

Supporting Children & Youth with **Developmental Disabilities**



Kids Included Together

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Introduction

When you learn that a child has a disability, it's important to see the child as a unique person and focus on the supports that work for them. Even if two children have the same diagnosis, they are still individuals who will need different things, at any given time. Child care and youth development professionals are often aware of a child or youth's diagnosis before they meet the child. Diagnosis is only one piece of information. It is important to always consider, *"What does this child need at this moment in time in this environment?"* This booklet gives some information about developmental disabilities with a specific focus on support and where individuals may need support, plus different ways to provide it in your program.

Additional information is available in the Inclusion Resources section at www.kit.org.

A Note About Language

Language sends powerful messages about value and identity. Although we use person-first language throughout this booklet, such as “children and youth with developmental disabilities,” “person with a disability,” or “a child who is deaf,” some people prefer identity first language, such as “disabled person,” or “deaf child.” Many people view having a disability as being a part of their identity, like their race, culture, gender, and other characteristics.

“If someone asked me which language I prefer, I would say identity-first language. One reason I would say I am ‘an autistic man’ as opposed to ‘a man with autism’ is because I want to stand in solidarity with the autistic community, which favors identity-first language over person-first language and sees autism as an important part of who we are. Another reason is because I use identity-first language when talking about other parts of my identity, such as race, and I feel that my disability deserves the same treatment.” Jevon Okundaye¹.

Most of the time, you will simply use the person’s name. When you do refer to the person’s disability,

respect their right to define themselves in ways that feel right to them. When working with children, listen carefully to the words their family uses and ask if you should use the same terms. (e.g., *“I noticed you say ‘learning challenges’ instead of ‘cerebral palsy’ during our meeting about supporting Leah when she transitions. Would you like us to use those terms also?”*) When working with older youth and teens, ask them how they choose to identify. Remember that a diagnosis is confidential information and should not be shared with others without permission from the youth or family.

Be aware of the language you use in the program and choose words that are respectful towards children and their families. When you do have to mention a developmental disability, choose your words carefully and avoid sending the message that disability is something that deserves pity (e.g., “**suffers** from cerebral palsy,” or “**confined** to a wheelchair”). Instead, say things like “she has cerebral palsy,” or “he uses a wheelchair to get around.” Discourage young people from using derogative or hurtful terms related to disability. **In your program, you’ll want to send a clear message that disability is not a tragedy, nor is it something to pity or fear.**

Understanding Developmental Disabilities

It is helpful to have background information as you consider what a child or youth needs in your environment. Developmental disabilities (DD) are a diverse group of conditions that begin during the developmental period and usually last throughout a person's lifetime. Developmental disabilities are not always visible and may affect a child's learning, mobility, language, or behavior. About 1 in 6 children in the United States have DD or other developmental delays. Autism spectrum disorder, brain injuries, cerebral palsy, Down syndrome, epilepsy, fetal alcohol syndrome, intellectual disability, and spina bifida are some examples of DD.

A Note of Caution

Young children, especially those with disabilities, are difficult to assess. The assessments used for infants and young children are far from perfect, have cultural biases, and often come up short for children who speak a language other than English. When working with young children, look at assessment information and diagnoses cautiously. Sometimes, knowing a diagnosis can affect adult

expectations and how they approach the person. Get to know children and youth as individuals and avoid placing limitations on what they can or cannot do. Given the opportunity, children of all ages and abilities will often surprise you with what they can do. Focus on learning the child's strengths and interests. This makes it easier to offer support for their challenges.

Supporting Children with Developmental Disabilities

The best thing you can do for a child is to get to know them and pay attention to things that seem to help them thrive. Most children, both with and without developmental disabilities, will need your help with various activities, tasks, or interactions at different times.

This booklet addresses three general areas of support important to consider for children and youth with DD: 1. Mobility and access, 2. Communication, and 3. Participation in program activities. Separate resources are available for social-emotional learning, which is also important to address.

Mobility and Access

Mobility & Access



All children have support to:

- Access all areas of the program
- Navigate program spaces
- Reach and use program materials
- Have respectful assistance with self-care

Communication



All children have support to:

- Share thoughts and ideas
- Ask questions
- Be understood
- Express needs

Participation



All children have support to:

- Learn rules and expectations
- Make choices
- Transition from one thing to another
- Join activities, games, and clubs
- Make connections

Some individuals with developmental disabilities have mobility limitations and may use a wheelchair, walker, or other adaptive equipment such as leg braces. Limited mobility, personal care limitations, or adaptive equipment should not limit where children and youth can go or what they can do in your program.

