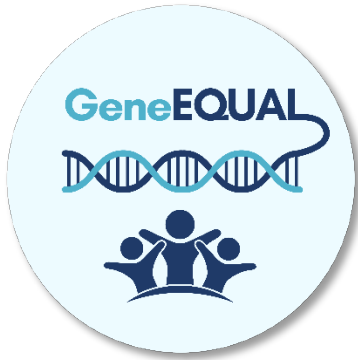




Life with intellectual disability



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How we made this booklet

Our Mentoring Group made this booklet together.

Seven people with intellectual disability and one person with another disability worked with the GeneEQUAL team for nine months.

We made all the big decisions. We chose the words, shared our real experiences, and pushed back when something didn't feel right. This was our booklet.

We then shared it with our community. Over 40 people with intellectual disability reviewed it, gave feedback, and helped us make changes.

This booklet shows how we see ourselves - in our own words, from our own lives.



What is intellectual disability?



Intellectual disability is a lifelong condition



It slows down our learning



It affects our skills and behaviours

- in good and bad ways



It affects our day to day lives



With the right support we live successful lives



We can have different support needs



Some people need a little support



Others need more support



Support needs can also change



Intellectual disability is often invisible



People cannot always tell by looking at us

There are different names for intellectual disability



For example learning disability

Or learning difficulty



It depends on the country you live in

We use intellectual disability in Australia.



Health

Many of us have other health conditions too



It is important to have regular health
check ups



We can learn to take care of our health

- with the right support



It can be difficult to cope with and focus on

- our disability and health needs at the
same time



These struggles to deal with health care and
disability needs

- can start mental health issues.

This is because it can cause stress and
anxiety.



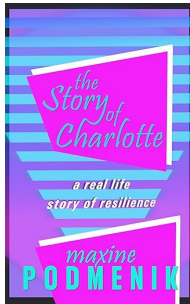
Our success can be seen

We can succeed in many areas of life.

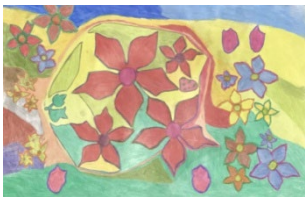


For example many of us can:

- study and do well at school
- get jobs and very good careers
- start and run successful businesses



Maxine said: “I have a business by writing my book and have sold 36 copies already.”



“I have a business with my drawings and different types of artwork.

I have already sold 29 products.” Mark



Many of us

- can get married

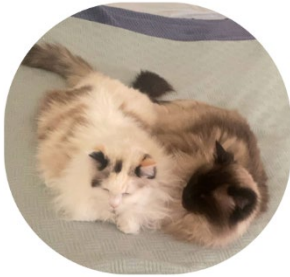
Tammy said: “I love being married and my husband is a great support to me.”



Many of us

- raise children

“I am a proud mum of 2 beautiful and kind loving children.” Skie



Many of us

- live by ourselves

Larissa said: “Proud to be living by myself and two ragdoll cats.”



Many of us

- prove people wrong when given chances



Sam said: “I always wanted to be a teacher but thought my disability made it impossible.

But now I co-teach future and current teachers at university.”



Many of us

- communicate without words



We can do many everyday things



We

- shop for ourselves and our family
- cook
- travel
- work
- study
- enjoy hobbies



We can have different ways to learn

We may need more time to learn new things



We can make choices about our daily life



Success can look different for everyone.



Strengths

We have different strengths like



- strength to keep on going
- will power
- being creative
- honesty
- kindness
- and a sense of humour.





We are able to think in different ways



We have strong values



We feel deeply for others

- because we had bad experiences

We do not want others to feel that way



We need chances to show what we can do



With person-centred support and chances

- we can reach our goals.



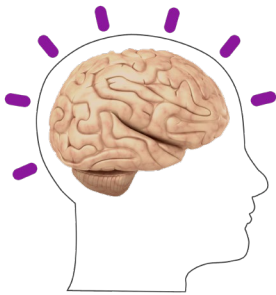
Struggles

We have different struggles



These struggles can range from low to very high

These can change in levels but are always there



Struggles can be caused by intellectual disability



Struggles caused by intellectual disability can be:

- communication
- social skills like meeting new people
- memory
- understanding





- money skills

- maths skills

- reading

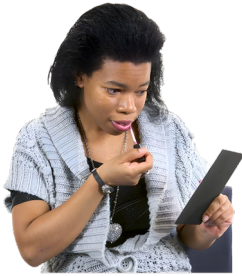
- writing

- self care

- movement skills

- emotional skills

- low confidence



We can also find doing big tasks hard

- and it can help to do it step by step



We can also struggle to:

- solve problems

- make choices



- speak up
- make complaints
- control feelings
- do things without support



Reading about struggles can make you

- feel worried or stressed



Take a moment to calm down

- drink a cup of tea
- do crafts
- cuddle your pet





We now will continue talking about struggles

Struggles can also be caused by **society**



Society means other people in your community



Society can give us extra challenges and struggles



Struggles caused by society are called **barriers**



Society often sees people with intellectual disability

- in a negative way

As a result we might not get a chance to:



