

Introduction to Intellectual Disability



What is intellectual disability?
Definitions of disability
A different view of disability
Recognising intellectual disability from other conditions
Appropriate language
Disability Etiquette
Communication tips
Writing in Easy English
Disability Standards and Discrimination

What is intellectual disability?

- a disability that affects the way you learn
- you can be born with an intellectual disability or acquire one under the age of 18
- it can affect a person in the following ways:
 - it may take longer to learn things
 - the person may have difficulty reading and writing
 - it can affect how the person's communication
 - it will affect the person's understanding
 - the person may find it difficult to maintain eye contact
 - the person may have difficulty understanding abstract concepts
 - it may affect the person's ability to plan and to problem solve
- it may affect the person's ability to adapt to new or unfamiliar situations
- it can involve the person presenting well – "cloak of competence"

Clinical definition of intellectual disability

Intellectual disability is a disability which occurs in the developmental period of life (i.e. before the age of 18) and is characterised by below average intellectual functioning. Most people with intellectual disability are born with the disability.

Clinically, and for the purposes of proving in a court that a person has an intellectual disability, intellectual disability is best assessed by a psychologist as:

- an IQ of 70 or under, PLUS
- deficits in at least 2 areas of adaptive behaviour, ie:
 - communication
 - self-care
 - home living
 - social skills
 - self direction
 - leisure and work
 - learning.

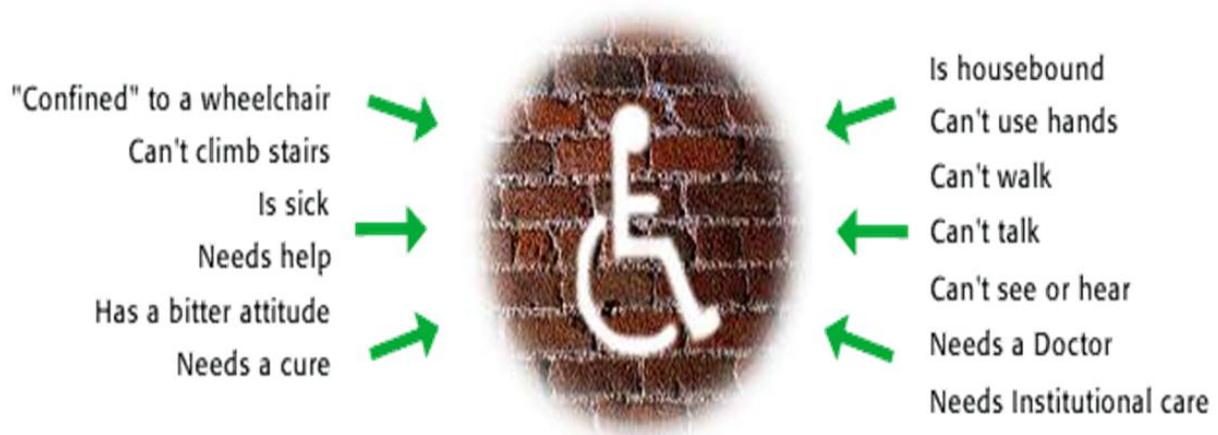
2-3% of the New South Wales population has an intellectual disability

In clinical terms, intellectual disability is often defined in terms of the severity of the disability:

Level of disability	% of people with intellectual disability	IQ
BORDERLINE		70-75
MILD	75%	55-70
MODERATE	20%	30-55
SEVERE	5%	under 30

This approach, however, encourages a focus on the deficits of the person, rather than the abilities and is a "medical" way of looking at disability, but for the purposes of proving to a court that a person does have an intellectual disability, it is what is required.

This is the medical model of disability

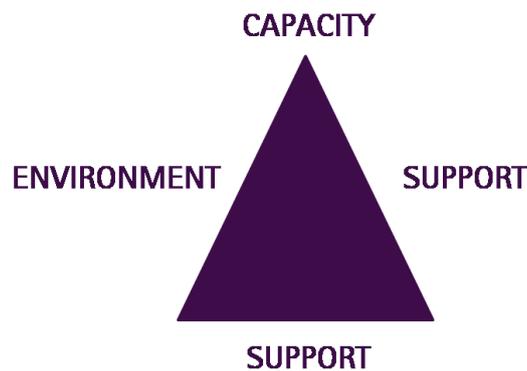


(diagram from self direction community project, 2001, www.selfdirection.org/dat/training)

"People with disability should adapt to the world as it is"

Sociological definition of intellectual disability

A more constructive and pragmatic definition is to define intellectual disability in terms of the support needs of an individual. This approach sees the effect of the disability as something that will vary and can be increased or decreased by external factors. It does not view intellectual disability as an unchangeable characteristic of the individual. This definition does not rely on the capacity of the person being set in stone, but also on the environment and the support that they receive.



