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Difference & Diplomacy

Wondering how to help your child be sensitive towards kids with disabilities? Here's what their parents want you to know.

By Lisa Bendall

"Mommy, why is that boy walking like that?"

The sudden question pierces the quiet hum of the grocery store. Your heart sinks. Your cheeks flush. If a hole were suddenly to open in the floor, you would gratefully slip through it. The small yet strident voice belongs to *your* five-year-old daughter.

How should you respond? Do you apologize to the family who, thanks to your child, has suddenly found themselves in the spotlight? Do you haul your daughter away by the arm? Or do you pretend you are the only customer in the aisle who didn't hear the question, absorbed as you are in the sale price of dog food?

When able-bodied children meet kids with disabilities, most parents want to teach them to respond appropriately — to understand and respect differences, not fear them. Yet it's not always easy to put principles into action, especially for parents who were raised before integrated classrooms and wheelchair-accessible public spaces became such accustomed parts of our social fabric.

So, what to do when your daughter blurts out her unself-conscious inquiry in the middle of the pet food aisle? For advice on this and other questions, we went to the experts: parents whose children have disabilities.

Their first advice: Shed the embarrassment. Remind yourself that your child is merely expressing interest in the world around her. She might as well have asked why the carrots are orange.

"It's just curiosity, which is fine with me," says Annette Walker of Ottawa. Her 14-year-old daughter, Akasha, has Rett syndrome. Akasha — called Kai ("Kay") by her friends and family — is non-verbal and uses a wheelchair. Her mom is used to kids approaching to ask why Kai doesn't talk or walk. And Walker doesn't mind. In fact, she likes the opportunity to educate them.

"I've actually had parents pull their children away from my child," she says. "That's more discouraging because that's where the whole ignorance about disabilities is passed on."

A simple response such as "his legs don't work well" is often all it takes to satisfy a young child's inquisitiveness. Children are marvellously open-minded about what fits into their range of normal.

Donna Platt agrees. Platt, who is raising a granddaughter with cerebral palsy in West St. Paul, Man., says most other kids are unfazed by the fact that 13-year-old Jessica doesn't walk. "The little ones love her wheels," says Platt, "and the older ones love to push her."

Adds Platt: “I think children would accept another child with two heads.”

To Ask or Not to Ask

Many parents struggle with whether to allow their children to approach other families to ask about their child’s disability. Cara Kropp of Carleton Place, Ont., is often on the receiving end of such questions and, like Walker, she is “really happy when kids ask.” Kropp’s eight-year-old son, Jacob, has autism. Because of his affected speech and unusual mannerisms, other kids definitely notice he is different.

If Kropp hears a parent shush her curious child, “I usually try to interject at that point and say it’s OK, and take over the explanation if need be.” She’ll tell children who wonder about Jacob that “he has autism and his brain works differently.”

Keep in mind, however, that while most families are comfortable with questions from children, questions from adults can come across as an intrusion. Much as they too may wonder about a child’s cleft palate or hearing aid, adults should refrain from prying.

“There’s something about an adult just coming up and saying, ‘So what’s wrong with you?’” says Kathleen Davidson, the mother of a six-year-old with delayed speech. “Kids are kids. Adults need a little bit more tact than that.”

Keep it Simple

It’s one thing to encourage your child to ask about other children’s disabilities. Sometimes you’re also the one trying to answer her questions.

Turns out you don’t need a medical degree. “The simple explanation is the easiest,” says Donna Platt. Does your child wonder why a little girl is in a wheelchair? Try: “She doesn’t walk well, and the wheelchair helps her get around.” Is your child curious about a boy who is using sign language? Let her know that “his ears don’t work so he’s talking in a special language with his hands instead.”

Six-year-old Colin Davidson’s apraxia affects the way he speaks. When children ask, his mom, Kathleen, usually tells them: “‘The muscles in Colin’s mouth aren’t working properly. It makes it hard for him to speak.’ Kids just accept that.”

Keep it age-appropriate. Preschoolers do not need detailed explanations. Take your cue from the complexity of their questions — kids school-aged and older may solicit more specific information. And tone is important. Answering questions in a matter-of-fact manner will send children the message that a disability is no big deal.

No Pushing or Pulling

Parents of children with disabilities stress that families should never pull their curious children away.

When Ted Kuntz is in public with his 19-year-old son, Josh, who has neurological disabilities, “kids will come up and touch his wheels or look in his eyes,” says Kuntz. “They come right into his face and they want to engage him. It’s often the parent who will yank them back and say ‘don’t’ — and discourage their natural curiosity.

“It becomes something quite traumatic for their own child,” says Kuntz, a family therapist in Coquitlam, BC. Children learn to associate “an experience of fear around the person with a disability.”

Kuntz, like many other parents, embraces the opportunity to promote awareness. “I like to invite them in and say, ‘Hi, what’s your name? Would you like to say hi to Josh?’”