- Can children access all areas of the program?
- Can children get in the door?
- Are they able to access all the activity areas?
- Do you have an accessible bathroom?
- Are they able to access your outdoor play space?



If you need help looking at your space, the Institute for Human Centered Design produced an Americans with Disabilities Act (ADA) checklist for existing facilities based on 2010 ADA Standards for Accessible design. It is available at <http://adachecklist.org/doc/fullchecklist/ada-checklist.pdf>.

What is the ADA?

The Americans with Disabilities Act (ADA) is a federal law that passed in 1990 that prohibits discrimination based on disability. The ADA requires programs to be accessible to people with disabilities. Programs are also required to make reasonable accommodations to their policies, practices, and procedures to include children with disabilities.

Some children may scoot or crawl to get around while their same-age peers are walking. Limited mobility may interfere with a child's capacity for independent self-care such as washing their hands, using the toilet, and feeding. Use a case-by-case approach to determine when children with mobility limitations should be promoted to the next classroom. Ideally, children should be with their same-age peers. Collaborate with the family

to determine the best plan of action for each child. Think about how you can address safety concerns for mobility in order to include children while they learn alongside their same-age peers. If they aren't ready to be promoted, think about what skill development you can focus on to help prepare them for the next classroom. Similarly, children who need more assistance with personal care than same-age peers should not be held back just because of their personal care needs.

Look closely at your policies, practices, spaces, and materials and adjust as needed to increase accessibility. If you identify physical barriers that prevent youth from

accessing your program, bring them to your leadership's attention.

If you are a staff member, tell your supervisor. If you are a director, take it to the appropriate agency that handles ADA related matters in your organization



(e.g., facilities, engineering, or safety department) or community. The leadership team should identify policies that are barriers to inclusion (e.g., child must be toilet trained to go to pre-K or child must be walking to go to toddlers) and collaborate with families as needed to make reasonable accommodations.

- Do policies and practices support moving children to the next classroom/program even with mobility or personal care limitations?
- Can children and youth navigate your program spaces?
 - How is fixed furniture arranged? Are there spaces to roll, or scoot around furniture?
 - Is there adequate space in and between activity centers with clearly defined pathways?

Take time to explore your space through the lens of a person using mobility equipment. Sometimes we think we have adequate space, but once the children, youth, and staff are there, we see how difficult it is to navigate when using a wheelchair, walker, or other assistive devices.

- Can children and youth reach games, toys, and activities?
 - If you have a foosball table, can someone using a wheelchair see over the top of it to play? If you have a sandbox, can a child using a walker get in and out?
 - If a child using a wheelchair loves to build with blocks or Legos, are the materials and space accessible for them to do this?

If the answer to your questions about accessibility is, “No,” think about how you can adapt the space to work for all children and youth. Adaptations require flexibility and creativity. For example, could you lower the foosball table a few inches? Could you place a small wooden ramp on the side so the child can get up higher to access it? Can you place a stable item next to the sandbox for a child to stabilize themselves as they step over the edge? For the child who loves to build with blocks, how can you incorporate a table into the building space?

- Do children have respectful assistance with self-care?
 - How can policies be adapted to reasonably accommodate a child who needs assistance with self-care?
 - Are there any physical accommodations that need to be considered? For example, a changing station for older children who do not have bowel or bladder control.



Look at your toileting policy, especially for school-age children and teens, to ensure it allows for accommodations as necessary to support children who need assistance with self-care. As children get older, adults tend to feel more and more uncomfortable assisting with self-care (using the bathroom, washing hands, eating, etc.). Some kids will need help with these tasks, and it should be viewed matter-of-factly and respectfully. When a kindergartener has an accident in an afterschool program, the staff have no problem taking them to the bathroom and helping them change. If a fifth grader needs some assistance transferring from their wheelchair to the toilet, the same approach should be used. **Handling it respectfully and matter-of-factly will help everyone feel comfortable with the support.**

The Department of Justice's ADA Home Page provides free information on ADA requirements. Commonly Asked Questions about Child Care Centers and the ADA is a good place to start: <https://www.ada.gov/childqanda.htm>.

