



Accessing Services for Individuals with Developmental Disabilities: Cultural and Linguistic Diversity

Introduction

Developmental disabilities are a group of conditions that affect an individual's physical, intellectual, and behavioral abilities. This can appear as language deficits, and other impairments throughout an individual's day-to-day life, which tend to last throughout their lifetime³. Families raising an individual with a developmental disability have unique challenges and accessing services comes with a plethora of difficulties². Accessing developmental disability services is more difficult for ethnic minorities, who struggle to access services due to many things including: a lack of knowledge of services available, income, ethnocentrism, cultural incompetence from service professionals, and cultural/language barriers^{1, 2, 6}.

Community Education

Ethnic minorities tend to have less knowledge about developmental disabilities and what supports/services they need to raise an individual with a developmental disability^{2, 4}. In my lived experience, this is likely due to how Hispanic/Latino cultures perceive disabilities. Typically, in the Hispanic/Latino culture an individual's cognitive and social functioning must be severely limited to be considered a disability⁶. When I discussed this with my parents, they brought up the point that they didn't know what a developmental disability was until it was explained to them by my brother's pediatric doctor. The doctor went on to explain my little brother had Down syndrome.

Second, my parents did not fully understand how Down syndrome would affect my brother's life. They mostly believed that it would cause him physical health problems in the future, but they were not aware of the cognitive and social effects of this disability. As my

younger brother grew, my parents began to understand that he would not be like other children.

When my parents tried to access resources to help my brother, they discussed that they were reliant on the expertise of medical professionals, government funded agencies, and the school system. They didn't know where to go, who to talk to, or what to do next after finding out my brother had a developmental disability. This is common with most families with an individual with a developmental disability, but higher in ethnic minorities^{2, 4}. A consequence of not being able to access services can be that ethnic minority families may go long periods of time without discovering that the child has a developmental disability and may not receive a proper diagnosis⁹. Individuals with developmental disabilities in ethnic minority families tend to be underdiagnosed due to lack of knowledge both in part of the family and service professionals⁹. This can have negative quality of life impacts on the individual with a developmental disability.

Addressing the problem:

1. Providers can find resources [here](#), provided by Center for Disease control and Prevention, to give to parents and people, so that they can have a better framework for the diagnosis.
2. Providers can make sure to explain diagnosis in plain language to help families understand the implications for their lives.
3. Providers can have a list of available support groups that can help families process and understand what resources are available.

Communication Barriers

Many ethnic minorities come to the United States either having English as their second language or are unable to speak English, making it difficult to access resources for their family member with a developmental disability. Illustrating this point, one study by Shapiro, Monzo, Rueda, Gomez & Blacher (2004)¹⁰, saw that Hispanic and Latina mothers felt there was always poor communication whenever they went to receive services for their child with a developmental disability. They felt they didn't understand what information they needed, that certain topics weren't explained well enough for them, or that it simply didn't translate the same as it did in English.

Depending on the language and the geographic location, it can be extremely difficult for an ethnic minority family to access resources/services when they don't speak English, or there is no one available who speak their native tongue. This was even a struggle for my parents, after we moved from California to Utah. The language/communication barriers made it difficult to access services for my brother, and at times cost my brother access to services that could have improved his quality of life. My mother stated that she often felt confused in meetings with service professionals, not fully understanding what they were telling her, and if there had been no translator she left these meetings feeling as though she didn't really know what to do to help my brother. Due to language barriers, many ethnic minorities may not get access to services for their developmentally disabled family member, and if they do, the language barriers may make it too difficult for an ethnic minority family to utilize the services correctly^{4,5}.

Addressing the problem:

1. Resources should be provided for ethnic minority families to better understand the diagnosis and its implications in their own language. Websites such as respectability.org can be helpful for families to make sense of what a diagnosis may mean for them.

2. Providers can invest in translation services that are human centric and can help not only families understand the words, but also process the changes for their families.

Cultural Competence

Perhaps the biggest reasons that ethnic minorities struggle to access and utilize services are ethnocentrism and cultural incompetence. Ethnocentrism is defined as "the attitude that one's own group, ethnicity, or nationality is superior to others."⁸ This implies that people, including providers, may come into a situation without the understanding of how someone else experiences the world and puts their own experiences onto the other person.

In the United States, there are standards called the National Standards for Culturally and Linguistically Appropriate Services in Health and Healthcare (The National CLAS Standards). The principle standard of CLAS is to "provide effective, equitable, understandable and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy and other communication needs"¹¹. This is a standard that is meant to encourage cultural competence, or being aware of other cultural practices that aren't your own, and being responsive to different cultural experiences. Cultural incompetence would be the opposite, not being open or understanding of other cultures and how it might impact the services they are trying to receive.

Some ethnic minorities feel that the relationship with service providers is difficult and that it tends to be due to cultural differences and biases⁷. One common reason for this relationship may be due to how parents and guardians of individuals with a developmental disability feel that their "parental expertise" is ignored¹⁰. In Shapiro et al. (2004)¹⁰, Hispanic and Latina mothers discussed how their input on what care or services their child with a developmental disability needed were often ignored or dismissed. The mothers felt that the service

professionals didn't value their opinion or thought they alone knew what was best for the individual with a developmental disability. This causes reason for concern because it diminishes the parent's involvement in assisting their family member with a developmental disability, which may ignore the significance of culture for the individual with a developmental disability. This is especially concerning in the cases of Hispanic/Latino families because family involvement is a crucial component of family structure and strongly influences the individual with a developmental disability's quality of life^{4,5}.

The aforementioned experience would happen a lot with my family, especially in the school system. One specific example, would be, that my mother and father asked if the school would place my little brother in speech therapy/speech courses, so that perhaps he would learn how to communicate more effectively with others. The school and special education teacher stated that "it would be a waste of resources," as it would do my brother no good, that he would not be able to learn to speak English well enough to warrant the use of these resources. This became a back and forth battle between the school, my family, and advocates for about 2 years, until my family were able to receive documentation from a speech specialist stating that it would benefit my brother to have speech therapy. Then, at last, he was enrolled in speech therapy classes which have had positive benefits in his life. The worst part about this situation was that my little brother's communication growth had been hindered for two years because of this school's lack of desire to work with my parents.

Another hinderance for ethnic minorities ability to access and utilize services for individuals with developmental disabilities is discrimination. Whether it be due to ethnocentrism, cultural incompetence, or racism, ethnic minorities are less likely to be referred to developmental disability services by service professionals in the United States⁵. Causing many

difficulties for families of individuals with a developmental disability.

Addressing the problem:

1. Providers can find helpful tools for gaining increased understanding about cultural competence [here](#). (University Centers for Excellence in Developmental Disabilities)
2. Providers should become familiar with how developmental disability is understood in cultures other than their own. Wenqi Du, of LEND Illinois outlines some important such considerations [here](#).

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