

Developmental Disability Across Cultures

Key points

- Culture is a pattern of ideas, customs and behaviours shared by a particular people or society. It is constantly evolving.
- Culture influences newcomers' approaches to disability, including:
 - their understanding of a disability and its etiology
 - whether to seek help
 - treatment options
 - their relationships with health professionals
- In many cultures, social interdependence and an individual's role within the larger family and community are highly valued, while independence and autonomy are valued less than in Western cultures. This perspective can affect how disability is perceived.
- Many cultures seek out spiritual healers and traditional 'alternative' medicines.
- In many cultures, attitudes toward a disability may include religious acceptance. Also, people may believe that a disability is caused by factors such as the influence of 'past lives', mystical intervention or the past actions of a parent.
- Health practitioners should acknowledge and consider the culture of the child and family in care.
- Health practitioners should avoid assumptions about a family's cultural practices and beliefs.
- Health practitioners should work with the social and cultural framework of the family, ideally by involving cultural experts. This may be crucial to success.

What is culture?

Culture is a pattern of ideas, customs and behaviours shared by a particular people or society. It is dynamic, yet stable. Health is a cultural concept in that culture frames and shapes how we perceive, experience and manage health and illness.¹⁻³

In 2010, the [World Health Organization](https://kidsnewtocanada.ca/http://www.who.int/suggestions/faq/en/) (<https://kidsnewtocanada.ca/http://www.who.int/suggestions/faq/en/>) broadly defined health as a state of complete physical, mental and social well-being. Different cultures view health in different ways.¹ For example:

- In Western medicine, health is mainly seen as an absence of disease, with focus on biological aspects of life.
- *Ayurveda*, an ancient Indian system of medicine, views health as a harmony between body, sense organs, mind and world.
- Traditional Chinese medicine sees health as a balance between yin and yang, or the 'hot' and 'cold' qualities of an individual.

What is cross-cultural competence?

When working with families from various ethnic, cultural and linguistic backgrounds, best practice involves cross-cultural competence.⁴ There are 3 basic steps toward achieving culturally competent care:

1. Being aware of your own beliefs and values, and clarifying these when needed.
2. Obtaining information on the culture and background of newcomer patients.
3. Engaging and working with newcomer patients, using approaches that are sensitive, receptive and responsive to their cultural perspectives.

Learn more about [cultural competence](https://kidsnewtocanada.ca/culture/competence/) (<https://kidsnewtocanada.ca/culture/competence/>).

What is a developmental disability?

Developmental disabilities have been defined as a set of abilities and characteristics that vary from the norm in the limitations they impose on independent participation and acceptance in society.⁵

Developmental disabilities may occur in isolation or together, and they include:

- intellectual disabilities
- sensory-related disabilities (e.g., related to [hearing](https://kidsnewtocanada.ca/screening/hearing/) (<https://kidsnewtocanada.ca/screening/hearing/>) and [vision](https://kidsnewtocanada.ca/screening/vision/) (<https://kidsnewtocanada.ca/screening/vision/>))
- communication and language disabilities
- physical disabilities

The [International Classification of Functioning, Disability and Health](https://kidsnewtocanada.ca/http://www.who.int/classifications/icf/en/) (<https://kidsnewtocanada.ca/http://www.who.int/classifications/icf/en/>) (ICF) recognizes that personal and environmental factors, including culture, share a complex relationship with functional capabilities and participation. Disability is a part of all human experience, in that every individual will experience some disability at some point over the course of their life. The following issues strongly influence the experience of disability:

- social aspects
- medical and biological dysfunction
- cultural and family attitudes
- availability and access to resources
- social and legal structures

How do different cultures view developmental disabilities?

The [Canadian Charter of Rights and Freedoms](https://kidsnewtocanada.ca/http://laws-lois.justice.gc.ca/eng/const/page-15.html) (<https://kidsnewtocanada.ca/http://laws-lois.justice.gc.ca/eng/const/page-15.html>) and the [U.N. Convention on the Rights of Persons with Disabilities](https://kidsnewtocanada.ca/https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html) (<https://kidsnewtocanada.ca/https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>) promote the acceptance, integration and inclusion of people with disabilities into mainstream society. The integration of a disabled child may not be the norm for a newcomer family's culture of origin.