But ease up on the coercion. As Platt says, “The worst thing adults can do is force the child who’s in the puzzlement mode, ‘Now you go over and talk to her.’ Just let kids be where they are because when they’re more at ease, they’ll make their own move.”

Accentuate the Positive

One parent suggests that, when discussing a disability, you also point out an ability — perhaps a child’s creative artwork or lovely smile.

Pat Tesan’s daughter Erin grew up with an intellectual disability, but there was at least one thing she could do better than many of her peers: swim like a fish. “We worked hard to get her safe in the water,” says Tesan, who lives in Coquitlam, BC. Swimming became an achievement Erin could feel proud of — and which other kids admired. By trying to keep disabilities in a positive context, you can help children see more similarities than differences.

Annette Walker’s favourite comment came not from a parent, but from one of Kai’s young classmates. She trotted up to Kai in the supermarket to say hi, while the mother said to Walker, “Do you mind if I ask what’s wrong with Kai?” The girl immediately corrected her mom: “There’s nothing wrong with Kai. She has a wheelchair like I wear glasses.”

“That’s exactly what I wanted these kids to see,” says Walker happily. “Kai was no different from them.”

Find Paths to Inclusion

One of the best ways to help your child learn to socialize with kids with disabilities is to make sure they spend time together. Integrated recreation programs or preschools are a good source of opportunities. And Donna Platt urges parents not to be daunted by the challenges of including classmates with disabilities in playdates or birthday parties. Most activities can be adapted. “If people put their mind around it for a little tiny bit, then all of a sudden the ideas start popping forward,” says Platt. Too often, “the first response is ‘I don’t know how to — so I won’t,’ or ‘It couldn’t possibly work — so I won’t try.’”

Get creative. Find the path to inclusion. And if you’re not sure, solicit ideas before surrendering. See “One of the Gang” below for a few to get you started.

Teach by Example

Sharon Maric of Winnipeg was pleased when other parents made a point of inviting her son Paul to birthday parties, “making him know that he was welcome,” she says. When they would speak with and pay attention to Paul, they were also modelling acceptance. “By their own behaviour they were saying, ‘I like this child. He counts.’”

Pat Tesan agrees that adults’ attitudes play a huge role. “I certainly see that in the school system. If a teacher is comfortable with a child in the classroom, the other

children will be. If a teacher shows fear or doesn't understand how to be with the child, then the other kids won't either."

Ponder the Benefits

The year Josh Kuntz was entering grade seven, two teachers at his school flipped a coin to divvy up the class list. The winner immediately selected Josh. "I've watched the kids when they're around Josh," the teacher said. "When they're around him, they're kinder and gentler. And if I have him in my class, I'll have a kinder, gentler class."

As Josh's dad recalls, "What that teacher recognized absolutely came true." Ted Kuntz points out that contributions from children with disabilities may not always involve physical or intellectual prowess. "Josh's gift is a gift of being. It draws out those human qualities that make us into a richer society, a more caring society."

Annette Walker says that since her daughter was mainstreamed in a regular class, her peers — particularly in the early years — accepted her as no different from them. "Kids seemed to pick up on this from day one. It wasn't pounded into their heads," she says. If, some day, one of those classmates has a son or daughter with a disability, Walker hopes that Kai's example will make the journey easier for them.

Word Power

How you speak about disability issues shapes your child's understanding of them. Try to avoid negative or loaded descriptions, such as "she suffers from autism" or "he is confined to a wheelchair." Language should be straightforward and precise: "She has autism"; "He uses a wheelchair."

The best rule of thumb is to put the child first, the disability second. And don't let the disability define the individual. So instead of "a diabetic," or "a Down's kid," try "a girl with diabetes" and "a boy with Down's syndrome."

It's important to note that many once-acceptable words are not welcome today, and some are downright upsetting. Parents cringe to hear "the R word." "'Retarded' is language from the past," says Sharon Maric of Winnipeg. Other out-of-fashion words that can hurt: "handicapped," "crippled," "invalid."

Better still, Maric adds, is "if you can avoid the label altogether, and call the child by name. If you are actually talking about the child's disability, fine. But try to make the child more important than the disability."

One of the Gang

For birthday parties and other occasions, a little imagination can help you come up with activities that include, and don't exclude, a child's abilities.

- Musical chairs might be a challenge for a child who is blind, but Pin the Tail on the Donkey could work fine.
- Hockey nets can be moved closer together, basketball nets can be lowered.
- Don't reinvent the wheel: Adaptations, such as special ramps for launching bowling balls, already exist for many activities.
- Capitalize on technology. Captioned and narrated movies (available from libraries or disability organizations) make video watching more enjoyable for kids who are deaf or blind.

- If the child can't kick the ball, seek out another active role for her, such as scorekeeper or referee.
- Remember that some children may be able to get out of their wheelchairs and participate in a floor activity.
- If the child needs assistance in an activity, consider partnering him up with a willing friend or family member.

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