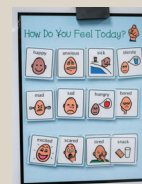
Communication

All people need ways to communicate and understand what is being communicated to them. Some youth have conditions that affect their ability to communicate effectively (speaking, listening, observing, and being understood) and need alternatives available to fully access your program. Some examples include:

- Visual communication supports (e.g., pictures or objects)
- High-tech assistive technology (AT) (e.g., tablets)
- Low-tech assistive technology (AT) (e.g., pointers, switches)
- Sign language interpreters



High-tech AT: Speech generating device



Picture communication system



Picture activity schedule

You want to ensure that children in your program can:

- Share thoughts and ideas
- Ask questions
- Be understood
- Express needs

Even if you are not sure how to go about this for individuals who do not use words, your intentions make a huge difference. Make an effort to ask children what they think, even if you haven't figured out a good way for them to answer yet. Think through what they can do to figure out ways for them to communicate. If the child or youth uses gestures, ask them to answer with a gesture. If they use a tablet, ask them to answer through the tablet. If the child draws, ask them to make a check mark or other symbol.

Collaborate with the child's family and school professionals (with parent permission) to ensure the children are able to share ideas, ask questions, be understood, and express their needs in your program.



Participation

When it comes to supporting participation, consider individual needs on a case-by-case basis. What one child with Down syndrome needs to participate is going to look completely different from what another child with Down syndrome may need in your program. Think through what each child and youth need to effectively:

- Learn rules and expectations
- Make choices
- Cope with transitions
- Plan free time

Learn Rules and Expectations

It is important to set clear boundaries and hold high expectations for children and youth, including those with developmental disabilities. Sometimes vague or abstract expectations are difficult for children to grasp. A child with DD may need several concrete examples to learn what it means to “respect yourself and others.” It might mean “give personal space”. It might also mean “use kind words.” Ask children and youth to help you define program rules and expectations.

Make Choices

There are many choices available to children in your program. They might choose which activity center to play in, which club to join, or if and when to have a snack. The choices available should be available for everyone. If a child or youth has trouble, figure out what they might need to be able to make a choice. For example, if Liomi wanders around during free time, try offering him a choice by showing him pictures of two popular activities (e.g., Do you want to paint or build with the foam blocks?), or by holding objects, such as a paint brush and foam block.

Cope with Transitions

Transitions happen when kids are moving from one activity or space to another. Transitions between activities can be stressful for all children. They must stop one thing and start another, and there is usually a lot more movement and noise. Transitions can be especially stressful for children or youth who have trouble coping with uncertainty in a loud and busy environment. When you are looking at support for a child with DD, think about what you can do to help them cope with transitions. Consider approaching children in advance of the transition to let them

know what is coming up, using a timer to show when the transition is going to happen, or allowing them to transition slightly ahead of the large group. For example, if Emma has trouble during the transition from homework to open play in the gym, consider asking one or two other children to walk with you and Emma to the gym to get the equipment set up before open play.

Join Games, Clubs, and Activities

In addition to making sure all children can choose which game, club, or activity to join, make sure that all children can join in. How a child participates might look different at times but should be meaningful to the child and foster inclusion. There are times when children with DD (especially those who use wheelchairs, and children with intellectual disabilities) are excluded; when with a little effort and out-of-the-box thinking, they could easily participate. A story from an article on youth with disabilities' participation shows how this can happen:

“ We were going to do some line dancing on the stage for the whole school. Guess what, [the teacher] wouldn't let me do it...Well, they could have just lifted me up on the stage and wheeled my chair up. I got to practice, but I didn't get to perform. [Interviewer: How did you feel?] Horrible, just horrible.

Help All Kids Connect

Take opportunities to help all children connect and form positive relationships. This happens naturally for some children while others need support to develop meaningful relationships in your program. Regardless of whether a child has a diagnosis or not, every child benefits when differences are respected and valued. Adults need to model acceptance and demonstrate efforts to include children with DD to create a welcoming environment, and so children recognize and demonstrate the value of including peers with DD. Be open and honest with children when they have questions and support them as they experiment with different ways to interact and play.

Everyone is Unique

Spend time explaining to children and youth in your program that all people are individuals. People's brains and bodies are unique. Not all people use words to talk, and not all people use their feet to move around. Some people see differently, and others hear differently. Some people will need help with things that are easy for others. Facilitate discussions and activities with children in your program to help them realize how everyone is unique and may participate in different ways.

Emphasize that it is okay to do things to help. Help children understand that all children like to play and have fun, but it may look different for everyone. Encourage them to help come up with ideas to be more inclusive. For example, Kevin, who is autistic, loved running and playing with his friends, but he did not understand the complex rules of Capture the Flag. His peers decided to make him the Supreme Tagger, so if he tagged you, you were frozen regardless of what team you were on. Kevin had full immunity. Kevin was great at other games and the children valued his participation. They learned to easily make accommodations for most things, as needed.



