

Using Family-Specific Language

Caring for children 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 for you and program staff 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, a caregiver, or a teacher as, "helpful for children 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, "children with autism" is preferred over "autistic children." Even though it is most important to think of children first as individuals (and not to define them by their conditions or traits), there may be times when you or program staff will need to ask families questions about caring for their child. It can be difficult to avoid using medical terms and jargon during these conversations, and you or they may need to directly address their child's condition or ability level. If you or staff members are unsure of what to say, model for staff members the best practice of asking families 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.

Read through the following three scenarios. Think about how you would approach these scenarios, and how you might support your staff in partnering with families.

- 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 Jorge, Mason's caregiver, 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 told Jorge they are looking forward to, "enjoying our baby and returning to a normal life."

Mason's cleft lip is noticeable, and parents of other infants in Jorge's room have asked Jorge questions such as, "What happened to that little baby" or "What kind of bottle is that?" Jorge is not sure how to respond or what Mason's family feels comfortable sharing. Jorge feels he should communicate with Mason's parents that others have asked questions about their child. How could you help Jorge support this family?

- Mia is a child in LaNesha's preschool classroom. LaNesha has made many attempts to share about Mia's learning, but Mia's family members rarely ask questions or talk about their lives. Although Mia's parents have never directly spoken to any program staff about it, you know from the enrollment paperwork the family completed that Mia has a diagnosis of cerebral palsy. Since enrolling in the program two months ago, LaNesha, has observed Mia to be a happy child who can do everything her peers can do, but is a bit slower than most children in class. LaNesha and her co-teacher, Tammy, have recently noticed that it is becoming increasingly difficult to help Mia put shoes on, and Mia has begun to trip and fall more frequently. LaNesha and Tammy are not sure if this is "normal" or to be expected for a child with cerebral palsy. They are concerned for Mia's safety and feel it is necessary to talk with the family.

How could you help LaNesha and Tammy support Mia's family? Think about how to be sensitive to the fact that the family has chosen not to speak about Mia's condition with teachers.

- Liam is an eight-year-old in Poppy's school-age program born with moderate hearing loss in both ears. Liam has a set of hearing aids but does not consistently wear them. On days when Poppy notices that Liam is not wearing hearing aids, Liam often says, "forgot them at home" or "couldn't find them this morning." Other times, Liam has the hearing aids, but they need new batteries and don't work.

Liam's ability to follow directions and interact with peers is significantly better when wearing working hearing aids. Liam already needs support with peer interactions, and challenges in this area are worsened when hearing is impacted. Although bullying is not an issue in your program, Liam's parents have told Poppy that bullying has been a problem at Liam's school. They feel that Liam's time in Poppy's classroom has positively impacted Liam's ability to make friends. Poppy feels the need to discuss Liam's inconsistent use of hearing aids with Liam's parents to best support Liam's learning and friendships. How would you support Poppy to address this issue with Liam's family? Think about how to be sensitive to the fact that the family is now experiencing a stressful experience at school.

After you think through how you could support staff members in the scenarios above, share your thoughts with a colleague.