

Using Family-Specific Language

Caring for infants and toddlers with special needs, disabilities, and exceptionalities is a wonderful opportunity to embrace diverse families in your community. You may hear different language or terms from families when they describe their child's condition or ability level. Some families will use "special needs" or "disability." Others will use specific terms such as, "He has Down syndrome" or "My child is deaf." Depending on how recently a family has learned about their child's needs and how they are coping, some families will avoid speaking about it at all even if they previously shared information with you.

It's important to take your cues from each individual family. Some families will be eager to share updates and suggestions they learn from doctors or specialists. If a family describes a recommendation to you as, "helpful for babies with Down syndrome," it is acceptable to mirror this same language as long as you are comfortable doing so. It is best practice to use person-first language. For example, "toddler with autism" is preferred over "autistic toddler." Even though it is most important to think of children first as individuals (and not define them by their conditions or traits), there may be times when you need to ask families questions about caring for their infant or toddler. It can be difficult to avoid using medical terms and jargon during these conversations, and you may need to directly address their child's condition or ability level. If you are unsure of what to say, ask the family how they prefer you speak about their child's needs or condition. This shows the family that their input is valued, and it builds trust in your partnership with them.

Case Scenario:

Mason is a four-month-old infant born with a cleft lip, a condition where the skin that forms a baby's upper lip does not completely join and leaves a slit in the skin. Mason stayed in the neonatal intensive care unit (NICU) and needed a feeding tube to eat the first few weeks of life. The family shared with you that their time in the hospital was an extremely stressful experience. Mason is now doing great and only needs the help of a specialized bottle nipple for eating. Mason's mother and father are thrilled to have Mason in your program, and Mason's mother is excited to return to work. They've said they are looking forward to, "enjoying our baby and returning to a normal life."

Mason's cleft lip is noticeable, and other staff and some family members' of other children in the program have asked you questions such as, "What happened to that little baby" or "What kind of bottle is that?" You are not sure how to respond or what Mason's family feels comfortable sharing. You feel you should communicate with Mason's parents that others have asked questions about their child.

How will you initiate this conversation with Mason's family? Think about how to be sensitive to the fact that the family has been through a stressful experience and are now excited for their child and themselves "to return to normal." Record some notes on how you would discuss the situation with the family, and reflect on your thoughts with a coach, trainer, or administrator.
