



# Life with DOWN SYNDROME



A Publication for New and Expectant Parents from the Up Side of Downs

**Did you know that a majority of people with Ds are happy with who they are?**

A study examining self-esteem and personal satisfaction of individuals with Ds (Skotko, 2011)

Question	% Agreed
Are you happy with your life?	99%
Do you like who you are?	97%
Do you like how you look?	96%
Are you sad about your life?	4%

## The Parents' Perspective

### Shock. Sadness. Anger. Dread. Fear.

These are the feelings most often expressed by parents when given the diagnosis of Down syndrome for their unborn or newborn child.

With the arrival of genetic tests like Sequenom, Harmony, Panorama and others, families can now know as early as the first trimester whether their child has a genetic disorder such as Ds. In Ohio, doctors are required by law to provide parents with contact information for resources and services in the community along with an Ohio Down Syndrome fact sheet.

### Is this enough?

Many of the questions parents have about the impact of this new baby on the family cannot be answered by medical professionals. Media, limited exposure to people with Ds, and statistics can impact their perceptions as well as ours.

- How will Down syndrome affect my baby's development?
- What does the diagnosis mean for me as a parent?
- How will this child affect the rest of my family?



- What is the best course to follow to help my baby reach his or her potential?
- What will he or she be like as a child, a teen and an adult?
- Will this child be happy?
- Will we as a family be happy?
- How will it change my life?

If you have recently learned that your baby has or will have Down syndrome, you have entered a whole new world. There will be challenges in raising your child as there are with all children, but you will experience great joy as well. The important statistics to know go beyond health and development.



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# How will this baby change my life?



## What about my family?

What does the diagnosis mean for me as a parent and us as a family? Clearly, there is no way to know for sure but again, the statistics are in our favor.

Marcia Van Riper, a nurse associated with the University of North Carolina, investigated the resiliency of 76 families of children with Down syndrome.

- Seventy percent of mothers in the study rated their family's functioning as either a 4/5 or 5/5 (5=excellent).
- Families of children with Ds often felt more stress due to the increased demands
- The findings supported the belief that families of children with Ds are resilient when facing challenges and are able to thrive.



## The 'Down syndrome disconnect': An open letter to medical professionals and expectant parents *(edited)*

The prejudices against babies with Down syndrome are mostly unfounded and generally untrue.

My son Kyle is an average child with Down syndrome. He has some of the associated medical conditions—hypothyroidism, glasses, one small heart defect and low tone. He also was born with bilateral clubfoot (not related to Ds). Make no mistake, I am not a Pollyanna who can't see past the nose on my face. I am realistic and know that my life will always be more challenging because of Kyle. I also believe it is in life's hurdles that we experience the most joy and satisfaction. Kyle's siblings may need to be responsible for him later in life. I have met many people who take care of a sibling with Down syndrome. All have spoken highly of the experience and how it adds value to their lives.

"Kyle's future is not scripted by any historically "true" perceptions of Down syndrome. Decades from now, the technologies and advantages of our time will be evident in the successes of people with Down syndrome. People with Down syndrome have value not only to their families, but to the world." - Katie

Bee (4/19/15) <http://liveactionnews.org/the-down-syndrome-disconnect-an-open-letter-to-medical-professionals-andexpectant-parents/>

## Parental Feelings Toward Son or Daughter with Down Syndrome\*

**I am proud of my son or daughter with Ds.**

**97% agree**

**I love my son or daughter with Ds.**

**99% agree**

**In general, I am embarrassed by my son or daughter with Ds.**

**5% agree**

**Overall, I regret having my son or daughter with Ds.**

**4% agree**

\* Approximately 2,000 parents were asked to rate their level of agreement with each statement on a Likert scale of 1 to 7 with "1" indicating "strongly disagree," "4" being "neutral," and "7" indicating "strongly agree." Results illustrate % of parents who circled "5", "6" or "7" for each statement.

Skotko, Levine and Goldstein (2011)

Am J Med Genet A. 2011 Oct; 155A(10): 2335-2347. Published online 2011 Sep 13. doi:10.1002/ajmg.a.34293

**People with Down syndrome have value not only to their families, but to the world.**

## When People Think Life Is Rough Because My Child Has Down Syndrome

(edited)

When people hear that our youngest daughter, Willow, has Down syndrome, I think many jump to the conclusion that our lives must be rough. They're right, kind of. Most of our days are peppered with problems, but Down syndrome isn't one of them. I also don't know if I can call our lives "rough." Busy? Yes. Challenging? Yes. Abnormal? No.

Take today, for example: Willow woke up with a cold. I can't blame Down syndrome. I can blame my daughter's desire to put everything in her mouth, including the germ-infested belt that's supposed to keep her strapped into my shopping cart. I sure hope it tasted good.

My dog got sprayed by a skunk. I can't blame Down syndrome. I can blame a very rude rodent. Did I mention this happened in our backyard? At 6:30 a.m.! What business does a skunk have in my backyard?

I forgot to comb my hair and apply antiperspirant before leaving the house to run errands. I can't blame Down syndrome. I can blame mommy brain. It just sucks that one of the places I had to go was the high school to turn in paperwork for a dance clinic my eldest daughter wants to attend. As I walked the halls, I felt like I was back in school myself. Everyone staring, whispering. I suppose I should also mention that I was wearing a bleach stained shirt and Crocs. So not cool.

