

PREPARING FOR ADOLESCENCE

By Cindy Lefler

The teen years can be a tough time for any kid, filled with struggles over issues of self-esteem, peer pressure, body consciousness and independence. For young wheelchair users, those issues can be magnified a hundredfold.

But according to 24-year-old Simon Cantos of Lansdale, Pa., with the right attitude, “kids in wheelchairs can be no different from any other kid.”

Cantos, who has Ullrich congenital muscular dystrophy, looks back on his teen years as “just like every other kid’s, only on four wheels. I was focused on my looks, having the right clothes, the right shoes — but I wasn’t focused on the wheelchair. Some disabled kids struggle with self-esteem issues, but it has less to do with the wheelchair and more to do with the mindset.”

It can seem premature — not to mention scary — to think about the challenges your 10-year-old may have to deal with during adolescence. But really, those teen years are just around the corner. Promoting your child’s emotional health now can help him or her grow into a confident and well-adjusted teenager. It will still be a tumultuous time of life — no one can predict for sure what those hormonal changes will do — but having a disability doesn’t need to increase the turmoil.

“Much depends on the approach taken with the child at home and in the school,” says Dr. Richard Finkel, a pediatric neurologist at the Children’s Hospital of Philadelphia who specializes in children with nerve and muscle disorders. “Kids are more resilient than you would expect; they have a drive to get out and get a life. Being in a wheelchair is not so dire a situation when the child has a lot of support from the family, the school and the community.”

One of the most important ways to ensure healthy development for any preteen wheelchair user is to make sure his or her school is living up to its federally-mandated responsibility of providing the most inclusive, least restrictive environment for the child, Finkel says. “The parents need to be aware of their legal rights and use that knowledge in a proactive way to work with the school.”

Gail Zoccola of Lititz, Pa., whose daughter, Linzey, has spinal muscular atrophy, recom-

mends becoming an expert on IDEA — the Individuals with Disabilities Education Act — the federal law ensuring services to children with disabilities throughout the nation. Zoccola also urges parents to become knowledgeable about the Americans with Disabilities Act in order to get services outside of the school. “These young adults are extraordinary people who are very capable of doing anything they want to do,” she says.

According to Suzanne Ripley, Director of the National Dissemination Center for Children with Disabilities (NICHCY), the more resources parents have, the more empowered they become. Since its founding in 1978, NICHCY has evolved into a central clearinghouse of information for parents of children with disabilities.

“While the focus is still on education, we know that disability issues are not limited to school,” Ripley says. “There are issues around the family, communities, health, recreation, and transportation. We have become an extensive referral resource for parents whose needs go beyond school issues.”

Having those kinds of resources is important, because kids — all kids — want more and more freedom as they enter adolescence. “Perhaps the hardest part of being a parent (of a wheelchair user) is promoting independence,” says Finkel. “Being a teen is all about learning to be independent, which in some cases is not easy to accomplish.”

For Jake McGovern, 15, who has Duchenne muscular dystrophy, greater independence came with getting a power wheelchair. Jake’s life is all about sports. A sophomore at Sun Valley High School in Aston, Pa., he keeps score at basketball games and announces at various sporting events. His mother, Mimi McGovern, says the challenge of raising a kid on wheels is less about the “emotional stuff and more about the logistical stuff” like transportation and accessible public facilities.

When children have personal care needs, their desire for independence can sometimes collide with the desire for physical privacy. Some



Linzey Zoccola says using a wheelchair was a positive thing as a teenager: “It made me feel unique.”

teens with disabilities, Finkel says, refuse to use the bathroom at school all day because they don’t want to ask an adult aide or a classmate to help them. For Linzey Zoccola, the privacy issue was solved with a young, female personal care attendant who was in tune with her need to fuss over hair and makeup. In 2002 Linzey acquired a yellow Labrador retriever service dog named Winston. Her new “buddy” eventually led her to her new career — she is currently interning at Susquehanna Training Dogs and learning to become a service dog trainer.

Now 22, Linzey says the wheelchair was a “positive thing” growing up.

“It made me feel unique — it was a topic of conversation,” she says, “During the teen years every girl has something to be self-conscious about — her hair, her weight, her freckles — so I felt just like everyone else.”

Even if your child’s teen years are still years away, it’s not too soon to get ready for them. Think of it as putting in curbscuts along the road to adulthood. With some resources to draw on, advance preparation and a positive attitude, your young wheeler can find a path free of unnecessary obstacles.

Resources

- Individuals with Disabilities Education Act information: idea.ed.gov.
- Americans with Disabilities Act: www.usdoj.gov/crt/ada/adahom1.htm.
- National Dissemination Center for Children with Disabilities: (800) 695-0285; www.nichcy.org.