So, adjusting the environment and the support to meet the person's needs can increase the person's capacity and reduce the effect of the disability!

The social model sees the 'cure' to the problem of disability in the restructuring of society. Unlike medically based 'cures', which focus on the individual and their impairment, this is an achievable goal and to the benefit of everyone. This approach suggests that the individual and collective disadvantage of people with a disability is due to a complex form of institutional discrimination as fundamental to our society as sexism, racism or heterosexism.



(diagram from self direction community project, 2001, www.selfdirection.org/dat/training)

Intellectual disability is different from other cognitive disabilities

- Mental illness
 - Often episodic
 - Affects perception and mood
 - E.g. Schizophrenia, Depression, Bipolar Affective Disorder (used to be known as manic depression)
 - For further information contact the Mental Health Information Service 9816 5688. Website www.mentalhealth.asn.au

- Brain injury
 - can be caused by stroke, accident or drug/alcohol
 - can impair memory, thinking, perception, attention and emotions. The brain injury can result in disinhibited behaviour or poor impulse control.
 - People rehabilitate over time i.e. years
 - For further information: contact the Brain Injury Association Ph 9749 5366. Website: www.biansw.org.au

- Dementia
 - loss of short-term memory
 - progresses into confusion/disorientation
 - Alzheimer's Disease is one type of dementia
 - For further information contact the Alzheimer's Association Ph 9805 0100. Website: www.alznsn.asn.au

- Autism
 - Lifelong developmental disability
 - Affects ability to relate to people and the world around them
 - Impairs social interaction, communication and behavior (eg may be compulsive)
 - Often experience overwhelming anxiety, frustration, confusion
 - Most people with autism have some degree of intellectual disability but not all. People with Asperger's syndrome generally have average to above average intelligence
 - Website: www.autismnsw.com.au



The Power of Language

The use of appropriate language is not just an exercise in political correctness. It is exercising respect for the people that you are speaking about or to.

Language is not fixed and changes with time to reflect changes in government policy, public perception and, for many groups, a move towards more equal opportunity.

Up to the 1980's policies of institutionalisation for "handicapped" people were the norm. People lived in cramped wards where their basic physical needs were met and little else. These people were seen as numbers in many cases. They were seen to have no value in society; they could not work or contribute in any way. Words like "mongol", "retard", "spastic" and "handicapped" were socially acceptable.

Today, due to new models of disability and a move towards people with intellectual disability living and working in the community, we have come to realise that people with intellectual disability have a place in society and make valuable contributions in daily life. People with intellectual disability have families, get married, get divorced, get emotional and get in trouble the same as everyone else!!!

Disability is not an illness. It is part of a person's identity but it is not all that a person is. People with intellectual disability do not suffer, are not afflicted with and are not victims of their disability.

When thinking about language, always think "person first".

Do say	Do not say
Person who has/ person with/ person who has experienced	Victim of/ crippled/ suffering from/ afflicted by. Do not use words that invite pity or reinforce impressions of frailty or dependence.
Wheelchair user/ person who uses a wheelchair	Wheelchair bound or confined to a wheelchair. Remember that a wheelchair can represent freedom to its user.
Person with a disability	Invalid. Don't equate illness with disability.
Person who has epilepsy	Epileptic. Remember this is a person first not a medical condition.
Person who has cerebral palsy	Spastic
People with disability/ with autism	The Disabled/ The Autistics. This makes people with disabilities seem like a group who are separate from the rest of society



Disability Etiquette

- Offer assistance to a person with a disability if you feel it is appropriate but wait for an answer before you help. Remember it is their right to say no. Do not assume you know the best way of helping – listen to instructions you are given by the person.
- Treat adults like adults. Do not use gestures more suitable for children.
- Do not refer to an adult as “cute” or “adorable”. Would you use these kinds of terms when speaking about a person who did not have a disability?
- If someone is a wheelchair user, do not lean on their chair. The chair is part of the personal space of the person using it.
- Make appropriate physical contact with people with disabilities according to the situation, the same as anyone else (e.g. handshake on introduction). Some people with intellectual disability may for various reasons have inappropriate social responses. (e.g. hugging or kissing new people or in work situations). It is important to establish appropriate boundaries that both you and the person are comfortable with. On the other side of this, a person who has autism may be uncomfortable with any form of physical contact but it is important to offer.
- Talk directly to the person not through a support worker or companion. Make eye contact.
- When speaking to a wheelchair user, position yourself at eye level if possible.
- Do not be embarrassed about using common expressions such as “I’ll see you later” when talking to someone with a visual impairment.
- Do not make assumptions about the severity of disability. Some people hide their disability better than others.
- Just because a person does not communicate verbally, doesn’t mean they do not understand.
- In the same way, just because a person speaks very well does not mean they DO understand. Ask questions to check understanding if you are unsure.
- Do not shout at a person if you think they cannot hear you or they do not understand. If they cannot hear you this will not help. You may need to write it down.
- Facial gestures and expressions help people who have hearing problems to understand you. Do not hide your mouth or look away when speaking.
- To attract someone’s attention, a light touch on the shoulder is okay.
- If someone has speech problems, give them your whole attention. Be patient. Do not correct or speak for the person. Resist the temptation to finish the sentence.
- If you have difficulty understanding, don’t pretend. Repeat what you do understand and let the person’s reaction guide you.

