

Study finds positive attitudes prevail within families of people with Down syndrome

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When expectant parents learn they will be having a child with Down syndrome, one of the first questions they may ask their health professional is "How will this affect our family?" A study from a research team led by a MassGeneral Hospital for Children (MGHfC) physician finds that, within most families, the experience of having a member with Down syndrome is generally a positive one. Their report will appear as the feature article in the April issue of the *American Journal of Medical Genetics Part A*, has been released online, and is a follow-up to three 2011 studies from the same group.

"Our study demonstrates that positive [attitudes](#) tend to dominate within modern-day families who have members with Down syndrome, although the challenges were not insignificant for some," says Brian Skotko, MD, MPP, co-director of the Massachusetts General Hospital Down Syndrome Program and corresponding author of the study. "These findings come at a crucial time when more pregnant couples are receiving prenatal diagnoses and wondering what the diagnosis will mean for them."

The 2011 studies led by [Skotko](#) - who at the time was at Boston Children's Hospital and Boston Medical Center - evaluated surveys of more than 2,000 parents or guardians of individuals with Down syndrome; more than 800 siblings of someone with Down syndrome, and 248 people with Down syndrome. Each survey was analyzed separately, but all three had similar positive findings - with parents/guardians and siblings overwhelmingly expressing love and pride for their family

member and almost all of those with Down syndrome being happy with many aspects of their lives.

The current study links the three previous studies together to ask whether the attitudes of parents, siblings and people with Down syndrome differ within families, such as whether the attitudes expressed by parents will be shared by other family members. It reanalyzed the responses of participants in the 2011 studies - who were members of six Down syndrome support agencies in California, Colorado, Georgia, Massachusetts, North Carolina and Texas - examining 42 family attitudes.

In 87 percent of families, everyone expressed feeling love for members with Down syndrome, who in turn expressed love for the other [family members](#); in 83 percent, everyone was proud of members with Down syndrome, who also felt pride in themselves. The extent to which the abilities of members with Down syndrome were impaired had little or no relation to attitudes within the family.

Small minorities of respondents - less than 10 percent in the following examples - did report some negative attitudes. Younger siblings (ages 9 to 11) were more likely to report being embarrassed by their sibling with Down syndrome if their parents also reported embarrassment, and siblings over the age of 12 were more likely to want to "trade in" their sibling with Down syndrome if their [parents](#) expressed regret in having the child. Parents' perceptions of the quality of relationships among their children with and without Down syndrome proved quite accurate.

"This study provides a more complete, interwoven portrait of the modern-day [family](#) with a member who has Down syndrome," says Skotko, who is an assistant professor of Pediatrics at Harvard Medical School. "I think it will be surprising to some that families who have children with Down syndrome feel so positive and even enriched. But

our respondents have shared a resiliency that has translated into meaningful life journeys."

He adds, "Of course, I don't want to gloss over the fact that some families - particularly those whose child also has disruptive behavioral issues or complex medical needs - share that their day-to-day experiences can be challenging. I hope our research will help physicians identify those families so that proper supports and resources can be put into place and that this report will bring some sense of comfort and confidence to families expecting a child with Down [syndrome](#)."

More information: Brian G. Skotko et al. Family perspectives about Down syndrome, *American Journal of Medical Genetics Part A* (2015). DOI: [10.1002/ajmg.a.37520](https://doi.org/10.1002/ajmg.a.37520)

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