

At MDAA we do **advocacy**. This means we work together with people with disability, families, and the community to promote, protect and secure the rights and interests of people from a non-English speaking background (NESB) with disability and their families and carers in NSW.

How we can help you and your family

Individual Advocacy: A worker, called an advocate, works with you when your rights are ignored. The advocate will 'stand beside' you and support you, so you can make your own decisions and get what you need. An advocate can help you stand up for your rights, for example, when you have problems with housing, immigration, work, school, and disability services.

How we can help your community

Advocacy Development: We work together with groups of people with disability and their families to learn more about standing up for your rights and needs. This can help you to have a say about the things that are important to you.

Community Development: MDAA can work with your community to increase knowledge and awareness about disability, disability services and the rights of people with disability.

Systemic Advocacy: We lobby politicians and government departments to make things better for people from a NESB with disability and their families.

Our advocacy and community development services are free.

Multicultural Disability Advocacy Association of NSW



opening doors

Disability experienced in India and Australia



Working for a NSW where the diversity of disability and culture is anticipated, supported and celebrated



Sikh Council of Australia, Inc.



Federation of Australian Indian Association (FAIA)
Incorporated in New South Wales



NSW Indian Welfare Association

Acknowledged by

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Disability experienced in India

This introduction focuses on experiences of disability for Indian people and families. Some of the attitudes and beliefs discussed here are also common to people with disability and their families in other cultures.

How we treated people with disability in the past

With a population of nearly 1.1 billion, India has a great variety of cultures and religions. But underlying the diversity and complexity of the Indian culture are certain core values. In general, the traditional response to people with disability across all Indian religions and traditions is care and support being provided by the family.

Overall disability was not seen in a positive way, and often people with disability were viewed as persons to be shunned. Some types of disability were more stigmatised than others and not recognised as disability at all, such as intellectual disability, mental illness and epilepsy. Physical and sensory disability were more apparent and recognised, especially blind people were often supported in schools and universities.

Harshul

Harshul was born blind. In his childhood he got much support at school and later he attended university, where he visited reading rooms with his friends and participated in study groups. In exams the university supported him with a “writer”.

As disability was something we did not speak much about, there was little knowledge about what a disability was. We did not support people with disability through education, training and

employment or promote their rights in society. Sometimes we made fun of people with disability.

People often tried to hide their disability from others, as they felt ashamed about being different. Many parents did not want to let the community know that one of their children had a disability, as they feared and experienced social isolation. People with disability did not participate in community life, especially people with mental illness or intellectual disability. Schools did not accept children with disability and employers did not hire people with disability.

People in the middle and upper classes thought that disability was simply a concern for the family and perceived it as the family's challenge. This prevented a shift in thinking about disability as a social issue and resulted in indifference by society and the state. For many poor families the story remains very different. The struggle to survive for many people born into the lower strata of Indian society is harsh, entailing extreme hardship to bring up or care for a family member with disability.

What are the myths or beliefs about disability in India?

For many Indian people the word 'disability' carries with it a feeling of pity. Disability is still hidden. People will avoid a family where there is a family member with disability and will not marry into this family. Usually we see our children as investments for the future. Often when a child is born with disability, the parents do not see that child as a source of support or income in the future. Because of our patriarchal society, a boy born with disability is more accepted than a girl born with disability. A girl with disability has great difficulties if she wants to marry. Sometimes the family has to pay extra dowry for the girl to be married.

As India is a country with very rich traditions and many diverse cultures, there are different assumptions and stories about

disability. It is very common that we view disability with superstition. Some people used to believe that a child born with disability was to blame for anything bad happening on the same day, week or month the child was born. So if an accident occurred, we would say that the 'evil spirit' or the 'bad energy' of the child born with disability was the cause of that accident. Another superstition is to blame the constellation of the planets when a child with disability is born. The parents often try to pray to the gods and invoke the blessing of the planets through mantra chanting.

When a child with disability is born the family experiences grief and distress, but also accepts it as one's fate or destiny. The Hindu belief in Karma, or payment for past deeds, underlies this accepting spirit. A child born with disability is considered as a sign of the past Karma for the child, the parents or the family and is accepted as 'sent from God'. In general the family does penance to redress the wrongs of the past.

