELLEM

University of Queensland

PAUL HARPUR

University of Queensland

FOTINI HARDY

MICHAEL ASHLEY STEIN

Harvard Law School

ANN FUDGE SCHORMANS

McMaster University



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Kathy Ellem , Paul Harpur , Fotina Hardy , Michael Ashley Stein , Ann Fudge Schormans

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*This book is dedicated to Professor Jill Wilson, a wonderful mentor and
a caring friend who believed in fighting for a better world for people
with cognitive disability.*

*One day, you too, will be strong enough to get out of the darkness
like I did.*

*I Believe in you! You just have to be BRAVE, STRONG, and FIGHT
for what is RIGHT! and when that time does come, hold your head up
and SMILE, because no one else but YOU know what you've been
through. Be proud that you've got a voice.*

— Rosie Smith

Contents

<i>List of Figures</i>	<i>page</i> ix
<i>List of Tables</i>	x
<i>Preface</i>	xi
<i>Acknowledgements</i>	xiii
1 Introduction	I
2 Violence against Young People with Cognitive Disability	22
3 Working in Partnership with People with Lived Experience: An Inclusive Methodology	40
4 Amethyst’s Story	67
5 Experiences of Young People with Cognitive Disability: The Complex Road to Adulthood	77
6 The Many Faces of Violence	106
7 Young People and the National Disability Insurance Scheme: ‘The Standard Cookie Cutter Approach’	141
8 Don’t Give Up on Us: Young People’s Experiences of Education and Employment	155
9 Housing, Home, and Mental Well-Being: The Need for Self-Determination and Safety	169
10 Young People’s Experiences of the Child Protection and Criminal Justice Systems	191

viii	<i>Contents</i>	
11	Having Someone in Your Corner	209
12	In the Voices of Participants: What Needs to Change	222
	<i>References</i>	245
	<i>Index</i>	271

Figures

3.1	Intersectional ecological systems framework for understanding the experiences of young people with cognitive disability	<i>page</i> 44
4.1	Experiences of abuse across Amethyst’s life	68

Tables

2.1	Location of violence against young people with cognitive disability	<i>page</i> 31
3.1	Understandings of violence against young people with cognitive disability	42
3.2	Inclusion principles as they related to this study	49
3.3	Participants: young people	58
3.4	Participants: practitioners	60

Preface

By Willie Prince and Kyah Peirce with help from Kathy Ellem

We are writing this as co-researchers on this project and collectively as people living with a disability. Our lives have been impacted by violence and we want to use this co-researching opportunity to help create a more inclusive and safe society. There's a lot of trauma . . . [a] lot of things going on, and not just in one area of the person's life, but in lots of areas.

Willie

This book recognises that young people are our future and that no young person should experience violence. Young people with cognitive disability are a group that are at increased risk of violence, including sexual assault; physical, emotional, and financial abuse; and neglect. If we are to end abuse and violence against young people with cognitive disability, we need to listen and understand the voice of young people themselves. We also need to listen to the communities in which young people belong.

This book aims to change the way people think and act around young people with cognitive disability. It includes the stories of young people and their families about what it was like for the young person to become an adult and how they managed that change. Service providers from different organisations also shared what it was like for young people. By sharing these stories, it is hoped that doors will open for young people both in Australia and internationally, where previously these doors were closed. The book is written to raise awareness and help young people.

The young people in this book come from many different backgrounds. Whatever young people's culture or life experience, they shared the common experience of having a disability. Our society needs to help people from different cultures and experiences to coexist with each other. People with disability from different backgrounds can work together to make change.

As co-researchers in this project, we made the informed decision to come together on the project, although we all had different life experiences. Doing research was new to us, but with help we were able to provide advice, give our opinions, and work together as a group. We spoke as one voice, not individual voices. As a group voice we were stronger.

As co-researchers, we learnt about the many ways in which organisations fail young people with cognitive disability, when they are meant to support them. These organisations don't listen to young people. They think that young people understand what they say, when they might not. They need to help young people understand also. These organisations need training. As people with disability, we can provide that training to them.

This book is not the only project we have been involved in to end abuse against people with cognitive disability. Each of us is a leader in our own right and we continue to fight against injustice towards people with disability. Our presence can help others who have survived violence and abuse.

We hope this book will help you, as reader, to embrace our young people as we do. If you are a family member, this book might show you ways to keep your young person safe. Everyone needs to help young people to make their own decisions and join the fight for change in services, government, and community! Do more research! The issues facing young people with cognitive disability need to be shared on TV and social media. Violence is not okay. Take the time to understand what is going on for young people! Let them know that it is their own body, and they have a right to say yes or no. Encourage young people with cognitive disability to speak up, stand on their own feet, and be strong!

Acknowledgements

From the outset, undertaking this research and writing the book has been underpinned by the principle of ‘nothing about us without us’. We start by recognising and thanking the participants who shared their life stories for this project. These are the young people with cognitive disability, their families, supporters, and professionals who help empower them. Without their bravery in taking the time to relive traumatic events, this book would not have been possible. Through telling their stories, they have illustrated how society has failed youth with cognitive disability when they transition to adulthood. It is now up to practitioners, policymakers, and community members to craft a more inclusive society, a society where abuse, exploitation, neglect of, and violence towards young people with cognitive disability is replaced with empowerment, equality, and a mutually shared sense of belonging and being valued.

The research informing this book was co-designed with people with a disability who were actively involved throughout as decision makers, advisors, and researchers. Thank you to Kyah, Willie, Rosie, Ebony, and Olivia for your generosity in sharing your experiences and wisdom. We extend our gratitude to Gillian O’Brien and staff from WWILD – Sexual Violence Prevention Association who supported co-researchers in this project. We are also indebted to the many research assistants who interviewed participants for this research. A full list of members of the research team is provided below.

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Research Team

The University of Queensland

Dr Kathy Ellem

Professor Paul Harpur

Dr Fotini Hardy

Dr Adrienne McGhee

Madeline Kadel

Leilani Garland

Heidi Gerton

Rachel Watson

Chris Hampson

Mitree Vongphakdi

Harvard University

Professor Michael Ashley Stein

McMaster University

Professor Ann Fudge Schormans

WWILD – Sexual Violence Prevention Association

Rosie Smith

Olivia Eiser

Kyah Peirce

Ebony Street

Willie Prince

Gillian O'Brien and staff