



Reaching Potential

Experiences of young people with
significant intellectual disability

Summary Report | Easy Read Version

SVA Consulting

Limb
Family
Foundation 

How to use this report



Social Ventures Australia wrote this report.



When you see the words '**we**' or '**our**', it means Social Ventures Australia.



When you see the words '**intellectual disability**' it means someone who might have difficulty with learning, talking, understanding and living by themselves.



When you see the words '**services**' or '**supports**', this means the people or organisations that are doing something to help you, such as making sure you have what you need to go to school or live where you want to live.



This report is written in an easy-to-read way.

You may see some hard words. We will explain what they mean.



You can find the original version of this report **here**.



What's in this report?

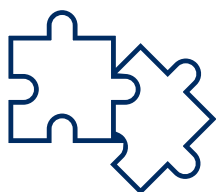
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Why did we write this report?



All young people should be able to do whatever they want in life.

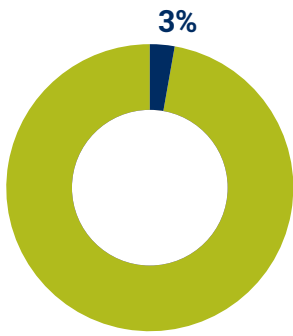
We know this can be hard for young people with intellectual disability.



They face additional difficulties like not being able to access the right supports, services and opportunities like other young people can.



This can make it harder for young people with intellectual disability to do things like see a doctor, go to school, meet with friends and get a job.



3 Percent of people living in Australia have an intellectual disability.

300,000 Young People living in Australia have an intellectual disability



Compared to people living in Australia **without** intellectual disability, people **with** intellectual disability:



Are **2 and a half times more likely** to have problems with their health



Are more than **2 times more likely** to die from something that could have been stopped from happening



Are **2 and a half times less likely** to finish year 12 of school



Are **2 times less likely** to have a job



Are **much more likely** to experience being left out of a community



The community needs to know the needs of young people with intellectual disability and include them in conversations about how to make things better.

The National Disability Insurance Scheme has helped people with intellectual disability but more can be done.



Coronavirus is a virus that has affected many people around the world. Coronavirus has made it even more difficult for young people to have access to everything they need.

We will talk more about Coronavirus later in this report.



We wrote this report so people can understand more about young people with intellectual disability and know how they can make life better for them.

We know there is still more work to be done.



What did we do?

We talked to 11 different people with intellectual disability and their carers.

A **carer** is someone who helps to look after a person.

We asked the people with intellectual disability or their carers to tell us their stories so we could learn about their lives.

Here are the people we talked to:

Mark and his mum, Anna

Mark is 7 years old.

Mark goes to a special school.

He loves planes.

He is a very happy person. Not much scares him.

Mark has difficulties with talking and he has **autism**.

Autism is when someone has difficulty with talking, understanding feelings, or making friends. People with autism may like specific things and prefer to do the same things every day. Everyone with autism is different. Some people with autism can do many things on their own while some may need help.

Mark and Anna want Mark to make friends and play with friends at school.

Shaun and his mum, Maddy

Shaun is 10 years old.

Shaun loves to swim, play sport and make pancakes.

Shaun is very friendly.

Shaun has a lot of difficulty with talking and he is learning **sign language**.

Sign language is how many people who are deaf talk. Sign language uses hand and finger shapes to form words and sentences. There are many sign languages in the world. Sign language in Australia is called Auslan.

Shaun and Maddy are getting help from therapists to improve Shaun's talking.

Leo and his mum, Sophia

Leo is 19 years old.

Leo is always on the move. Leo has fun most of the time.

Leo finds it hard to learn, talk and understand. Leo also has autism.

Leo and Sophia are trying to find somewhere for Leo to go during the day where he can be with his friends.

Sophia wants Leo to feel safe at this place.

Joe and his mum, Sandra

Joe is 21 years old.

Joe is very friendly and caring.

Joe finds it very hard to learn. Joe has a difference with one of his **chromosomes**.

Each person has 46 **chromosomes** inside them which carry unique information that is passed on from parents to children. Having too many, not enough or different looking chromosomes can cause disability.

Joe and Sandra are looking for a job for Joe

Mitch and his sister, Fran

Mitch is 24 years old.

Mitch loves his family.

When Mitch isn't busy, he likes to play on his ipad.

Mitch finds it hard to learn, talk and understand and he also needs some help with movement.

Mitch and Fran are working on improving Mitch's life skills so that he can live by himself.

Katherine and her mum, Lisa

Katherine is 24 years old.

Katherine likes to ask lots of questions and to make people laugh.

Katherine likes swimming, art and being outside.

Katherine sometimes finds it hard to learn, talk and understand.

Katherine has autism and **anxiety**.

