

Support for families who have children with Down syndrome

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Life is getting better for people with Down syndrome, but there's still a long way to go.

Here are a few tips for parents of children with the world's most common genetic condition.

And a few more for parents of typically developing kids on how to be a good ally.

(The tips were compiled from conversations with adults living with Down syndrome, their parents, a visit to a support group, conversations with lawyers and other research.)

If your child has Down syndrome

1. Get involved with a parent support group. Countless options pop up on Google. And Facebook has several, as well. These people know what you're about to go through. And they're willing to help. I connected with Sharing Down Syndrome and met a 21-year-old, Parker Bradshaw, who has Down syndrome and was educated in Mesa public schools. Today, he takes religion, orchestra and sign language at Mesa Community College. He also works two days a week at a bakery. The group's director said he was a great self-

advocate, to which he replied, “thank you.” Bradshaw also is a football fan. “I like watching it,” he said. Even though they’re playing poorly, “I still like the Cardinals.”

2. Get involved in inclusive activities as early as possible. Join play groups and attend park meetups. But studies show exposure to typically developing children has benefit for kids with developmental delays, and vice versa.
3. Get special attention early. Get into physical therapy, speech therapy and language therapy as early as possible. It can help tremendously.
4. Join a group that will help you learn to write an IEP, an individualized education plan, and when it comes time to attend an IEP meeting, don’t go alone. It gets emotional, and it’s easy to forget things. Take an advocate, a lawyer, a friend, anyone who can help you navigate the process.
5. Make sure you advocate for your child as an individual. People with disabilities, including Down syndrome, can range from those who need extensive care and assistance to those who function independently with minimal support. It’s as important to recognize this within the disabled community as it is with any other group.

If you want to be an ally

1. Learn as much as you can about the condition. There are a range of developmental delays. Down syndrome is one. People born with the world’s most common genetic condition can be high function. They can go to college, hold jobs and form relationships.
2. Model appropriate language. Never use the “r-word,” and if you don’t even know what that is, good. Remember, put the child first, as in “the young girl, who has Down syndrome.” Or, “the teenage boy, who has Down syndrome.”
3. Invite kids with disabilities to birthday parties, play dates and anything else you would invite a child to. Kids with developmental delays experience a range of emotions, just like anyone else. They can recognize when they’re being excluded; and they experience loneliness.
4. Teach kids to be active bystanders. It’s not enough to say, “don’t be a bully.” Show kids how to stand up for victims.
5. Join a Down syndrome support group. Visit some of the activities. Volunteer with your kids.

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