Robert's 7 Point Plan

Robert Strike is a leading advocate for people with intellectual disability in NSW, and has years of experience in the community sector working to improve the lives of members of the community.

- Look beyond the disability label - you will be surprised. Labels are for jars not people!
- Talk to us, NOT at us or through others.
- Hearing is not enough. Listen to us and respect what we say.
- Do things with us, NOT for us.
- Explain things slowly and get straight to the point.
- Talk to us face to face.
- Be honest with us...we have antennas for bullshit!!!

Improving Communication with People with an Intellectual Disability

Tips	Blockers
Allow plenty of time	Being rushed
Build rapport, start with something easy and of interest to the person	Not taking time to put the person at ease
Invite the person to say if they aren't sure what you mean	Assuming the person will tell you if they don't understand
Let the person tell the story in their own words and in their own time first. Then clarify	Doing all the talking. Firing question after question. Closed questions or questions that suggest an answer
Deal with one piece of information or question at a time	Too much information or double barrelled questions
Check understanding but make sure the person knows this is to make sure you've explained well enough	Giving more information without making sure that the person has understood
Ask open questions – encourage the person to tell their story at their own pace	Asking closed questions or leading questions that suggest an answer
Allow time for a response even if this is slightly uncomfortable. Wait longer than you normally would	Rushing / not waiting for the answer. Needing to fill the silence. Coming in with more information when the person is still thinking about the last
Use plain everyday language	Jargon, technical language, long sentences, double negatives
Relaxed body language	Impatient or worried body language
Checking for understanding	Problem solving instead of listening



Easy Read

Having an accessible environment is about being proactive not reactive. This means thinking about how we present all of our information. Are letters that are written to clients accessible? Can clients access all the information that you would expect any other client to access?

To make written information more accessible the following tips are important...

- Size of print should be 14 or 16 point
- Font should be easy to read (the nearest to handwriting is the easiest to read. The font in this document is Comic Sans and is considered the most accessible)
- Use no more than one or two fonts
- Line spacing should be 1.5 – 2
- Use headings when you change subject or have a lot of text
- Use short sentences. (Think of a world where the only punctuation is a full stop!)
- Have one idea per sentence
- Try not to use abstract concepts
- Illustrations are important to help you get your point across if possible
- Black writing on yellow paper is the easiest to read
- Test your information if possible with a person with an intellectual disability.

NSW Disability Services Act 1993 & Disability Services Standards

All NSW government funded services for people with disabilities have to meet the Disability Service Standards.

These standards have been developed from the Disability Services Act 1993 (NSW). The basis of the Disability Services Act (DSA) is that people with disabilities have the same basic human rights as other members of Australian society. They also have the rights needed to ensure that their specific needs are met. There are also Commonwealth Disability Standards which are very similar.

Through regulating services to people with disabilities, the DSA aims to:

- maximise potential for people with disabilities;
- allow for further integration of people with disabilities;
- achieve positive outcomes such as increased independence, employment opportunities, etc;
- promote positive image.

There are 10 Disability Standards, they are:

1. Service Access
2. Individual Needs
3. Decision Making and Choice
4. Privacy, Dignity and Confidentiality
5. Participation and Integration
6. Valued status
7. Complaints and Disputes
8. Service Management
9. Family Relationships
10. Protection of Human Rights and Freedom of Abuse

Making a complaint

If you believe that a service is not meeting one or more of the Disability Standards, you can make a complaint to the

Community Services Division
NSW Ombudsman
Tel: 9286 1000

The Ombudsman oversees a system of Official Community visitors to residential services for people with disability who can be helpful with problems in such services.

Discrimination

Discrimination is treating a person, or group of people, less favourably than others would be treated in the same circumstances because of their membership of a particular group, such as having a disability, or being a woman.

