

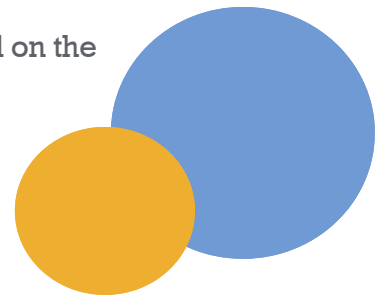
How will having a baby with Down syndrome affect my family?



One of the best ways to find an answer to this question is by speaking to family members of individuals with Down syndrome. In addition, there are many books and articles written by family members about their personal experiences. These accounts can offer a great deal of comfort and reassurance because, as you hear or read other people's stories, you will find that there is a consistent theme throughout the various experiences.

The message that you will hear time and time again is that the positive impacts of having a family member with Down syndrome far outweigh the difficulties or challenges that may come up. The majority of families share that they are stronger and closer as a result of the experience of dealing with a disability, and that they are more focused on the things that really matter in life.

Adapted from NDSS



celebrating extraordinary lives

There have also been many research studies that explore how having a child with Down syndrome affects families. Studies show that while these families do experience additional challenges, their levels of well-being are comparable to those of families who do not have a child with Down syndrome. Researchers say that what seems to determine if families are resilient and able to thrive is their ability to access individual, family and community resources. Be sure to take advantage of all the resources available in your community, and focus on building a support network to get you and your family through any tough times.

Adapted from NDSS

In research conducted by Dr. Brian Skotko of Children's Hospital Boston in 2011, results suggest that the experience of Down syndrome is a positive one for most parents, siblings and people with Down syndrome themselves. The first study evaluated surveys from 2,044 parents or guardians, representing an estimated response rate of 29%. Its findings:

- 99 percent of parent/guardians said they loved their child with Down syndrome
- 79 percent felt their outlook on life was more positive because of their child
- 5 percent felt embarrassed by their child
- 4 percent regretted having their child.

The second study evaluated responses to similar questions from 822 brothers and sisters age 9 and older (estimated response rate, 19%). Of the siblings age 12 and older:

- 94 percent expressed feelings of pride about their sibling
- 7 percent felt embarrassed by their sibling
- 4 percent would "trade their sibling in" for another
- 88 percent said they felt they were better people because of their sibling with Down syndrome

Of siblings aged 9-11:

- 97 percent said they loved their sibling
- 90 percent felt their friends are comfortable around their sibling

Siblings, asked what they would tell prospective parents having a child with Down syndrome, most often conveyed that the experience would be joyful and rewarding, though many also said there would be challenging moments.



The mission of the DSAGC is to empower individuals, educate families, enhance communities and together, celebrate the extraordinary lives of people with Down syndrome.

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