Different cultures have different views of disability and treat children with development disabilities in different ways. For example:

- 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 disabilities may be reluctant to seek supportive services.¹
- In some South Asian cultures, such as in 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 seen as a disturbance in the natural order. In traditional communities, a family may wonder whether their child with a disability has been taken over by a *djinn* (spirit) or they see him as a ‘changeling’. Parents may even feel isolated from the rest of their community because of the perceived stigma of having a child with developmental disabilities.⁶
- Families from some cultures may worry that having a disabled child will affect the marriage prospects of other family members, especially daughters.⁶

The concept of what one person is capable of achieving as an individual, or overall ‘competence’, also differs across cultures. Some cultures emphasize social relationships rather than a person’s ‘mind’ or abstract, intellectual abilities. For example:

- Some African cultural groups think of competence to be largely a function of an individual’s ability to recognize and observe social practices, along with a willingness to overcome difficulties. This cooperative view of social and individual endeavour has been shown to increase social functioning and maturity in intellectually disabled children when compared with more individualistic Western approaches.⁵
- For families from India, fulfilling family roles and duties, knowing how to show respect and to whom, and knowing social customs are the most important determinants of individual competence.¹

Children’s behaviour is also perceived differently among cultures. For example, a child may be seen as “stubborn” if she cannot follow instructions, and decreased capacity may be explained as the result of “weak memory”.

Consider varying cultural views of autism spectrum disorder (ASD):

- In Saudi Arabia, it has been reported that there is a later age of diagnosis for ASD in girls than in boys. Boys are expected to be outgoing, while girls are more expected to be shy.⁷
- Limited ability to maintain direct eye contact is viewed differently in Asia, where direct eye contact is seen as disrespectful.⁶
- Indian culture focuses on social conformity, and the socially disruptive behaviours associated with ASD are reported more frequently than communication challenges.¹

Cultural understanding of what causes developmental disabilities

Different cultures have different views of the causes of developmental disabilities. 'Blame' for a disability may be placed on the mother or both parents, or the child's condition may be considered an "act of God". Here are some examples:¹

- Traditional Confucian beliefs see the birth of a child with a developmental disability as a punishment for parental violations of traditional teachings, such as dishonesty or misconduct. The child's disability may also be seen as punishment for ancestral wrongdoing. The wider community may feel that the parents are responsible and be less likely to provide the family with sympathy or support.
- Individuals from South-East Asian cultures may believe that developmental disabilities are caused by "mistakes" made by parents or ancestors.
- Indian cultures offer multiple causes for a disability, ranging from medicines or illness during pregnancy and consanguinity, to psychological trauma in the mother and lack of stimulation for the infant.
- In other cultures, the will of God or Allah, karma, evil spirits, black magic or punishment for sins may be seen as causes of disability. Some cultures freely combine traditional beliefs with biological models such as disease degeneration and dysfunction. Mexican, Haitian and Latin American cultures may see disability as the result of a mother (or family) being cursed.

How does culture affect the treatment of developmental disabilities?

Culture influences key aspects of and approaches to treatment for developmental disabilities, including:

- whether to seek help
- what treatments to use
- the availability of resources
- the expectations parents have of, and for, their child
- relationships between families and care professionals

Newcomers from cultures that rely on support from family and friends are less likely to seek professional help. Families may not seek treatment or support at all if they feel it is inappropriate to ask for help from ‘outsiders’. They may feel shame or be unwilling to accept help even when it is offered, and their own communities may reinforce the view that the family must bear full responsibility for meeting the needs of all its members. For example, South-East Asian cultures tend to believe it is inappropriate to accept services or support from others.⁶

Treatment approaches for developmental disabilities can also vary widely from culture to culture:¹ For example:

- In some Southeast Asian cultures, such as in Laos, a shaman—a health care and spiritual provider—is called on to perform healing, preventive and diagnostic rituals.
- African cultures also seek out traditional healers with experience in herbal remedies or healing rituals. Social relationships are often important in interpreting illness, treatment and healing.^{8,9}
- Asian cultures may rely on complementary and alternative medicine (CAM), especially acupuncture, sensory integration and Chinese medicine.
- Indian families may combine yoga, *Ayurveda* and homeopathy with conventional medicine.

Families from cultures with a more collectivist orientation may bring a contrasting approach to treatment plans for a child or youth with a disability. They might focus on a treatment that facilitates family and community activities rather than individual

competence and autonomy. Read more about [how culture influences health \(https://kidsnewtocanada.ca/culture/influence/\)](https://kidsnewtocanada.ca/culture/influence/).

What health professionals can do

Never make assumptions about the needs or wants of a newcomer family based on their ethnic background or cultural practices. There are always differences among and within cultural groups. Some families choose to keep certain traditional practices or beliefs while adopting other culture-based beliefs from their current environment.⁴

Health care professionals should learn about and be mindful of the hierarchy of family and society in the different cultural groups they see in practice. There may be tensions between Western service delivery models and traditions that value independence, collectivism and close family relationships. Health professionals should be sensitive to these issues. For example, in families from patriarchal societies, women are more likely to follow the instructions of men, and men are more likely to speak on their behalf. Some South Asian households include multiple extended family members, with parents, children and grandchildren (usually a son's family) living together. One mother might be responsible not only for the care of her child with a disability, but also for other family members and running the home.^{6,10,11}

The parents of children with developmental disabilities also report a variety of [barriers to service and treatment \(https://kidsnewtocanada.ca/care/barriers/\)](https://kidsnewtocanada.ca/care/barriers/),⁶ including:

- lack of accurate information about available services
- confusion about medical care and the purpose of treatment
- lack of fluency in English or French
- lack of transportation
- concerns about the financial impact of treatment on their other children
- concern over stigmatization and discrimination.

