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Parents, siblings, and people with Down syndrome report positive experiences

Survey results may inform decisions about prenatal testing

Boston, Mass. – Three related surveys led by a physician at Children's Hospital Boston suggest that the experience of Down syndrome is a positive one for most parents, siblings and people with Down syndrome themselves. The results, published in three reports in the [October issue](#) of the *American Journal of Medical Genetics*, may serve to inform expectant parents and clinicians providing prenatal care.

"New prenatal tests for Down syndrome are set to come out as early as the end of this year," says Brian Skotko, MD, MPP, a clinical fellow in genetics at Children's Hospital Boston. "Many more women will then learn about the diagnosis prenatally and will need to grapple with very personal pregnancy options. In [previous surveys](#), mothers have reported receiving inaccurate, incomplete and occasionally offensive information about Down syndrome from their healthcare providers."

Skotko and collaborators Susan Levine, MA, CSW, of Family Resource Associates (Shrewsbury, NJ) and Richard Goldstein, MD, of the Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute, sent surveys to 4,924 households on the mailing lists of six nonprofit Down syndrome organizations around the country. The surveys asked respondents to rate their agreement with statements on a scale of 1-7, and also included some open-ended questions.

The [first study](#) evaluated surveys from 2,044 parents or guardians, representing an estimated response rate of 29 percent. 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 percent). 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

The [third study](#) evaluated survey responses from 284 people with Down syndrome (estimated response rate, 17 percent). The average age was 23, and 84 percent were living with one or both parents/guardians. The findings:

- 99 percent said they were happy with their lives

- 97 percent liked who they are
- 96 percent liked how they look
- 86 percent indicated they could make friends easily
- 4 percent expressed sadness about their life.

“As international discussion is mounting over the new prenatal tests, family members have now had their say about life with Down syndrome,” says co-author Levine. “And, more importantly, the people with Down syndrome themselves have clearly stated that they consider their lives valuable.”

In open-ended questions, parents reported learning a variety of life lessons – the top five being: personal self-growth, patience, acceptance/respect, love, joy. Asked what they would tell other prospective parents of a child with Down syndrome, the top responses fell into these categories:

- You will experience joy/rewards
- There will be struggles/challenges
- You will experience love
- Important to identify good support group/resources
- Children with Down syndrome are more alike than different from typically developing children.

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.

Respondents with Down syndrome most often gave these kinds of messages for parents:

- Love your baby/your baby loves you
- Life is good/happy to be alive/positive
- Don't worry/it's okay.

Their main messages for doctors were:

- Life is good/I'm happy to be alive/positive
- Please take care of our medical needs
- Please give information to parents about school options for people with Down syndrome
- Value us/we're okay.

The researchers acknowledge that the surveys are subject to selection bias, since members of nonprofit Down syndrome groups may not be representative of the general population of Down syndrome families; respondents were largely white and middle to upper class. There is currently no population-based registry for people with Down syndrome.

“Prenatal decisions about Down syndrome present profound and deeply personal challenges to expectant parents,” says co-author Goldstein. “What has been missing has been the perspective of those living with Down syndrome. This study now provides the largest and most comprehensive portrait of life with Down syndrome to date.”

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Children's Hospital Boston is home to the world's largest research enterprise based at a pediatric medical center, where its discoveries have benefited both children and adults since 1869. More than 1,100 scientists, including nine members of the National Academy of Sciences, 11 members of the Institute of Medicine and nine members of the Howard Hughes Medical Institute comprise Children's research community. Founded as a 20-bed hospital for children, Children's Hospital Boston today is a 396 bed comprehensive center for pediatric and adolescent health care grounded in the values of excellence in patient care and sensitivity to the complex needs and diversity of children and families. Children's also is the primary pediatric teaching affiliate of Harvard Medical School. For more information about research and clinical innovation at Children's, visit: <http://vectorblog.org>.