Anxiety is when you feel worried or sad when something happens, or you think something bad will happen. Anxiety can cause a sore head and an upset tummy. The anxiety can go away and get better but for some people it can stay for a long time.

Katherine and Lisa are testing different medicines that can help Katherine's anxiety.

Nathan and his mum, Jodie

Nathan is 25 years old.

Nathan likes to spend time with his friends and he loves to talk.

Nathan has **Cerebral Palsy** and he uses a wheelchair.

Cerebral Palsy is a type of disability where some people have difficulty moving and sitting or standing by themselves. It can sometimes be hard to walk and talk. Each person with Cerebral Palsy is different. It usually starts when a person is born.

Nathan and Jodie are building a house for Nathan and his two friends to live in.

We will tell you more about Nathan later on.

Dave and his mum, Sandra

Dave is 28 years old.

Dave can understand two languages, English and Lebanese.

Dave finds it hard to talk and he needs help to make decisions.

Dave and Sandra are trying to make his day program safer.

Pete and his sister, Steph

Pete is 28 years old.

Pete trusts many people.

Pete likes to have fun and play tricks on his family.

Pete finds it hard to learn, talk and understand and he also needs some help with movement.

Pete and Steph are working on helping Pete to do things by himself.

Emma and her dad, Brad

Emma is 28 years old.

Emma is very happy and cheerful.

Emma has lived by herself for 6 years.

Emma finds it very hard to learn, talk and understand.

Emma has autism.

Emma likes things to happen the same way each day.

Emma and Brad are working on helping Emma to make decisions by herself.

Connor and his carer, David

Connor is 36 years old.

Lots of people know about Connor because he is very good at taking photos and making art.

Connor had a **seizure** when he was born.

A **seizure** is when messages in the brain move too fast or in a different way. This can make people have a fit which can cause someone to shake and not have control of their body.

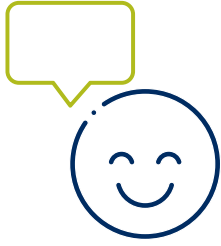
Connor sometimes finds it hard to learn, talk and understand.

Connor wants an ongoing job so he can move into his own home.

After we spoke to all the people with intellectual disability we came up with six main things that impact on the lives of young people.

We looked for information from research, other reports and programs to find out what things can help young people to have better lives.

We also talked to people that work in the community, people who conduct great research and people that support young people with intellectual disability around Australia.



A story to share

We will tell you a bit more about Nathan now.

Nathan lives with his mum, Jodie in Melbourne.
Nathan doesn't have any brothers or sisters.

Nathan is 25 years old.

Nathan likes to spend time with his friends and he loves to talk.

Nathan has Cerebral Palsy and he uses a wheelchair.

Nathan can remember names, find places
he visits often and talk with others.



At school

When Nathan was little, he went to two schools –
a school for children with disability and a school
for children with and without disability.

Nathan liked school when his support
teacher understood what he needed.

Nathan was able to make friends at the
school for children without disability.

It was harder for Nathan to make friends at the
school for children with disability because he was
put in a different classroom to that of his friends.

Jodie tried to get Nathan in the same class as his friend but
this did not happen. Jodie thought the school for children with
disability could have helped Nathan more to make friends.



After school

Nathan is now an adult.

When Nathan is bored, his carers often think he is being naughty.

But Nathan is not being naughty, he wants to talk with his carers.

Jodie worries that Nathan's carers do not understand him well enough.

Jodie knows that Nathan is **respectful** to other people.

Respectful means when you are polite and kind to people.



What does Nathan want?

Nathan wants to live in his own home with his friends.

Nathan is used to living away from Jodie as he often stays in **respite homes**.

A **respite home** is where people with many care needs may go to stay so that their carer or family can have a rest.

Nathan has lots of friends that Jodie has helped him to make.

Nathan has a good support network that can help him to look after himself.



6 things that can help

We listened to everything that everyone told us.

We found there are 6 things that people can work on to make life better for young people with intellectual disability.



1. Help young people with intellectual disability to do the things that they want to do

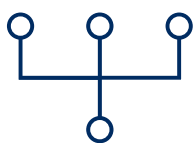
What we learnt

- Young people with intellectual disability should be helped to be able to do what they want to do in their life.
- This was a common hope for carers and families and should be what support services focus on doing.
- Young people with intellectual disability are not always asked about what they want to make their life better.
- Some people don't know how to talk with people with intellectual disability. This means young people with intellectual disability can get left out of conversations.
- Young people with intellectual disability need help to understand all the service options that they can use to do what they want to do.



What can help?

- Young people with intellectual disability must be included when making decisions about their life.
- They must get the supports and information that they need to participate and know what is possible.



2. Create opportunities for young people with intellectual disability to go to school, get a job and be a part of the community.

