

About Down Syndrome Fact Sheet



Down Syndrome
Australia

About Down syndrome

Down syndrome is the most common genetic disability. There are approximately 13,000 people in Australia who have Down syndrome. The birth rate for Down syndrome is one in every 1,100 births in Australia.

Down syndrome is not an illness or a disease. Down syndrome is caused when a person is born with an extra chromosome. People with Down syndrome have 47 chromosomes instead of 46. They have an extra chromosome 21, which is why Down syndrome is sometimes known as trisomy 21. Down syndrome is named after Dr John Langdon Down who first described it.

Down syndrome impacts intellectual development, some physical characteristics and aspects of a person's physical health. Because no two people are alike, this will vary from one person to another.

Although we know how Down syndrome occurs, we do not know why it happens. Down syndrome occurs at conception, across all ethnic and social groups and to parents of all ages. It is nobody's fault. There is no cure and it does not go away. Down syndrome can be detected prenatally or at birth and is confirmed by a blood test.

What does it mean to have Down syndrome?

Most of the young people growing up with Down syndrome today will lead quite ordinary lives in the community. Some people with Down syndrome may not need much help to lead an ordinary life, while others may require a lot of support.

Having an intellectual disability

Down syndrome is the most common cause of intellectual disability that we know of. Everyone who has Down syndrome will have some level of intellectual disability. There will be some delay in development and some level of learning difficulty. Because everyone is unique, the level of delay will be different for each person.

When a baby is born, there is no way to tell what level of intellectual disability the child may have. Nor can we predict the way in which this may affect a person's life. However, we do know that having Down syndrome will not be the most important influence on how that person develops and lives their life. Instead, what happens after birth will be much more important as family, environmental, cultural and social factors will shape their life, just like everyone else.

A lot of people with Down syndrome speak fluently and clearly, however – for many – speaking clearly can be difficult and they will need speech and language therapy to achieve this. Some people will find it very difficult to develop language or speak clearly at all. However, regardless of a person's ability to speak, people with Down syndrome can understand a lot more than they can express with words. This often means that their abilities are underestimated, which can lead to frustration and isolation.

Living an ordinary life

People with Down syndrome are not different from anyone else.

They have the same needs and aspirations in life that we all do, including:

- a good place to live
- meaningful employment
- the opportunity to enjoy the company of friends and family
- love and intimacy
- having a role in our community.

However, achieving these goals can be harder for people with Down syndrome than it is for everyone else. Many people with Down syndrome are likely to need some level of support to help them achieve the kind of life that most people take for granted.

In the past, many people with Down syndrome have not had the opportunity to develop to their full potential. Often, they have been separated from the rest of the community, living in segregated settings such as care institutions. Low expectations were placed on them and there were limited opportunities for learning and personal growth.

Today, people with Down syndrome have access to better health and medical advancements, as well as better education and developmental opportunities, which have provided an improved quality of life.

To be a part of a community you have to be in it. This means that people who have only experienced life in a segregated setting may find it difficult to be included in the general community. Life for people who grow up being included in families and communities will be very different than it has been for those who have always lived in care facilities.

Encouraging children with Down syndrome to go to a school and attend activities with their peers from their community has many benefits. It opens the way for a smooth transition to adulthood and encourages meaningful inclusion in the community.

People with Down syndrome need opportunities to reach their full potential, like we all do. When given these opportunities, they become valued and productive members of their families and the community.

Being an individual

One of the greatest challenges that people with Down syndrome face is the attitudes of other people who do not understand what it means to have Down syndrome. Despite much change, many people still don't see the individual person. Instead they just see 'Down syndrome' and expect everyone with Down syndrome to be more or less the same.

People with Down syndrome are very different from each other, just as we are all different. Every person with Down syndrome is unique, with their own talents, abilities, thoughts and interests. And, like everyone else, people with Down syndrome have strengths and weaknesses. While one person may read very well but find basic mathematics difficult, another might be a first-class cook and live independently in the community, but will have to work hard to speak clearly. People with Down syndrome are also likely to share similar passions, culture, interests and skills as other members of their family, as we all do.

People with Down syndrome do not all look alike. In fact, people with Down syndrome look more like other people in their own family than they look like others with Down syndrome. Although there are some physical features associated with Down syndrome, there is large variation in how many of these features an individual may have. For some people, one feature may be very prominent while in another it may not exist at all. Importantly, the physical characteristics of Down syndrome that a person may have do not tell us anything about that person's intellectual ability.

Another common misconception is that all people with Down syndrome are happy and affectionate. People with Down syndrome experience all the same emotions as everyone else. They may be happy, sad, embarrassed, frustrated, thoughtful and fall in and out of love, just as we all do. They may, however, find it difficult to express their feelings in words. This can lead to frustration and the expression of feelings through behaviours.