Here are some important steps for health professionals to take when working with families of children with developmental disabilities:

- Be aware of your own beliefs and attitudes.
- Connect with voluntary groups, [local community organizations \(https://kidsnewtocanada.ca/beyond/resources/\)](https://kidsnewtocanada.ca/beyond/resources/) and professionals who have a working knowledge of different minority ethnic communities.

- Ask parents to share their beliefs about what has caused their child's disability. This perspective helps to facilitate their understanding and expectations of treatment.
- Ask the family to educate you about treatment approaches within their community that you may not know about.
- Ask the family about their hopes and dreams for their child.
- Learn about and respect cultural communication, language and nuance. Read about the appropriate [use of interpreters \(https://kidsnewtocanada.ca/care/interpreters/\)](https://kidsnewtocanada.ca/care/interpreters/).
- Be mindful that there is never a single cultural profile to which the needs of a specific cultural group may be expected to conform.
- Recognize similar values between cultural groups, such as the importance of family and support for elders.
- Recognize that there is a range of adherence within any community to cultural beliefs.
- Encourage the creation of support groups for families of children with developmental disabilities.

New ways of sharing care

A 4-year-old Lebanese girl is referred to you for global developmental delay. The family immigrated to Canada 15 months ago. Both parents are working outside the home to make ends meet, and English is still a challenge for them. The paternal grandparents are the child's daytime caregivers and they carry her around most of the day. The family still feed her by hand. The parents recognize that their daughter is delayed compared with her 6-year-old brother, but have been hesitant to bring her to a doctor for fear of having to pay for extra care and schooling. At time of assessment, the developmental age of the child may be underestimated because of a lack of opportunities presented in the home.

With the aid of an interpreter, the parents come to realize that there will be no extra cost for care or schooling. You suggest that the grandparents attend sessions with the intervention team to encourage them to begin to work with their granddaughter in the home, recognizing their important role and encouraging their caring style. The child is registered for a preschool program.

Learning points

1. The [use of an interpreter \(https://kidsnewtocanada.ca/care/interpreters/\)](https://kidsnewtocanada.ca/care/interpreters/) is very important for reaching a mutual understanding on sensitive topics. Use a

professional cultural interpreter wherever possible. Avoid the use of children or adolescents as interpreters for the family.

2. If a learning or behaviour issue is reported, help connect the family with appropriate preschool programs and [intervention services](https://kidsnewtocanada.ca/beyond/resources/) (<https://kidsnewtocanada.ca/beyond/resources/>).
3. Extended family members often play an important role as caregivers. Their attitudes toward independence and learning for a child with a disability may differ from yours. Validate their role while encouraging them to help the child learn new, more independent tasks. Consider including them in the intervention.

Read more about steps you can take when [working with newcomer children and their families](https://kidsnewtocanada.ca/culture/competence#working_with_children) (https://kidsnewtocanada.ca/culture/competence#working_with_children).

Selected resources

Useful links

- Best Start Resource Centre. [Growing Up in a New Land: Strategies for Working with Newcomer Families](https://kidsnewtocanada.ca/http://beststart.org/resources/hlthy_chld_dev/pdf/Growing_up_new_land_FINAL.pdf) (https://kidsnewtocanada.ca/http://beststart.org/resources/hlthy_chld_dev/pdf/Growing_up_new_land_FINAL.pdf). A manual for service providers working with newcomer families, particularly in public health, with emphasis on child development. [Growing Up in a New Land: A Guide for Newcomer Parents](https://kidsnewtocanada.ca/http://beststart.org/resources/hlthy_chld_dev/index.html) (https://kidsnewtocanada.ca/http://beststart.org/resources/hlthy_chld_dev/index.html). A booklet for newcomer parents with children 0-6.
- Centers for Disease Control and Prevention. [National Center on Birth Defects and Developmental Disabilities](https://kidsnewtocanada.ca/https://www.cdc.gov/ncbddd/index.html) (<https://kidsnewtocanada.ca/https://www.cdc.gov/ncbddd/index.html>).
- [Developmental Disabilities Association](https://kidsnewtocanada.ca/http://develop.bc.ca/home-page/) (<https://kidsnewtocanada.ca/http://develop.bc.ca/home-page/>), B.C.
- Martin-Herz SP, Kemper T, Brownstein M, et al. [Developmental screening with recent immigrant and refugee children: Preliminary report](https://kidsnewtocanada.ca/http://ethnomed.org/clinical/pediatrics/abstract-developmental-screening-with-recent-immigrant-and-refugee-children-a-preliminary-report) (<https://kidsnewtocanada.ca/http://ethnomed.org/clinical/pediatrics/abstract-developmental-screening-with-recent-immigrant-and-refugee-children-a-preliminary-report>). EthnoMed, 2012.
- [United Nations Enable](https://kidsnewtocanada.ca/https://www.un.org/development/desa/disabilities/) (<https://kidsnewtocanada.ca/https://www.un.org/development/desa/disabilities/>) is

the official website of the U.N. Secretariat for the Convention on the Rights of Persons with Disabilities.