Slowly the old beliefs of fate and evil spirit are giving way to early intervention and treatment, proper care and support, providing equipment and education.

Were there any events that changed attitudes to people with disability?

India has developed very quickly in recent years. Attitudes towards people with disability are changing especially due to influences from outside India, via television and media and increasing levels of literacy and education. Education is now free for children up to the age of 12 years, and in some states of India free meals attract children to attend classes. Also many people are travelling to foreign countries for education or holidays, and they come back to India with greater awareness about many issues, including disability.

Mahavir

Mahavir is a blind man, who studied at university and continued with a postgraduate education program. He had to face many negative attitudes from teachers and lecturers. They discriminated against him because of his disability. Nevertheless he did not let this stop him and finished his studies.

In the past many eminent leaders, as for example Dr Ambedkar or Mahatma Gandhi, contributed to raising awareness of disability and at present, political and religious leaders like Satya Sai Baba, Mata Amrithanandamayi and Baba Amte support people with disability to improve their living situations and raise awareness in the community.

Has the language we use to talk about people with disability changed?

We have many languages in India. In the past in all of those languages we often used crude words to talk about people with disability, such as 'mad' or 'lame'.

In recent years the way we speak about disability has begun to change. We are now talking about disability in a more positive way, especially about people with an intellectual disability. For example the word 'challenged' instead of 'disabled' is used more often now. But even so some of us still sometimes use negative terms when we talk about people with disability.

Are there differences in the way city and country people respond to disability?

The majority of people in India live in rural areas, where people often have stronger bonds to the community than in cities. This results in less isolation of, more compassion towards and time for people with disability. The problem in country areas is the lack of

resources. Services that do exist are poorly equipped. In cities the traditional way of many generations living together is decreasing, due to Western influence and employment of both parents. Parents do not have as much time to care for a family member with disability.



Most facilities, organisations, schools and hospitals are in cities. Sometimes families who have a child with disability are forced to move to or close to a city to get better services for the child. Buildings and streets in cities are often more accessible for people with a physical disability than in rural areas. But public accessibility in general has still to be improved in India. It is still common that people are simply unable to go out in public due to physical barriers.

In Indian cities it is quite common to find poor people with physical disability on the streets using their physical impairment to beg. This may cause people to view persons with disability with pity and look down on them and it may result in negative attitudes towards people with disability. On the other hand it is seen as a source of income, which other poor people without disability do not have.

What role do families play in caring for people with disability?



For us the family is the basic unit of existence. In the past 'family' included several generations living in the same household. This way of living is becoming less and less common, because more people move to cities in search of jobs. Nevertheless family bonds remain strong and siblings try to live near each other, to meet often and to support each other.

Families try to give their best in caring for a child with disability. If it is beyond their ability to care for the child, only then will they seek other aid. We see disability not only as a problem for the person with the disability but in a real sense as 'family disability'. The family tries to cope with the demands and needs of the person and to share the stress, especially the women in the household. It is common that the daily care of a person with disability is left to the women in the household.

With smaller family units it is getting more important to find affordable services to care for a family member with disability. Often there are no other options for a person with disability than to stay at home due to the lack of support services. Families who can afford it, pay for private services or for carers. Poor people rely on care within the family or on charities.

What services are there for people with disability?

Internationally acknowledged estimates say that about 70 million people with disability live in India, however the 2001 census estimated the number as 22 million. There are more and more non-government organisations (NGOs) and government services, but they still help only a very small proportion of people with disability.

Disability is strongly linked to poverty and the success of rehabilitation services for people with disability depends largely on



the success of community development programs. An improved quality of life for people with disability and their families would also benefit a large disadvantaged section of society, the poor.

In recent years, hundreds of NGOs and voluntary organisations have established professional centres for people with disability in all parts of the country. They offer counselling, day treatment, therapy, community education,

vocational rehabilitation, sheltered employment and referral networks for people with disability and their families. Though the government has set up national institutions to create awareness and develop specially trained personnel, service delivery still depends largely on the NGOs.

Unfortunately most of these services are not easily available to the majority of the population in India. Economic hardship, poor transport facilities and a lack of education make it harder for parents to access general services for a child with disability.

In most of our cities there are schools for children with different types of disability. In local schools we sometimes have trained teachers to establish integrated classes for children with physical and sensory disability, but children with mental illness or intellectual disability cannot go to ordinary schools.

