Children with Disability – Culture and Identity

A child or young person (child) with disability is the same as all other children. They have the same emotions, the same human rights, and the same need to be loved and protected.

Like all children, a child with disability will develop a unique individual identity, which is their sense of self and where they fit into society. Unlike all other children, a child with disability will also have to process how society views them in the context of their disability, which is not always positive and not always inclusive.

> To me, disability is not a monolith, nor is it a clear-cut binary of disabled and nondisabled. Disability is mutable and ever-evolving. Disability is both apparent and nonapparent. Disability is pain, struggle, brilliance, abundance, and joy. Disability is sociopolitical, cultural, and biological
>
> - Alice Wong, Disability Visibility: First-Person Stories from the Twenty-first Century

Exploring 'who I am' is an important, scary, and sometimes confronting process for all children. Imagine then dealing with dual realities of having a disability and being in the care system. This is the case for many of the children you will support in the Permanency Support Program (PSP).

You will need to help support a child with disability to see their uniqueness, their resilience, and their abilities. It is also your role to link them with services that support them and will embrace and affirm their abilities.

What is Disability?

Disability is defined as any condition or impairment that impacts on a person's daily activities or communication. Some children may experience more than one disability, and some conditions can lead to others. A disability may be caused by genetic disorders, illness, accidents or develop during pregnancy.

A disability may be easily visible to others or hard to detect, it can be temporary or permanent. The type of disability a child has will determine how much it impacts on the child's physical, intellectual, and emotional functioning (Australian Network on Disability, 2020).

Types of Disabilities

There are many different types of disability that will have very different impacts on a child and the people who care for them, these include:

- physical – affects mobility or skill in performing tasks i.e., difficult walking, moving or using hands
- intellectual – affects the ability to learn
- neurological – affects the brain and central nervous system
- sensory – affects the ability to hear or see
- mental illness – affects thinking processes
- immunological – presence of organisms causing disease in the body
- learning disability.

Learn more at Raising Children Network's Guide to Disabilities.

Prevalence

Disability is common in Australian children, with almost 1 in 10 children aged between 5 and 18 years old diagnosed with a disability (AIHW, 2022). Disability is less common in younger children with less than 6% of children aged 4 years and younger diagnosed with disability (ABS, 2024).

Children with disability are an especially vulnerable population. Remember, children in care are more likely than other children to have a disability. Australian research suggests that children with intellectual disability, and mental and behavioural problems have a greater risk of experiencing maltreatment than children without disability (Maclean et al., 2017).

Aboriginal children are more than twice as likely to have disability, than non-Indigenous children (DiGiamcomo et al, 2017). Children from a culturally or linguistically diverse background (CALD) experience disability at the same rate as the national average (SSI, 2018).

The Impact of Disability on a Child’s Identity

The degree to which a child’s identity will be shaped by their disability will depend on many factors:

- the type of disability and support they need to participate in everyday life
- how the child has felt others perceive their disability
- the child’s age and emotional development
- the child’s gender and sexuality
- the child’s culture and the cultural views on disability
- the views and acceptance of their immediate network.

Broadly speaking, a child’s disability may impact their sense of identity in the following ways:

- a child who focuses on ‘impairment’ may feel imperfect, less than their peers or unlovable
- a child may overcompensate in other areas and strive for perfection to cope with their idea of having disability
- a child may deny their disability and try to shift focus from it
- a child may be empowered by their disability when they can recognise their abilities and resilience.

A child’s experience of disability will be unique to them. A child's experience of disability is a combination of their age, developmental stage, how they experience their mind and body, and the society they live in. Be curious about their individual experience.

Not all children with disability will identify as having one. Use the language they use to describe their experiences.

Various cultures may have different beliefs about disability. Consult with others, especially co-workers who share the child’s culture to help you explore beliefs and understandings of disability with the family.

It is not the child’s disability that creates a barrier to their participation. It is our society that does (People with Disability Australia). Consider how you can change environments and your communication styles to create equity for people with disability. For more information watch this YouTube channel dedicated to children with disability.

