GeneEQUAL

Life with intellectual disability

Easy Read

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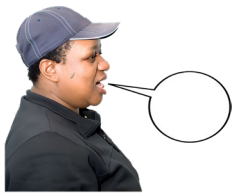

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How we made this booklet

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

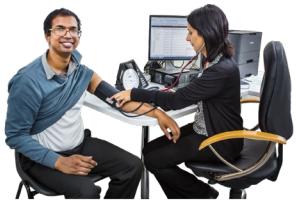
There are different names for intellectual disability

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.

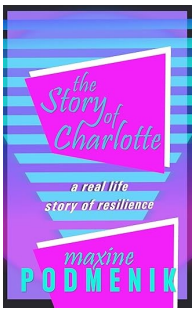
This is because it can cause stress and anxiety.

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

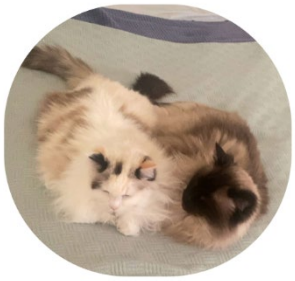
- can get married

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

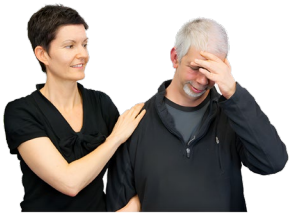
We have different strengths like

- 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

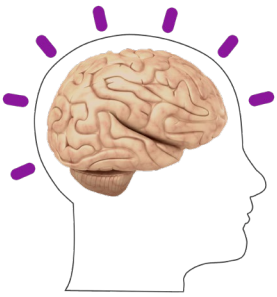
- we can reach our goals.

Struggles

We have different struggles

These struggles can range from low to very high

These can change in levels but are always there

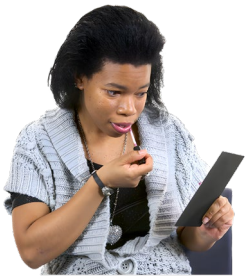


Struggles can be caused by intellectual disability

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

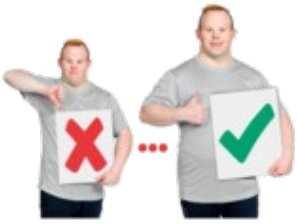
We often trust too much

- 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.

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What people have said about this booklet

Julie Loblinzk Refalo OAM

"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."

Scientia Professor Julian Trollor AM

"*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

"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."

Professor Nick Lennox

"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."

Emeritus Professor Trevor Parmenter AM

"*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

“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.”