Use the Support Plan as Your Guide

When a child or youth with a diagnosed developmental disability enrolls in a youth program setting, a support plan might be developed in collaboration with the family, specialists, and possibly the school system. The support plan serves as a guide for youth professionals to support the child or youth's mobility, access, communication, participation, and social-emotional learning. As you review the support plan and share it with other staff, ask questions. Review it with the child or youth's parents to see whether there are pieces of the plan that they can show or train staff on. For example, maybe a child with a diagnosis of cerebral palsy uses leg braces and a walker for mobility. Parents might need to train staff on how to adjust or reposition the leg braces if they loosen, fall off, or cause the child discomfort. Some children with DD may attend your program without a formal support plan. As you discover accommodations that increase their opportunities to participate, include those in lesson plans, or informal support plans developed with the youth and your team. For example, Alexis, who has

cerebral palsy, could participate independently in afterschool activities, and was comfortable asking for help or accommodations. Her biggest challenge was that she often fatigued walking from one program area to another if they were not adjacent and did not have energy left to engage by the time she got there. She did not want a wheelchair in the program. They adapted a wagon that she could easily get in and out of and peers or staff helped her get safely back and forth between activity areas. Alexis did not need a formal Inclusion Support Plan, but they did create protocols around how and when the wagon could be used to ensure safety.

Create Diverse and Accepting Environments

Children and youth have a natural curiosity about the world around them, including differences in themselves and others. Individuals with DD sometimes have visible differences that evoke children's curiosity. The following practices will help you create a diverse and accepting environment.

Provide Honest and Simple Explanations

Respond to questions with honest explanations that are easy to understand. Children often share observations to test out their ideas. By remaining sincere and non-judgmental, you can help kids figure things out for themselves. For example, if a child says, *“Why is he drooling? He looks like a baby,”* an honest and simple response might be, *“He is six years old, just like you, and he likes to play with other six-year-olds. Sometimes it’s hard for him to control the muscles in his face. His friends can help him by offering him a tissue.”* If a youth asks, *“Why can’t she talk?”* You can explain, *“Some kids use words, and other kids use sounds and gestures to talk. If you watch her closely, you can learn what certain sounds mean. I have noticed she makes a higher-pitched sound when she is excited about something. Maybe you will notice something I haven’t noticed yet.”*

Facilitate Natural Friendships

Friendships not only enrich our lives but are important tools in our social and emotional development. Through friendships, peers can learn, be challenged, and grow. Friendships provide a sense of well-being and support, which is important for success in life. Be careful about

forcing friendship or praising a child for befriending a child with DD. You want to encourage natural friendships between children with and without DD.

Natural friendships are reciprocal, built on common interests and a genuine connection.

As you work to provide support for children with developmental disabilities in your program, remember to consider the following: what does this child need, at this moment in time, in this environment? What can I do to make sure that this child has the support they need to communicate, participate, make friends, and access everything we have to offer?

¹ Jevon Okundaye is a Black autistic young man. This is from a post in his blog series “Ask a Self-Advocate.” <https://www.massadvocates.org/news/ask-a-self-advocate-the-pros-and-cons-of-person-first-and-identity-first-language>

¹ Hebbler, K., & Spiker, D. (2016). Supporting young children with disabilities. *Future of Children*, 26, 2, 185-205.

¹ Kramer, J.M., Olsen, S., Mermelstein, M., Balcells, A., & Liljenquist, K. (2012). Youth with disabilities’ perspectives of the environment and participation: A qualitative meta-synthesis. *Child: Care Health, and Development*, 38, 6, 763-777.



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At KIT Academy, you can access online training on how to meaningfully include kids with disabilities or complex needs. KIT Academy offers all of the Kids Included Together best-in-class disability inclusion and behavior support training and resources. You'll find information to help guide you on all kinds of topics for all age groups. Feel free to look around and search our eStore at LearnOnline.kit.org/store.

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Changing **Attitudes**™
Changing **Practices**
Changing **Lives**

Research shows that ALL children benefit from shared experiences and friendships among kids with and without disabilities. Kids Included Together (KIT) was founded in 1997 to teach inclusive practices and behavior support to child and youth program providers and educators, so no child is excluded. KIT also provides observations, consultations, and recommendations to ensure organizations are confident in serving all children, including those with disabilities or other complex needs.

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