What we learnt

- Young people with intellectual disability should have good services and support from a very early age.
- This can help young people with intellectual disability to live the life that they want to live
- Young people with intellectual disability are not always fully included at school, at work and in their community.
- Services and supports that are ready to work with young people with intellectual disability are hard to find.
- It can be very hard for people with intellectual disability to do what they want after finishing school.



What can help?

- People who work at schools, learning places, workplaces, employment services and in disability services must work together to support young people with intellectual disability.
- Young people with intellectual disability must be provided with an environment that makes them feel supported and included.
- Young people with intellectual disability need plans that last a long time to help them as they grow older.
- There must be money and trained people ready to support young people with intellectual disability to learn, find a job and participate in the community.



3. Create safe homes for young people with intellectual disability

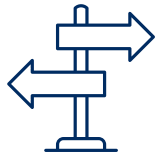
What we learnt

- Many young people with intellectual disability want to live in their own homes.
- Carers also want young people with intellectual disability to be able to live in their own homes.
- Safe and suitable homes for people with intellectual disability are difficult to find. Good support is not always available to let young people with intellectual disability live where they want to live and with who they want to live with.
- Different supports are needed to help young people with intellectual disability as their carers get older.



What can help?

- Everyone needs to work together so that young people with intellectual disability can find homes and supports so that they can live where they want to live and with who they want to live with.
- Young people with intellectual disability and their carers should get help in planning their supports for the future.



4. Help young people with intellectual disability to choose and access the right services

What we learnt

- It is important that young people with intellectual disability can access the very best services
- The National Disability Insurance Scheme is giving young people with intellectual disability more services to choose from, but it is still difficult for people that need lots of support.
- It can be hard for young people with complex intellectual disability to find the right supports.
- Support plans don't always give young people with intellectual disability what they need
- Sometimes there is not enough money to pay for services.
- There is not enough staff that understand how to work with young people with intellectual disability.
- There is not enough support to help young people with intellectual disability make good choices



What can help?

- Everyone including people who work at the Government and people who work for the National Disability Insurance Agency need to work together.
- Everyone needs to work together so young people with intellectual disability can get better services and be supported to make good choices.



5. Help young people with intellectual disability to be healthy

What we learnt

- Being healthy is an important part to having a better life.
- Young people with intellectual disability can have many and complex health difficulties
- Health services need to be able to provide **holistic care**

Holistic care means to treat medical problems but also look at social and other things that may cause problems for people with disability.

- People who work in health like doctors, nurses and therapists often don't know how to talk and care for young people with intellectual disability.
- There are sometimes problems with how prepared the health system is to support young people with intellectual disability that have more complex difficulties.
- There are more barriers when young people with intellectual disability also have difficulties with their mental **wellbeing**.

Mental wellbeing is how someone reacts to good and bad things in life. It includes how people think, manage their feelings and what they do each day.

- It can also be hard for people who work in health and people who work in disability to work together.



What can help?

- Everyone needs to work together so young people with intellectual disability can have access to good health care
- People who work in health and mental health services need to improve their understanding and ability to support the different health needs of young people with intellectual disability.



6. Create an environment where young people with intellectual disability are valued by everyone.

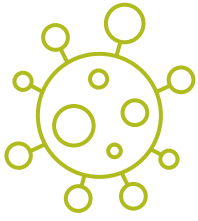
What we learnt

- If young people with intellectual disability are valued in communities then their lives are improved
- People in the community can think badly about young people with intellectual disability. This is disappointing and wrong. The community needs to understand more about young people with intellectual disability.
- The community needs to think more positively about young people with intellectual disability.



What can help?

- Everyone needs to work together to show how important people with intellectual disability are in our community.



Coronavirus

Coronavirus is a virus that has affected many people around the world.

A virus is an illness or disease that can easily spread from one person to another person.

Coronavirus spread very quickly around Australia.

Many people were asked to stay at home to stop the spread of coronavirus.

Coronavirus made life harder for some young people with intellectual disability.

It showed how young people with intellectual disability continue to be left out of the system.

Here are some of the things that were made harder:

- It was harder to access support services
- More young people with intellectual disability were likely to be hurt or not looked after properly
- It was harder for services to help young people with intellectual disability

We still don't know what is going to happen after. For example:

- There might be less jobs for young people with intellectual disability
- Young people with intellectual disability might find it difficult to access services that are being provided on the internet

Contact us


If you would like to speak to us about this report you can contact us by:



Email: info@socialventures.com.au



Website: socialventures.com.au



Cover image:
Anthony Romagnano,
Grace Jones, 2018

Social Ventures Australia

Brisbane | Darwin | Melbourne | Perth | Sydney | ABN 94 100 487 572 | AFSL 428 865
info@socialventures.com.au | socialventures.com.au | @Social_Ventures

SVA Consulting



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