- access education
- be employed
- learn life skills



- fit into community
- access services
- fill in forms correctly



- get the right supports
- get support from services to get government funding



- make friends
- have relationships
- have children
- engage in next steps of life



We often face discrimination

People often



- look down at us
- think we cannot do much
- judge us quickly



- take advantage of us
- speak over us
- speak for us



- speak to our support person instead of us
- tell our story for us
- do not listen to us



- overpower us
- misunderstand us



And sometimes people

- limit us
- make decisions for us



People can also make us feel

- less
- broken
- not wanted
- like we are invisible
- like we are not equal
- our needs do not matter





As a result we

- do not believe in ourselves
- feel we must say “yes” all the time
- do not fit into society
- stop trying to reach our goals
- limit ourselves by what others think of us
- burn out trying to change ourselves
- lose understanding of who we think we are
- lack confidence in ourselves
- do not have hope for our future



We are at greater risk of mental health issues



We often trust too much

- when it comes to relationships and scams



We often trust people who have more power

- health care workers
- teachers and other education staff
- bosses
- police



This needs to change

It is not us who need to change

It is society who needs to change.



Who made this booklet

People with intellectual disability made this booklet



1. Julie Loblinzk Refalo OAM

2. Skie Sarfaraz

3. Sam Hurd

4. Mark Podmenik

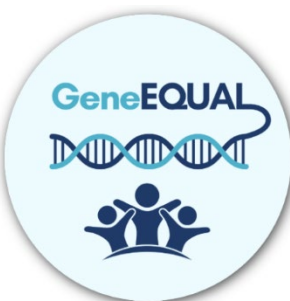
5. Maxine Podmenik

6. Tammy Carlon

7. Luke Wheatley



Together with Iva Strnadová and the **GeneEQUAL** team.



GeneEQUAL is a program to support people with intellectual disability

- get better health care.

This booklet was made possible with funding from the National Health and Medical Research Council (NHMRC) of Australia, Grant Number 2015753.

Endorsements



An **endorsement** is a person saying that they

- have read our booklet
- and think it is important.



When someone gives an **endorsement**

- means they give their official support.



The people listed below work making health care better

- for people with intellectual disability.



Their endorsement shows they support the GeneEQUAL team.



Julie Loblinzk Refalo
OAM
University of New South
Wales
&
Self Advocacy Sydney
Australia

“My life living with an intellectual disability has been difficult and complex.

I struggled most of the time understanding information.

I have spent many years learning so I can support others with intellectual disability.

Lots of websites have information on the subject, but there is no information from people themselves.

We came up with the idea to write an Easy Read version.

This means a lot to me being involved in this. It shows we can write something in an accessible way using the right language.

Society needs to change.

I am a part of a team that supports accessible information.

And I am so proud working with this great team.”



Emeritus Professor
Nick Lennox
The University of
Queensland
Australia

“Take a moment to read Life with Intellectual Disability, it is a gift to you.

It will move you to a place of deeper understanding, insight, and humility.

People with intellectual disability generously share their lives to enrich our lives and community.”



Heath Dickens
Chief Executive Officer
Council for Intellectual
Disability
Australia

“Inclusion starts with understanding. Life with intellectual disability is an excellent resource to help people understand intellectual disability and realise that people with intellectual disability have the same aspirations as everyone. This is such an important part of creating a truly inclusive society.

Congratulations and thank you to everyone involved in creating this amazing, accessible resource.”



**Scientia Professor
Julian Trollor AM**
National Centre of
Excellence in Intellectual
Disability Health
Australia

"Life with intellectual disability conveys powerful messages about the realities of living with an intellectual disability.

It offers valuable insights and encourages us to work collectively towards a more inclusive society.

I am so grateful to be taught these important lessons by people with lived experience.”



**Professor Jan
Walmsley**
The Open University
United Kingdom

“What a wonderful thing to do. I cannot believe it has taken till 2026 to ask people with intellectual disability to explain what it means to them.

Fabulous to celebrate the good things and what people can achieve, at the same time as highlighting the many barriers people face in realising their potential.

This must be required reading for families, for social workers, nurses and doctors, for anyone who comes across people with intellectual disability in their work, and in their lives.”



**Emeritus Professor
Trevor Parmenter AM**
University of Sydney
Australia

“Life with intellectual disability lays to rest many of the myths surrounding people who have been labelled with the term.

At worst throughout history their very existence has been challenged.

This beautifully produced book so eloquently reveals the richness of their lives and the important contributions they are making to our society.

This is a must read for school and higher education students.

The community would benefit from copies being in all local libraries.”



**Professor Michael
Kidd AO**
Chief Medical Officer of
Australia

“Life with Intellectual Disability reminds us that all people with intellectual disability have the right to information they can read and understand.

This includes information about their own lives, their many contributions, and the challenges they face. I congratulate the team of authors with intellectual disability who have shown strong leadership and set a new standard for how important resources like this should be made.”

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<https://doi.org/10.5281/zenodo.19687601>

For more information and resources visit:

www.geneequal.com

