

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.



opening doors

Disability experienced in China and Australia



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

Acknowledged by



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Disability experienced in China

This introduction is about the experiences of disability for people and families from Mainland China and other Chinese communities. Some of these experiences are also common to other cultures.

What are the common myths and beliefs about disability in China and other Chinese communities?

Mainland China is a very large country with many different cultural communities. While officially China is not a religious country, Confucianism, Taoism and Buddhism still provide most of the basic structure for many beliefs and ways people behave. Christianity is an increasing influence in Chinese communities. These influences on culture and beliefs are also important for other Chinese communities outside

Mainland China.



Generally, across all the different communities it is fair to say that our attitudes and beliefs about disability are more negative than positive, seeing people with disability as abnormal. Many of us believe strongly in disability being about fate.

Traditionally many of us see each life as a link in a chain between the past and the future. This chain is about ancestral connections and personal rebirth. Because of these traditional beliefs, disability is often seen as people in the present paying for bad deeds done in the past by the person in a previous life or by the person's ancestors.

Children are seen as a gift from heaven, carrying the future of the whole family. Mainland China has a 'one child policy', which has some unintended results for girls and children born with disability. To carry the family tree forward most of us would prefer to have a boy. Girl babies and babies with disability disappoint these expectations and the 'one child policy' may push parents towards abandoning their baby.

However the policy also allows parents who have a child with disability to have another child. Parents love their children whatever their ability, but are torn between their own feelings, cultural and religious beliefs, the expectations of those around them, and the practical demands of day-to-day life. Society is generally very competitive and for many, the struggle for resources is harsh and there are few allowances made for differences in ability. Access to health care and specialized services are costly and not available in rural areas.

Chinese culture is full of important cultural practices. In some communities disability is seen as bringing bad luck and women are discouraged from going near people with disability during pregnancy. In many cases it will be more difficult for family members of people with disability to form friendships or find marriage partners.

Responses to disability vary a lot depending on the type of disability a person has. Having a physical disability is likely to encourage pity and the family and the person will probably experience the disability as a burden. For some people having a family member with mental illness is like “having a bomb in the family” as many of us are afraid of mental illness. We often see mental illness as a ‘weakness’ that the people have brought upon themselves. We also have a lot of fear around people with intellectual disability; we often ridicule them and they have a hard life. Blindness is often seen either as the worst kind of suffering or as a gift and connection with the supernatural (many fortune tellers are blind). People who are deaf are most likely to be able to ‘pass’ as their disability is not visible. Although people who are deaf often receive an education they are also seen as stupid because of their lack of speech.

How we treated people with disability in the past

Generally when a child with disability was born the child would often be regarded as a burden and as bringing shame on the family. The parents would generally feel a lot of sadness and would look for help and a cure to make the baby ‘normal’. The family would often hide the person with disability from the community. This could cause the person with

disability and the family to become isolated. This sometimes led to breakdown in family relationships.

Sometimes we also blamed mothers for causing the disability saying that they did something wrong during the pregnancy. Children with disability usually received little or no education and there were no specific services for people with disability.

Chi

Chi was a school student in Mainland China who had a physical disability. Because of his disability Chi was never able to get the ‘best student award’ regardless of his high academic achievement. This was because assessment was based on 3 elements: academic achievement, morality and physical health. Chi’s disability meant he would always fail the 3rd element.

Hua

Hua had polio as a young child and used crutches to get about. She was prevented from finishing school, as the education system did not consider providing Hua with an education as worthwhile. It was assumed that Hua would never be able to work.

In Hong Kong in the past when a child with disability was born there was little advice or support for the parents and there were few specialist services or resources such as wheelchairs. Some people with mental illness were put in institutions and it was not uncommon for people with disability to commit suicide.

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

The desire to be seen as a civilized country by the West is influencing changes in laws and community attitudes. The government promotes

self-sufficiency of families rather than regarding disability as a social and community issue. This is evident in laws that punish parents if they fail to carry out their caring duties.

There are particular individuals who have become famous as advocates for people with disability such as Zhang Hai Di, a woman with a high



level spinal injury who has become the most well-known person with disability in China. She is self-taught and is now a translator, writer and public speaker.

The government is promoting the importance of mental health and with this came better treatment services for people with mental illness and overall better attitudes towards people with mental illness.

The involvement and achievements of Chinese athletes in past Paralympics has also raised awareness of disability and the status of people with disability. The Beijing Paralympics in 2008 will continue this on a much bigger scale.

In Hong Kong having a more open communication system allowed more contact with international disability and human rights organisations as well as the desire to be seen by the West as a modern western style state. This led to a greater range of services.