- World Health Organization, Regional office for Europe. [The case for change \[Background paper\]](#) (https://kidsnewtocanada.ca/http://www.euro.who.int/_data/assets/pdf_file/0003/126408/e94421.pdf). The 2010 Better health, better lives: Children and young people with intellectual disabilities and their families conference. Bucharest, Romania, November 26 to 27, 2010.

Additional reading

- Chung KM, Jung W, Yang JW, et al. Cross-cultural differences in challenging behaviors of children with autism spectrum disorders: An international examination between Israel, South Korea, the United Kingdom, and the United States of America. *Res Autism Spect Disord* 2012;6(2):881-9.
- Coles S, Scior K. Public attitudes towards people with intellectual disabilities: A qualitative comparison of white British and South Asian people. *J Appl Res Intellect Disabil* 2012;25(2):177-88.
- Edwardraj S, Mumtaj K, Prasad JH, et al. Perceptions about intellectual disability: A qualitative study from Vellore, South India. *J Intellect Disabil Res* 2010;54(8):736-48.
- Helman CG. *Culture, Health and Illness*, 5th edn. Boca Raton, FL: CRC Press (Taylor & Francis Group), 2007.
- Kleinman A. *Writing at the Margin: Discourse between anthropology and medicine*. Berkeley, CA: University of California Press, 1997.
- Lam LW, Mackenzie AE. Coping with a child with Down syndrome: The experiences of mothers in Hong Kong. *Qual Health Res* 2002;12(2):223-37.
- McConkey R, Truesdale-Kennedy M, Chang MY, et al. The impact on mothers of bringing up a child with intellectual disabilities: A cross-cultural study. *Int J Nurs Stud* 2008;45(1):65-74.
- Miles M. Concepts of mental retardation in Pakistan: Toward cross-cultural and historical perspectives. *Disability, Handicap and Society* 1992;7(3):235-55.

References

1. Ravindran N, Myers BJ. Cultural influences on perception of health, illness, and disability: A review and focus on autism. *J Child Fam Stud* 2012;21(2):311-9.
2. Oxford English Dictionary.
3. Matsumoto D, ed. *The Handbook of Culture and Psychology*. London: Oxford University Press, 2001.
4. McLean M, Wolery M, Bailey DB, Jr. *Assessing Infants and Preschoolers with Special Needs*, 3rd ed. Upper Saddle River, NJ: Pearson Education, 2004.
5. Odom SL, Horner RH, Snell ME, Blacher J, eds. *Handbook of Developmental Disabilities*. New York, NY: Guilford Press, 2007.
6. Baker DL, Miller E, Dang MT, et al. Developing culturally responsive approaches with Southeast Asian American families experiencing developmental disabilities. *Pediatrics* 2010;126(Suppl 3):S146-50.
7. Al-Salehi SM, Al-Hifthy EH, Ghaziuddin M. Autism in Saudi Arabia: Presentation, clinical correlates and comorbidity. *Transcult Psychiatry* 2009;46(2):340-7.
8. Van der Geest S. Is there a role for traditional medicine in basic health services in Africa? A plea for a community perspective. *Trop Med Int Health* 1997;2(9):903-11.
9. Kromberg J, Zwane E, Manga P, et. al. Intellectual disability in the context of a South African population. *J Policy Practice Intellect Disabil* 2008;5(2):89-95.
10. Bernier R, Mao A, Yen J. Psychopathology, families, and culture: Autism. *Child Adolesc Psychiatr Clin N Am* 2010;19(4):855-67.
11. Summers SJ, Jones J. Cross-cultural working in community learning disabilities services: Clinical issues, dilemmas and tensions. *J Intellect Disabil Res* 2004;48(Pt 7):687-94.

Editor(s)

Cecilia Baxter, MD

William Mahoney, MD

Last updated: March, 2023

This project is funded by the Government of Canada.



© 2023 Canadian Paediatric Society.

All rights reserved.

Caring for Kids New to Canada is a resource for health professionals. The information here is not a substitute for medical advice, nor does it indicate an exclusive course of treatment or procedure to be followed.

Variations, taking into account individual circumstances, may be appropriate.