Chandra

Chandra had polio as a young child and his legs were paralysed. Nevertheless he finished school, obtained a degree at university and now works as a bank officer. He got his driving licence as well and drives a car with automatic gears.

Over the past 50 years a disability movement has developed in India and NGOs have played a major role. The main problem is that most of the NGOs lack resources. Many activist groups have formed in different parts of India. The *Disabled Rights Group* was formed by the National Centre for Promotion of Employment for Disabled People in New Delhi and is represented in all different parts of India, North, South, West and East. They hold seminars to generate awareness about the rights of people with disability. Another group, ADAPT (*Able, Disabled, All People Together*), formed by activists of the Spastics Society of India, Mumbai, is a voluntary organisation working for children and youth with disability. The *Sri Ramakrishna Mission* is also well known for providing services for people with disability. Moreover private life care centres have

started to open in cities, with substantial donations from private businesses.

These NGOs and groups promote community care and life care centres assist people with disability to become independent by teaching handicrafts. Community based rehabilitation is very appropriate in our culture, where social and community bonds are quite strong and this should help people with disability become integrated into the community. These rehabilitation programs are limited to children and adults with high support needs, who need continued specialised support.

The government of India, with the assistance of the *National Institute of Disability, Research and Rehabilitation*, has set up the *National Information Centre on Disability and Rehabilitation* in Delhi, a centre that collects and provides information about disability. The *National Commission for Promotion of Employment for People with Disability* works on increasing employment opportunities for people with disability.

The Indian national government has not so far set up a social security system to support people with disability financially. This leaves the state governments mainly responsible for government social services, and the services vary from state to state. In some states people with disability have some subsidy for public transport. In recent years, hundreds of NGOs and voluntary organisations have established professional centres for people with disability in all parts of the country. They offer counselling, day treatment, therapy, community education, vocational rehabilitation, sheltered employment and referral networks for people with disability and their families. Though the government has set up national institutions to create awareness and develop specially trained personnel, the service delivery still depends largely on the NGOs.

What does the community know about the rights of people with disability? How has this changed over the years?

Thinking differently about disability has started in India only in the recent past. When we speak about disability we mostly mean physical or sensory disability, as mental illness and intellectual disability are still not usually recognised. The community still does not know a lot about the rights of people with disability. Sometimes even people with disability do not know much about their own disability. One of the main reasons for this is illiteracy.

The self-advocacy movement of people with disability gained strength during the 1970s, but there was no law enacted till the 1990s. In 1995 the *Persons with Disabilities Act* was introduced to protect the rights of people with disability and promote and ensure equality and full participation of people with disability. Unfortunately the Act is not fully implemented yet. Another Act was introduced in 1999: the *National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act*. Moreover, we have a certain percentage of jobs in government or semi-government departments reserved for people with disability. Unfortunately, accessibility to public buildings and areas is still not an important issue for the Indian government.

Although services for people with disability have developed in recent years and awareness of disability has risen, it is difficult to get the desired changes as quickly as we would like. The attitude behind many laws and services is still that of welfare or charity to be given to people with disability. There is no indication that these laws result from respect for the right of people with disability as citizens.

There are efforts made by the media to address the needs of people with disability and to promote awareness of disability. Doordarshan (TV) and All India Radio telecast programs

promoting rehabilitation of people with disability. Popular movies and TV serials sometimes show persons with disability as powerful and positive central characters. But still there is a general indifference towards the integration of people with disability into mainstream society. Famous people with disability try to change this.

Sudha

Sudha Chandran is a famous dancer and actor in India. She lost her right leg in an accident and got a prosthetic limb. With the prosthesis she continued her career, finished her studies at university and is now acting in TV serials.

We have seen changes and there is a disability movement in India, but as in many other places around the world there is still a long way to go.

Web Sites used in writing this document

<http://www.cirrie.buffalo.edu/india.html>

<http://www.disabilityworld.org/Aug-Sept2000/International/india.html>

<http://www.interights.org/pubs/Bulletin%2014.3%20Word%20Docs/Legal%20Protection%20for%20Disabled%20Persons%20in%20India.doc>

http://www.disabilityworld.org/09-10_01/women/ghai.shtml

http://www.choike.org/nuevo_eng/informes/1406.html

Disability experienced in Australia

What is Disability?

