

CHAPTER 3: CREATING AN INCLUSIVE MINDSET

BARRIERS TO ACCESSIBILITY AND ACCEPTANCE

The [Council for Exceptional Children \(CEC\)](#) is an international organization that has been advocating for better educational experiences for students with disabilities for 100 years. The CEC sets professional and ethical standards for special educators and serves as a resource for special education professionals. Inclusion has been considered best practice in special education for nearly 50 years and highlighted in the CEC ethical guidelines is the expectation that special educators will promote meaningful inclusion in their schools and communities. ([CEC, 2015](#); [NASET, 2024](#))

According to the [Cambridge Dictionary](#), inclusion is “the idea that everyone should be able to use the same facilities, take part in the same activities, and enjoy the same experiences, including people who have a disability or other disadvantage.” In an inclusive classroom, all students, regardless of ability, will have equal access to available opportunities and resources. Likewise, inclusive schools will ensure that parents with disabilities have equal access to school resources and opportunities to be active members of the school community.

When we consider barriers to inclusion, physical obstacles often come to mind first. However, negative attitudes and a lack of necessary supports can also hinder participation. According to the Centers for Disease Control (CDC), the seven most common types of barriers to participation for people with disabilities are attitude, communication, physical, policy, program, social, and transportation. Of these seven, physical barriers are perhaps the

easiest to identify, but also the most expensive to correct. Physical barriers are any hindrance that interferes with a person's ability to move around and access their environment. A typical example of a physical barrier would be stairs that prevent a person who uses a wheelchair from moving freely throughout a building or even from entering it. Similarly, a child with mobility challenges could find it difficult to navigate around an overly crowded classroom ([Disability and Health Promotion, 2024](#)).

While we may be less aware of communication, program, and policy barriers to inclusion, it is also important to identify and correct these situations when possible. Those with visual impairments may need large print or Braille versions of written messages. Those with hearing impairments may require closed captioning for videos or a sign language interpreter at a parent meeting. Procedural barriers would include any policies that interfered with the provision of reasonable accommodations to participants with a disability. These policies could prevent a student or other family member from accessing programs, services, or opportunities that are available to other members of the school community classroom ([Disability and Health Promotion, 2024](#)).

Social barriers are perhaps the hardest to address, but also the most important. Social barriers contribute to diminished well-being for people with disabilities. For example, those with disabilities are less likely to complete high school or to be employed than those without disabilities. Children with disabilities are four times as likely as children without disabilities to experience violence. Creating inclusive school communities can help change these outcomes. To do this, inclusive schools need to be places where kindness, empathy, open-mindedness, and a respect for others is modeled every day. Similarly, inclusive school communities must be welcoming and supportive places for all family members regardless of disability classroom ([Disability and Health Promotion, 2024](#)).



IMPACT ON FAMILY SYSTEMS

An increasing number of families are raising a child with a disability. This is likely the result of a combination of factors. First, there are simply more children with disabilities than there were in the past. This is mainly attributed to medical advances that have increased the survival rate for babies born with conditions that can result in disability. Additionally, most children with disabilities are no longer placed in an institution as was commonly advised well into the 1970s ([Minnesota Governor's Council on Developmental Disabilities, 2016](#)). For the most part, these children are now likely to grow up in their family homes alongside their siblings. Finally, with the enactment of the Individuals with Disabilities Education Act (IDEA) and its legislative precursors, these children do not need to attend residential special schools in order to receive an education. Generally, children with disabilities can now be educated right in their neighborhood schools ([Reichman et al., 2008](#)).

While it is undoubtedly better that these children can grow up with their families, living with a child with a disability does affect the entire family. On the positive side, it can bring families together and strengthen family bonds.