Cultural Perspectives on Disability

Aboriginal

There is no word for disability in Aboriginal languages. People with disability are included and cared for like everyone else. Aboriginal culture is diverse, but some general features of the Aboriginal perception of disability include:

- Aboriginal people with disability are generally not excluded from their communities
- sometimes a disability may be seen as 'payback' for a past wrongdoing, or may be seen as something special
- independence may not be seen as a major issue in some Aboriginal communities
- disability may be viewed as a family or community problem rather than a personal one
- some people with severe disability may be seen as the responsibility of 'welfare'
- a person may be identified and named after their disability. For example, a person with an eye injury may be known as 'one eye' (First Peoples Disability Network Australia).

Other Cultural Perspectives

Every family will perceive disability differently, and this perception will be influenced by their circumstances, community, and culture. How disability is understood may impact on the care of a child with disability.

Examples of How Disability Can Be Viewed

- In Cameroon, Ethiopia, Senegal, Uganda, and Zambia common beliefs about the causes of childhood disability include sin or promiscuity of the mother, an ancestral curse or demonic possession (Toolkit on Disability in Africa).
- In some South Asian cultures, such as parts of Pakistan, a girl is expected to be like her mother, and a boy like his father. When this does not occur, it can be interpreted as a disturbance of the natural order. In traditional communities a family may view a child with disability as being taken over by 'djinn' or spirits, or they may see the child as a 'changeling'. Parents may also feel isolated from the rest of their community (Barker et al., 2010).
- Traditional Confucian beliefs, such as those held in China, value an accepted family hierarchy based on age, gender, and generational status. Harmony in family and society is maintained by self-restraint and collectivism, with everyone acting in accordance with their hierarchical status. Maintaining 'face' means that "shameful" family affairs cannot be disclosed to outsiders. The family of a child with disability may be reluctant to seek supportive services (Ravindran and Myers, 2012).
- Families from some cultures may worry that having a child with disability will affect the marriage prospects of other family members, especially daughters.

Cultural Considerations for Supporting a Child with Disability

When working with a CALD child, family, or carer in the Permanency Support Program (PSP) be curious about the family's perception of the child's disability. Seek cultural consultation to understand cultural beliefs and culturally responsive approaches to talking about disability. A family may feel shame and guilt, preventing them from seeking support outside of the family.

To support a child with disability from a CALD background:

- be curious about what a day in the life of the child would be like, e.g., ask a child what is important to know about their life, how you can help or what is it that you need to know about their disability. Watch this video to learn more about what a good day/bad day looks like. Also available at this link is a template you may find valuable
- be interested in their abilities and their needs, e.g., ask 'What is your favourite thing to do? What are you good at?' Historically, services have just focused on what is important for them, to keep people healthy and safe. Working in a person-centred way requires that we see the person first – what matters to them, not just what the matter is with them. We need to learn both what is important to the person and what is important for them and find the balance that works for them.
- show dignity and give the child a voice
- give the child or young person every opportunity for them to participate in assessments, safety planning and case planning (if appropriate) - this is their right! And if they don't document why not?
- involve and build the child's support network – they often feel isolated and invisible
- be a positive social response, this will influence a child's future safety and access to supports
- believe what a child is telling you and validate their voice
- be concerned about distress, behaviour, or illness, due to a child's disability this may be overlooked (hold the same standard about what constitutes abuse or neglect)
- clearly explain your role and prepare a child for any next steps
- offer a support person that the child feels safe with
- use an interpreter if English is not a child's spoken language. This is crucial in explaining disability and diagnosis as often there will not be equivalent words in different languages.

Intersectionality

'Intersectionality' is a framework that describes how aspects of one's identity – race, class, gender, and other individual characteristics – can intersect to produce or heighten either privilege or marginalisation. Children (including parents with disability) who belong to two or more marginalised populations may experience a compounding effect of inequality, such as Lesbian, Gay, Bisexual, Transgender, Queer or Questioning, Intersex, Asexual or Ally, +: Other Non-Heterosexual People (LGBTQIA+) people with disability, culturally and linguistically diverse people with disability and Aboriginal people with disability. It is important that your services and other resources are developed in partnership with an awareness and responsiveness to the complexity of these issues and needs and promote a person-centred approach.