A disability is something that stops a person from doing things they want to in their day-to-day activities. At least 19%, or one in five people in New South Wales, will experience one or more of the following:

- blindness or vision impairment (even when wearing glasses or contact lenses)
- deafness or hearing impairment (even when fitted with a hearing aid)
- chemical sensitivity
- speech difficulties in their first language
- blackouts, fits or loss of consciousness
- disorientation in unfamiliar environment
- slowness at learning or understanding
- acute anxiety
- difficulty making decisions
- incomplete use of hands or arms
- difficulty in gripping or holding or carrying small objects
- physical weakness over distance or long waiting periods
- lack of balance and coordination
- incomplete use of feet or legs
- difficulty walking on uneven ground, stairs and slopes

- pain, fatigue and discomfort
- difficulty breathing
- long term illness
- medical conditions and/or physical trauma leading to one or more of the above

In Australia disabilities are often categorised into different types, such as: physical disability (e.g. polio, arthritis, burns, obesity, broken bones, amputation), intellectual or learning disability (e.g. autism, down syndrome, attention deficit disorder), psychiatric disability or mental health problem (e.g. post traumatic stress disorder, schizophrenia, depression), sensory disability (deafness, blindness) and neurological disability (e.g. brain injury, spinal injury – paraplegia and quadriplegia, cerebral palsy, Parkinson’s, multiple sclerosis).

A disability can be permanent or temporary. Many people with disability say that what usually stops them from fully participating in the community is not their disability, but the barriers put up by society and the negative attitudes of the community.

What support can people with disability get?

In Australia people with disability have the same human rights as other people. This includes having the right to be part of the community, make their own decisions and receive services that assist them to have a reasonable quality of life.



People with disability have the right to all the services people without disability can get. General community services need to provide services to people with disability. Just because somebody has a disability should not mean that they cannot get general services. In many instances people with disability can get support and assistance from the same places as people without disability.

However, to ensure that people with disability have the same opportunities there are specialist services available only to people with disability. These services include:

- Services assisting you to get a job or more training such as *Employment and Vocational services*.
- Services assisting you and your family to have a break from each other such as Centre-based and In-Home *Respite Care*.
- Services assisting you with your personal care such as *Attendant Care Services*.
- Services assisting parents when you first find out that your child has a disability such as *Early Intervention Services*.
- Services assisting mainly younger people with disability to learn more skills such as the *Transition to Work Program, Community Participation Programs, Community Access Services or Day Programs*.
- Services assisting you to live in the community with support such as *Accommodation Support Services*.
- Services assisting you with technology, equipment, therapy and para-medical specialist services, such as *PADP (Program of Appliances for Disabled People)*.
- Services assisting you to have your rights respected and to get information, such as *Advocacy and Information Services*.

How to find out more about services for people with disability

While there are many services for people with disability, it is not easy to find out about them or find out what the right service is for you. Also sometimes the services are full and have a waiting list, or sometimes you don’t know who to ask and what service to ask for.

Here we have listed only a few services, services that say they will organise an interpreter if you need one:

The Translating and Interpreting Service (TIS) of the Department of Immigration and Multicultural and Indigenous Affairs is available to any person or organisation in Australia requiring interpreting services. TIS is available 24 hours a day, 7 days a week.

TIS phone: 13 14 50

You might have to pay a fee depending on the circumstances and depending on whom you are calling.

One good starting point to find out about things is Centrelink.

Centrelink phone: 13 10 21

Centrelink Multilingual Call Centre phone: 13 12 02

TTY phone: 1800 810 586

If you can go to your local Centrelink office, one good person to talk with is the Disability Officer.

Also a good place for you to start is the Commonwealth Carelink Program.

Commonwealth CarelinkCentres phone: 1800 052 222

TTY phone: 1800 555 677

Speech-to-Speech Relay phone: 1800 555 727

Another disability information service is IDEAS.

IDEASphone: 1800 029 904

You can also call the Multicultural Disability Advocacy Association (MDAA) which promotes and protects the rights of people from a non-English speaking background (NESB) with disability and their families and carers.

MDAA phone (02) 9891 6400 or 1800 629 072