On the negative side, it also comes with time, financial, and emotional costs. For the most part, the level of this impact is relative to the severity of the child's condition and the resources available to the family. For instance, if a child is significantly impacted by the disability, one parent may need to leave the workforce to be a full-time caregiver for the child, resulting in a loss of income. Plus, the cost for medical care and other health related expenses may create a further financial burden on the family. In addition to the economic impact, a disproportionate amount of family time and resources may need to be devoted to the child with a disability, which has implications for relationships with other family members including other children. ([Reichman et al., 2008](#)). Every family is different and the way in which having a child with a disability will affect the family will vary depending on the characteristics of the household, including family size, socioeconomic status, and cultural background; however, this is a factor that teachers must be sensitive to.



SUPPORTING PARENTS AND FAMILIES

Parents are essential team members in establishing goals and developing plans for their child's education. The CEC ethical guidelines emphasize that

special educators must actively involve families in educational decisions that affect their children ([CEC, 2015](#)). It should be noted that the use of the word “parent” is intended to be inclusive of any adult who serves as an essential caregiver for a child. It is crucial that teachers work to build positive partnerships with the parents and families of the children they serve. In some cases, a child’s disability will be identified at birth. In others, the process of identification will occur after the child enters the school system. A teacher may even be the first to suggest that the child might have a disability. In either case, it is important that parents feel that teachers and other school professionals understand them and are working with them to provide their child with an appropriate educational experience.

Parents go through many emotional stages upon learning their child has a disability; however, it should be noted that they do not necessarily progress through these emotional states in an orderly sequence. It is also not unusual for parents to go through some stages more than once. Teachers should be aware that periods of transition, such as moving from one school program to another, one school building to another, and even one teacher to another, are more likely to trigger these emotional states in parents. Strong emotional reactions are also more likely to occur at certain times in the child’s life, such as when he or she misses an important developmental milestone. ([The IRIS Center, 2020](#); [Smith, 1993](#)).

Parents report that often their first feelings are ones of denial and anger. They refuse to accept that their child might have a disability and express anger toward those who tell them otherwise. Depending on the cultural and religious background of the family, they may also feel anger with God for allowing the disability to happen. This is often followed by grief and depression. Parents are faced with a reality that is different from what they had dreamed for their child. Parents, particularly mothers, may even feel guilt that perhaps they did something to cause the disability. Anxiety about

how to best meet the child's needs and fears about the child's future are also common. ([The IRIS Center,2020](#); [Smith, 1993](#)).

At some point, parents begin to accept the diagnosis and adapt to the challenges of raising a child with a disability. Some parents will arrive at this stage sooner and for others it will take longer. Educators can support parents by being sensitive to the family's emotional experience during this adjustment period. They can also help connect families with others who are parenting a child with a disability. In the United States, there are parent centers in every state whose role is to support parents of children with disabilities. ([Center for Parent Information and Resources, 2024](#)). In addition, many communities have local support groups and the internet has made it possible for parents to join online support groups for those with even fairly rare conditions. Eventually, most families reach a stage where they feel both hope for their child's future and stronger as a family. They can celebrate and take pride in their child's accomplishments. They may even take on advocacy roles for their child as well as for others with disabilities ([The IRIS Center,2020](#); [Smith, 1993](#)).



PARENT EXPERIENCES

To illustrate that this emotional experience is common to families everywhere, four families from Nicaragua share with us their experiences in learning that their child has a disability. Gladys is the parent of Alejandro, a 9-year-old boy with Down syndrome. She shares her story of learning of her son's diagnosis shortly after his birth, working through the emotional states that followed, and coming to a place where she could begin to appreciate the gift that her son is to their family. Mario's parents report a very different story as they sought for a long time to find answers about their son's learning struggles and were relieved to finally receive a diagnosis when he was eight years old. Aida Isabella's mother shares her emotional struggles in accepting her daughter's disability. Finally, in a video interview, Jenny & Pablo share their journey to find a school that would help Pablo grow and learn.