Discrimination can be direct or indirect

Direct discrimination means someone is treated unfairly compared to someone else in the same or similar circumstances and this happens because of their being part of a particular group e.g. because of their sex, race, age or disability.

Indirect discrimination is about unfair exclusion. It is where rules, practices, policies which appear to be neutral, and to apply to everyone, do in fact have an unequal impact - in effect excluding a group of people from an opportunity. If the requirements imposed are unreasonable then it amounts to unlawful discrimination.

When is discrimination unlawful?

The following Acts make certain types of discriminatory behaviour unlawful:

- Anti-discrimination Act (NSW)
- Disability Discrimination Act (Commonwealth)
- Racial Discrimination Act (Commonwealth)
- Sex Discrimination Act (Commonwealth)
- Human Rights and Equal Opportunity Commission Act (Commonwealth)

These Acts are concerned with discrimination in a person's public life.

The most important Acts for people with an intellectual disability in NSW are the NSW Anti-Discrimination Act 1977 and the Commonwealth Disability Discrimination Act 1992

NSW Ant-Discrimination Act 1977 provides that discrimination may be unlawful if it is based on one of the following grounds:

- Race
- Disability
- transgender status
- sex
- age
- homosexuality
- marital status

And in the following areas:

- applying for a job
- goods and services
- at work
- registered clubs
- at school, college or university
- accommodation

Commonwealth Disability Discrimination Act (DDA)

The DDA makes it unlawful to discriminate against a person based on disability in the following areas:

- employment and work related
- goods and services
- education
- Commonwealth laws and programs
- Land
- clubs and associations
- accommodation
- access to premises used by the public
- sport

Disabilities are covered whether they are categorised as physical, intellectual, psychiatric, sensory, neurological or learning disabilities. Discrimination against a person because they have some physical disfigurement, or because they have some disease-causing organism (eg HIV) present in their body is also covered, as is discrimination when the person does not actually have a disability but is perceived by others as having a disability. The Act also makes it unlawful to discriminate against a person because of their association with a person with a disability.

How do you complain?

There are two ways of seeking redress for discriminatory acts against people with an intellectual disability

1) Human Rights and Equal Opportunity Commission (HREOC) Complaints can be made within 12 months after the discrimination has happened. Complaints can also be made where an act of discrimination is proposed but has not yet happened.

Tel: 1300 656 419 - Complaints Infoline

2) Anti-Discrimination Board (ADB) Complaints can be made to the Anti-Discrimination Board within twelve months of the time of the discriminatory act.

Tel: (02) 9268 5555 or 1800 670 812

How complaints are handled

Both acts are aimed at changing attitudes. There is therefore much more emphasis on education, negotiation and conciliation than on imposing penalties.

Both bodies will try to conciliate a settlement. If your complaint to the ADB cannot be resolved by conciliation, then it can be referred to the Administrative Decisions Tribunal. If your complaint to HREOC cannot be resolved by conciliation, it may have to be heard by the Federal Court which is likely to cost more in time and money than the State Tribunal.

Complaints

It is ok to complain

If you want to make a complaint there are different places to go, it depends on what you want to complain about. Below is a list of contacts to make complaints for different reasons.

Anti Discrimination Board (ADB)

The ADB is the place to go for discrimination under the NSW Anti-Discrimination Act 1977.

Tel: (02) 9268 5555 or 1800 670 812

Human Rights Commission (HRC)

HRC is the place to go for breaches to Commonwealth law such as the Racial Discrimination Act, Sex Discrimination Act, Human Rights and Equal Opportunity Act, Disability Discrimination

Tel: 1300 656 419 - Complaints Infoline

1300 369 711 - General enquiries and publications

NSW Ombudsman, Community Services Division

NSW Ombudsman, Community Services Division is the place to go to make a complaint about a service funded by DoCS (Department of Community Services) or DADHC (Department of Ageing, Disability and Home Care).

Tel: (02) 9286 1000 or 1800 451 524

Abuse and Neglect Hotline

Can take complaints and refer callers for assistance regarding abuse or neglect of people with a disability

C/- People with Disability (PWD) 9370 3100/1800 422 015

The Starfish

An old man was picking up objects off the beach and tossing them out into the sea. A young man approached him and saw that the objects were starfish. "Why in the world are you throwing starfish into the water?"

"If the starfish are still on the beach when the tide goes out and the sun rises high in the sky, they will die", replied the old man.

"That is ridiculous. There are thousands of miles of beach and millions of starfish. You can't really believe that what you're doing could possibly make a difference!"

The wise old man picked up another starfish, paused thoughtfully, and remarked as he tossed it out into the waves, "It makes a difference to this one."