It's now 11 a.m. and I realize I've got a lot of work to get done. Laundry, dishes, more laundry, more dishes and I suppose I should also fit in a shower. Why am I still sitting at this computer? I can't blame Down syndrome. I can blame life. It allows me to forget about the smelly

dog in the kitchen, ignore the fact that Willow's runny nose might abruptly end her nap and dream about the good times. Because, when you have a child with Down syndrome, there are many. Sure, life is rough. But Down syndrome is not to blame. In fact, Willow's extra chromosome almost always gives me reason to smile.

If you've read this far, I'm hoping your eyes have been opened to the fact that Willow's diagnosis is not the reason for our hardships. Everyone has challenges. Life can beat us down, stomp on us and spray us full of stinky stuff, but that's life! Blame luck. Just don't blame Willow. Her 21st chromosome has definitely made our lives busier and has taught us more about the medical world than we ever wanted to know, but I can honestly say I wouldn't change a thing. Willow is awesome. Willow is perfect. And, Willow is the only reason I smile on this stinker of a day.

Jennifer Hines <http://themighty.com/2015/10/when-people-think-life-is-rough-because-mychild-has-down-syndrome/>

## To the Mom Who's Devastated by a Prenatal Down Syndrome Diagnosis (edited)

OK, the grief and the fear are all part of the process, and there's really no way to just "mind over matter" your way through this. Maybe it's insensitive of me to even say that. But if I could go back in time, I would give my pregnant self a great big hug and I'd tell her it's going to be totally fine. Those BTDT (been-there-done-that) moms who are telling you that **you will absolutely love your child just as much as you as you would love any other child, that your life will be full of joy, that a Down syndrome diagnosis isn't the end of the world... they're right.**

**But if I could go back in time, I would give my pregnant self a great big hug and I'd tell her it's going to be totally fine.**

In hindsight, I wish I had relaxed, enjoyed my pregnancy, celebrated the upcoming birth and realized just how much love and joy my new daughter would bring to our family. Yes, there are challenges, and the Down syndrome does continue to be a source of fear and some sadness when I get too focused on the what ifs and the future unknowns. However, the grief and fear I felt while pregnant is nothing compared to the love I now feel for my daughter. I look back and feel utterly ridiculous. So, to the new pregnant mom, I don't want to belittle your feelings. **I do, however, want to give you hope.**

Michelle Diviney <https://themighty.com/2016/06/advice-formoms-devastated-by-a-prenatal-downsyndrome-diagnosis/>

# HAVING A BROTHER OR SISTER WITH DS: Perspectives from Siblings

**Among those brothers and sisters who responded to the survey:** (Skotko, Levine and Goldstein, 2011)

- The vast majority of all ages, expressed love and pride for their siblings with Ds. Most notable was that such feelings were not related to the functional skills of their sibling with Ds; nor were they related to their health conditions or educational challenges.
- As siblings matured, particularly as they entered high school and beyond, they began to identify themselves as better people because of their sibling with Ds.
- Many felt their perspective on life was enhanced, with a deeper appreciation for human variation.
- When asked to provide advice for expectant parents, the most popular response was to convey the joy and rewards that would come with having a family member with Ds. Of course, not all brothers and sisters felt so uniformly positive.
- A minority of the siblings did feel sorry that their brother or sister had Ds, particularly those whose siblings had significant learning disabilities.
- Some felt embarrassed by their siblings, which is not an atypical finding for any sibling. Those younger brothers and sisters who did feel embarrassed more likely had older siblings with Ds; the older siblings, conversely, were more likely to feel that way when their sibling with Ds was younger. These patterns are consistent with typical patterns within sibling relationships, but the feelings are likely to be more pronounced when the sibling with Ds has behavioral issues.
- Very few brothers and sisters would want to trade their sibling with Ds for a different sibling who did not have Ds.
- A small percentage felt burdened by the extra chores or caregiving responsibilities that they were asked to perform by their parents.
- The vast majority of older siblings plan to be involved with their brother or sister with Ds when they become adults.

Skotko, Levine and Goldstein (2011) <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3348944/>

*The vast majority feel that their current relationship with their sibling with Ds is a good one.*

*You are not alone and we would love to be part of your journey!  
We wish only the best for you and your baby.*

Visit us at [www.usod.org](http://www.usod.org).

## OTHER RESOURCES:

National Down Syndrome Congress - [ndscenter.org](http://ndscenter.org)

Global Down Syndrome Foundation - [globaldownsyndrome.org](http://globaldownsyndrome.org)

Genetic Support Foundation - [geneticsupportfoundation.org](http://geneticsupportfoundation.org)

Ohio Department of Developmental Disabilities - [dodd.ohio.gov](http://dodd.ohio.gov)

Akron Children's Hospital Down Syndrome Clinic - [akronchildrens.org/cms/down\\_syndrome\\_program/](http://akronchildrens.org/cms/down_syndrome_program/)

Help Me Grow - [helpmegrow.org](http://helpmegrow.org)

National Down Syndrome Society - [ndss.org](http://ndss.org)