GLADYS' STORY

I had regular medical checkups and ultrasounds performed during my pregnancy and there was no indication of Alejandro's diagnosis. When he was born, everything seemed fine until the pediatrician examined him. The pediatrician stated outright that my son had Down syndrome based on his physical features such as a short neck, the palmar crease on his hands, and separated toes. This was too much of a shock. I felt indignant and upset by what I had heard and did not accept it in the beginning. When my husband walked into the room, all I said was that I wanted to get out of there as the doctor was stating a "wrong" diagnosis about our son. My husband supported my opinion, and we left the hospital.

When we got home, I noticed that Alejandro hardly cried at all and would stay asleep for long periods of time. This concerned me, so we decided to seek the opinion of another specialist. Dr. Mejia was able to explain in a wise way that my son was special. He was not as abrupt

as the previous doctor, but I still refused to accept his diagnosis. Because of this, I started meeting with a mental health specialist and began therapy to help me accept my son's diagnosis. This process of working on acceptance lasted until my son was three months old. I never blasphemed against God, but the feeling of failing him was always there. Miraculously, I came to understand that my son, such a beautiful being, was given to our family as a privilege, a gift from God.

Our son has received therapy from different special education centers. At first, it bothered me to see the other children there with conditions such as excessive drooling, paraplegia, and behavioral problems. At first this experience caused me trauma and took away my hopes of seeing progress in my son, but I knew that I was his mother and the person who needed to help him make that progress. Initially, I was opposed to him attending Los Pipitos, a center where children with different disabilities are educated; however, my mother-in-law began to take Alejandro to this center. I was also invited to meet with the psychologist there. I remember that she was a very sweet woman and with wise words she helped me to understand the whole situation even more and to deal with my son's diagnosis. Alejandro began school at the age of 3 and attended Los Pipitos until the end of preschool. He currently receives special education at the Tesoros de Dios Center, where he has achieved goals that help him to relate to others as well as to learn basic life skills.

Today when I talk about Down syndrome, I have mixed feelings because it has been a long road. Every experience has added up to me becoming a better person. I have learned how to be tolerant, patient, compassionate, united, loving, and a creator of quality time with my child. I am also grateful to God for my son. I am happy to have him alive and enjoying good relationships. He has also awakened in my

marriage and family the strength to face all kinds of obstacles. This is a situation that one never thinks of living. My son is the reason that we move forward and do not give up. God gives us the strength every day to watch over his well-being.



Gloria Castillo, Personal Communication, October 2021. Story and photo used with permission.

Mario's Story

Mario was born without complications and was a happy baby, bringing much joy to his family. His mother noticed that at the age of six months he was still not crawling and did not babble. Mario walked at one year and three months without any difficulty, but when he was two years old, he still could hardly pronounce words. This motivated his parents to send him to a preschool so that he could have social contact. When he did not obtain satisfactory results by the age of three, his worried parents sent him to a different school. In the long run, this was to Mario's advantage since there he was able to find a lot of support from preschool through third grade. He also benefited from

being in school with his sister, Antonella. However, even at the age of seven, Mario was not able to speak clearly and fluently.

When Mario turned eight years old, he began attending the Tesoros de Dios Center. There Mario was given the diagnosis of intellectual disability. His parents were provided with information about Mario's condition and Mario began to receive therapy. In this center, Mario and his family found a great refuge. Mario has been able to make progress thanks to the support of his teachers (education, speech therapy and psychology). Mario is able to share that he has a lot of gratitude in his heart for Tesoros de Dios because in this center he has felt valued as a human being. His parents appreciate the good communication and support they receive from the teachers and other staff members.

Magda Matus Balmaceda, Personal Communication, October 2021. Used with permission.

Aida Isabella's Story

Aida Isabella's mother really desired to have a daughter and was immensely happy when she became pregnant. She had experienced a miscarriage earlier and this time, she quit her job and followed all the doctor's recommendations to ensure the health of the baby. She had ultrasounds during the first and second trimesters and was told that the baby was developing very well. When she was seven months along in the pregnancy, there was an earthquake followed by many aftershocks. Aida's mother is unsure of the effect of the earthquake on the baby's development, but at that time she started to experience high blood pressure and the baby's heart began to beat with an abnormal rhythm.

