



Growing up with Down

Photos and Story by Rachel Psutka

Reaching the cusp of adulthood is a step that everyone makes at some point in their lives. But when an individual has an intellectual delay, reaching that milestone of independence and freedom is cause for even more celebration.

One of these individuals is Josh Daley, 16, a rap-loving, energetic basketball fan with a penchant for fizzy drinks and chips. Josh has Down syndrome, a naturally occurring chromosomal arrangement present in about one in 800 births in Canada. Down syndrome commonly results in delayed learning and some health concerns, but these vary between individuals. The biggest challenge is to find effective methods of teaching each person, something that can start soon after birth.

Unlike many children with Down syndrome, Josh has seen life in a standard classroom, attending an elementary school with regular kids his own age for a few years before segregating due to his needs. A fighter on her son's behalf, Janice Daley has been trying to find the best method of preparing Josh for life as an adult ever since his birth.

"All the skills take a lot more practice, a lot more teaching, whereas typically developing children just come across these skills, especially social skills," Daley explains. "We really had to teach Josh how to hold in his tongue, how to interact with others, how to ask for things. Speech was one that we really worked hard on so he could order things at restaurants and chat to his friends about things."

Daley has faced her share of challenges in raising a child with intellectual delays. When Josh was born with an extra chromosome, her marriage fell apart and Janice found herself raising two young sons on her own by the time Josh was four years old. Despite these hardships, Daley never wavered on her commitment to raising her sons with equal opportunities.

"I was adamant when Josh started school that he was going to be in a regular class, and I was adamant about that because he learns so much from his peers and he gave so much back to his peers. In Grade 2, I was told that he could no longer be in a regular classroom, that he wasn't learning. The school wouldn't listen to me. They really made it rough and basically

would just send him home," Daley explains.

Ontario has approximately 290,000 students in elementary and secondary schools receiving special education programs and services. In most situations, parents and guardians agree with the teachers and supports on the needs of the student. But when parents raise their concerns, they're met with a lengthy review process.

For working single parents, like Daley, this level of protest was not possible.

"I gave in, knowing that he had to be in school and I had to be at work, so I let that piece go, pretty much," Daley says.

As Josh has progressed to his high school years, Daley is more accepting of his path, though strong in her opinion that her son could have thrived in a non-segregated environment.

"He loves school, and he's learned lots of really neat things, but I think he could've learned all those things in a regular classroom. He loves his teachers and he loves the friends that he's with, but he also loves going to the regular art classes and regular gym classes.

I do still strongly believe that he could've been in a regular, inclusive classroom all the way through, with supports of course," says Daley.

Nancy Burt, an educational assistant who has worked with children with special needs for 37 years, disagrees.

"By being in an academic setting, we're not teaching them the skills that they need to have by the time they graduate. They don't know how to cook, they don't know how to clean, and they don't know how to manage their money. Sure, some of them can list off the provinces, but where's that going to get them when they're 30 years old?" Burt questions.

"I wouldn't be worried about other kids making fun of them, but I would worry about them feeling dumb," says Josh's teacher Adam Speight, agreeing with his assistant. "They would feel like they didn't fit, and I don't think that's right. Everyone in this room feels like part of a family, they feel like they belong and so they can learn and be wrong and be right. And they do it together"



From left to right, starting at top:

Josh Daley, 16, plays with his iPod at his after-school program for children with developmental delays. The program was started to accommodate local families who could not find regular after-school care.

Josh gets some help from his mother Janice while baking peanut butter cup cookies.

Josh examines a knife at his school co-op placement with a local catering company.

Josh takes a break during a night of swimming at the YMCA. A former Special Olympics swimmer, Josh is taking the year off to play basketball and participate more with his high school.

Physical education class is a favourite of Josh. A student at Centennial Secondary School, Josh takes a break with girlfriend Courtney Chaumont in between activities.