Reasonable Adjustments

According to the *Disability Discrimination Act 1992* (DDA), an adjustment is reasonable unless making the adjustment would impose an unjustifiable hardship on the person. Under section 6 of the DDA, making reasonable adjustments for people with disability is implicit in the requirement to avoid indirect discrimination.

Indirect discrimination may arise if:

- A person with disability is required to comply with a service requirement or condition that they cannot comply with and which those without disability are generally able to comply with.
- There is a failure to provide an adjustment to enable a person with disability to access or participate in a service, where that adjustment could reasonably have been provided.

The requirement for reasonable adjustments applies to all mainstream services, not only specialist services, and must be incorporated into all aspects of your organisation's service delivery. This is the responsibility of all staff in your organisation.

This responsibility is especially important for you as a frontline worker as the first point of direct contact for many people with disability engaging with your organisation. You are uniquely placed to recognise disability and assist people with disability accessing the National Disability Insurance Scheme (NDIS) participant pathway.

For the most part, reasonable adjustments must be person centred and meet the need of the individual. There is no one size fits all approach to reasonable adjustments.

Making Person-Centred Reasonable Adjustments

- take the initiative to ask the young person and/or their parent/carer what they need and how best to support them
- listen carefully to the person
- check in with the young person and/or their parent/carer to see whether the reasonable adjustment is working
- if the reasonable adjustment is not working, explore alternative options with the them so you are learning together.

You must be flexible, responsive, and actively support the removal of any barriers.

National Disability Insurance Scheme (NDIS)

You can also support the parents or carer get advice from the NDIS on eligibility for funding. The NDIS funds disability-specific:

- supports needed because of the impact of a parent's disability
- training programs for parents and carers who have a disability themselves.

An Example of a Person-Centred Reasonable Adjustment:

After several visits with Aaron, a 16-year-old Aboriginal boy and his family, you suspect that Aaron may have a hearing impairment. Acknowledging that there is no specific word for 'disability' in traditional Aboriginal language, you ask Aaron whether he can hear you OK or whether he would like you to speak louder. Aaron's answer is yes, and his mum explains that sometimes Aaron doesn't hear too well which is why she and his dad often answer questions for him. Aaron tells you he relies on those close to him to speak loudly and close to his ear, and at school he often reads the lips of his teacher and friends. Sometimes his teacher makes Aaron sit at the back of the classroom even though his mum has asked the teacher to move him. You refer Aaron to a local Aboriginal advocacy service to provide additional support for Aaron and his family, for example, they can ensure that the school understands what Aaron requires and provides reasonable adjustments. You arrange for future meetings to be at a place that is quiet and easily accessible to both Aaron and his family. You also speak with more volume, not shouting, and look in Aaron's direction when communicating. You refer Aaron to the local Aboriginal Medical Service (AMS) to further investigate if he requires a hearing aid or other communication supports.

You develop a one page person centred profile which outlines Aaron's strengths, and how best to support him. For communication that is not face to face, you obtain agreement that you will text Aaron rather than calling wherever appropriate, because it is easier for him to read rather than listen.

Helpful Resources

- National Ethnic Disability Alliance - key issues and information about advocacy for people with disability from CALD backgrounds
- Support for parenting a child with disability
- Raising them Strong – Caring for Kids with a Disability booklet - helpful information for carers who care for an Aboriginal child with a disability
- First Nations Disability Network Australia - range of helpful resources and contacts to support good Aboriginal practice with families who have a child with disability.
- Intellectual Disability Rights Service – provides legal support and assistance understanding right for parents who have or are at risk of having their children removed.
- Neuro-affirming practice – two courses from Emerging Minds that aim to increase understanding and application of neurodivergent-affirming practice approaches.

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