A new ultrasound showed that the baby was not developing normally and had a problem in the formation of her spine as well as hydrocephalus. When they received this news, the father began to cry immediately, but the mother remained strong until she could get to her parents' house where she began to cry. She locked herself in her room and complained to God, "Why me?" She hit the bed and the pillows and felt like she was being punished by God for being a rebellious daughter. She did not understand what the future would hold and was looking for answers. "Feeling in my belly the movement of Aida, feeling the life I carried in me, I never rejected her. Rather I wanted to know what she really had."

Aida's parents sought professional help to understand the diagnosis of their child. It felt like "the whole universe that we had gained by receiving the news of the pregnancy had collapsed to nothing." The doctor told them that children like Aida were just a hindrance and that she was going to have to beg for all her needs. He also said that these children usually only live for one or two years. The doctor then told them that children like Aida go through several surgeries without getting better and that it was better to let her die. However, her family always had faith that the doctors were wrong and that the child would be born well. They began to mourn the loss of their dreams and friends began to give them words of encouragement and sympathy when they found out about Aida's diagnosis.

All of this led the family to continue to seek information so that they could be prepared as much as possible for the birth of their little girl. They visited many places where there were children with this diagnosis. At one place, they met a young woman who gave them hope and encouragement that Aida Isabella would be fine as long as she had the love of her family. They had less than a month to prepare

psychologically and be ready to receive with open arms their beautiful girl. A final ultrasound was performed which indicated that the baby needed urgent surgery. Aida Isabella was born by cesarean section so that surgery could be performed immediately and the wellbeing of both mother and child could be guaranteed.

Jessica María García Mendoza, Personal Communication, October 2021. Used with permission.

Jenny & Pablo's Story

In this [video](#), a mother and son share their journey to find a school that would help Pablo grow and learn. Their story is used with permission.

In summary, the stories shared here by these parents are not very different from the stories of families everywhere. Many parents report similar feelings of anger, guilt, grief, depression, and fear. It is important that parents and families feel supported by the school as they work through these emotions, gain a better understanding of their child's condition, and participate in planning for their child's future.



FACILITATING INCLUSION

Parents can find the special education system, and especially the IEP process, daunting with its specialized vocabulary and complicated procedures. Once again, teachers can be a valuable resource in helping families navigate this system. As already mentioned, this is a good time to connect families with the parent center in their state. The parent center will have materials about special education and the IEP process that are written in a way that is accessible for those who are new to the field of special education. Parents often report feeling anxious about the IEP process and unprepared to participate. As a result, they may not ask questions, express opinions, or advocate for their child. This is unfortunate and completely counter to the CEC guideline that families must be involved in making educational decisions for their children and counter to what research shows is best for the child's academic performance. When parents and schools are able to work together, studies show that students achieve better learning outcomes ([Center for Parent Information and Resources, 2019](#)).

Parents want the best for their children. Many of the advocacy groups that promote acceptance and improved educational opportunities for children with special needs were started by parents who wanted a brighter future for their child. Parents have also brought court cases against schools, resulting in legislative rulings that shaped special education procedures and requirements. However, the parent-school relationship doesn't need to be an adversarial one. Teachers can work with parents to create a relationship based on collaboration, respect, and a commitment to positive outcomes for the child. Schools can ensure that barriers to inclusion are removed so that all family members can be active members of the school community.

Communion and Disability Ministry

Christianna Marcy wrote this piece after an internship experience with [Joni and Friends Ministry](#). In the essay, she explores ways that religious organizations, such as churches, can create inclusive communities for people of all abilities.

[Communion and Disability Ministry](#)



CHAPTER 3: SOURCES

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Recommended citation:

VanTol, K. (2024). Creating an inclusive mindset. *Foundations of special education* (2nd ed.). Dordt University.

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