In Hong Kong and Taiwan we have started Harmony Education where people with disability, mostly intellectual disability, go into community centres and schools and talk about their lives and experiences. This is helping to change attitudes and beliefs about disability.

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

In the past we often used harsh and unfair language to describe people with disability. Now people are generally more gentle and do not talk about people as objects.

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

In country areas compassion for people with disability is more likely to be common because people in small communities usually have stronger ties. It is also easier for people with intellectual disability to get by in rural areas, as there is always farming work and the communities are smaller in the country.

However someone with a physical disability would have greater supports and possibilities for work in the city. In the larger cities resources and services are much better with mainstream schools where students with disability are not separated from those without disability. There are independent living programmes.

Sui

Sui and her husband had a herb farm and distribution business. In the town where Sui lived there were sometimes babies and young children who were abandoned because of their disability. Sui started taking in these children with disability. She cared for the children and as they grew up they helped her on the farm. She grew to care for the children a great deal, so much so that she chose not to go with her husband when he moved to Hong Kong

What services are there for people with disability?

Culturally and traditionally in China governments have not provided education, health or other social services. People pay for services, which are generally provided by the community where the people live. There is a lot of variation in the type, distribution and quality of these services

The number and range of services for people with disability have increased a lot in the past 20 years, some of this through the work of Deng Pu Fang (Deng Xiao Ping's son) who has a physical disability and is the director of the China Disabled People's Federation. Since 1990 education for children with disability has been compulsory, however schools have not necessarily been made accessible to enable children with

physical disability to attend. Over the past few years the government has been encouraging the inclusion of children with disability much more broadly in society and this is giving parents hope for their children's future.

Services such as special schools for deaf or blind children and rehabilitation are usually run by large charities with support from the government. International non-government organisations provide some services but there are no local non-government organisations. These services and resources are not free but prices are often negotiated and there are fewer services in smaller cities and rural areas. There are many children who are not able to access these services and there are generally no special education classes or schools for children with intellectual disability.

Very few people with disability have jobs in the community, while many work in workshops known as 'charity factories' where most of the workers have disability. In regard to transport there is some subsidy for people with disability and there is better access for this in the cities.

In Hong Kong and similarly in Taiwan, support services for young children and schools from 1st-9th grade are free and health care costs are low. There are parent support groups, special schools and classes in mainstream schools as well as rehabilitation, employment services and advocacy services. These formal support structures are similar to those in Australia. There is a disability pension (bare minimum) and government housing with priority listing for people with disability.

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



Normally there is a large extended family to support family members. However when there is a family member with disability often the extended family is reluctant to be involved or the shame may push parents to hide the person with disability. Traditionally it is the role of mothers, sisters and grandmothers to

care for family members who have disability, but now fathers are beginning to take an interest and share the role. These changes in gender roles and domestic duties are occurring more rapidly in the southern parts of China. People with intellectual disability are often involved in providing care and support to other family members, especially older family members needing care.

However with Chinese migration to many countries across the world, extended families are breaking up and this is making it harder to continue traditional ways of caring for parents and people with disability.

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

In Chinese culture the concept of rights is different, especially as collective needs are more important than those of the individual. With increased contact with western ideas, the concept of individual rights is slowly finding a place in Chinese thinking.

A few people with disability in China are lobbying for the rights of people with disability but they are generally people who have been involved in international disability events. China is a large place with a very large population, many of whom still have little contact with outside influences.

China is moving forward on rights in some areas. There is now an annual conference between China, Hong Kong, Taiwan and Macau on disability, which brings together many people to share ideas, beliefs, ways to work and change. At a symposium in 2000 on Intellectual Disability, the China Disabled Persons Federation reported increased implementation of 1991 legislation protecting the rights of people with disability, particularly people with intellectual disability. However there is also legislation that prevents people with intellectual disability from marrying or having children.

In Hong Kong there is awareness and some legislation: 1996 saw the introduction of the Hong Kong Anti Discrimination Act. However the Joint Council for the Physically and Mentally Disabled said in their submission to the UN in June 2003, there is clear evidence of widespread violations of human rights in Hong Kong. Despite this, the hope is that people with disability will have an active involvement in the creation of a new UN Convention on Disability being discussed.

While there have been changes and there is a rights movement, like many places in the world there is a long way to go before disability is seen as just another kind of difference, like race or wearing glasses.

Web Sites used in writing this document

<http://www.minds.org.sg/papers/mms34.htm>

<http://www.aasianst.org/absts/1997abst/china/c95.htm>

http://www.hkcss.org.hk/rh/er/UN%20Ad%20Hoc%20Meeting%20June%202003_%20HK%20Statement.doc



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 *Adult Training, Learning and Support Services, 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 by calling 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.

IDEAS phone: 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