

# Creating support for families of children with Down syndrome with a co-diagnosis: A survey

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Little is known about the effects on families of having a child with Down syndrome and an additional diagnosis (co-diagnosis). In fact, little is known about the incidence of specific co-diagnoses or the methods of reaching these diagnoses. However, there is an interest in improving diagnostic tools and support mechanisms for people with Down syndrome who have a co-diagnosis such as autism spectrum disorder, attention deficit disorder (ADD), obsessive-compulsive disorder (OCD), or other behavioural and medical diagnoses.

## History

Creating Solutions is fiscally sponsored by the Community Initiative Funds of The San Francisco Foundation, a non-profit organisation. Established in 2005, Creating Solutions publishes *Disability Solutions* and coordinates The Down Syndrome-Autism Information Center (DSAIC). The mission of the DSAIC is “to do good work for and with families of individuals with Down syndrome and autism spectrum disorders, to improve the quality of life and communities.” Its aim is to collaborate with families, research, medical, and education professionals, support groups, universities, and others to create a one-stop centre with up-to-date information related to the co-diagnosis of autism spectrum disorder in people with Down syndrome.

Since its establishment, the Down Syndrome-Autism Information Center has implemented a listserv and initial website presence along with collaborations with medical professionals interested in this area. Families who seek information and assistance from the DSAIC, however, are just as likely to have a child with a co-diagnosis of autism spectrum disorder as a number of other co-diagnoses such as attention deficit disorder, obsessive-compulsive disorder, or undiagnosed “autistic-like” behaviours. Simply put, the DSAIC, though focused on the co-diagnosis of Down syndrome and autism spectrum disorders, has become a source

of information and support for families who have children with Down syndrome and another diagnosis.

The Down Syndrome Research Directions Symposium gathered people interested in Down syndrome around the world who are engaged in scientific, academic, and medical research as well as clinicians, practitioners, and family members. Participants gathered to share current research, knowledge, and programmes and to establish a collaborative network to further research and directions for people with Down syndrome. To prepare for this Symposium, Creating Solutions designed and distributed a survey using an online survey tool, *Survey Monkey* ([www.surveymonkey.com](http://www.surveymonkey.com)). The survey, titled “Creating Support for Families of Children with a Co-Diagnosis,” was distributed through the DSAIC network to families of children with Down syndrome who have a co-diagnosis including five Down syndrome listservs, such as the Down syndrome-autism listserv and the announcement listserv for *Disability Solutions*.

## Survey

### Methods

The purpose of the survey was to identify areas of concern for families of children with Down syndrome who have a co-diagnosis and to discern potential areas of interest for research directions.

The survey was designed for families of people with Down syndrome who have

a co-diagnosis and thus blocks those who say they do not have a family member with a co-diagnosis from answering further questions.

## Results

1. Does your child with Down syndrome have an additional diagnosis such as autism spectrum disorder, AD/HD, OCD, or “challenging behaviours”? (See TABLE 1).
2. Please tell us a little about your child who has a co-diagnosis. (See TABLE 2).
3. When a child with Down syndrome has an additional diagnosis or challenging behaviours, education, support, and future planning becomes more complex. Which of these is the most challenging for you? Please rate these by the level of impact for your child or family. Use 1 as the greatest challenge and 4 as no challenge at all. (See TABLE 3).

Families of children with Down syndrome who also have a diagnosis of autistic spectrum disorders, attention deficit hyperactivity disorder, obsessive-compulsive disorder, and other conditions often feel isolated, or that information and research related to Down syndrome does not apply to their child with an additional diagnosis.

The age of diagnosis appears to be earlier than what is published regarding children with both Down syndrome and autistic spectrum disorder<sup>[1,2]</sup>. This is likely due to the inclusive nature of the term “co-diagnosis” for the survey.

|   | %    | n   |
|---|------|-----|
| Yes   | 71.6 | 121 |
| No  | 13.6 | 23  |
| We suspect so, but have not pursued a diagnosis | 14.8 | 25  |

Table 1 | Replies to question 1

To gain a snapshot of which areas families felt were the greatest challenge the numbers from columns 1 and 2 were combined. This reveals the top three areas that are the greatest challenge for families are teaching strategies, community and recreation activities, and positive behaviour supports. These top three concerns paint a picture of where these families are spending the majority of their energy with regard to their child with Down syndrome and another diagnosis or suspected diagnosis.

Limitations to this survey include the small number of respondents and the inability to separate responses by the type of co-diagnosis the person with Down syndrome experiences.

### Select parent comments

Parents were encouraged to share comments regarding which type of information they would like the academic and research community to explore with regard to their child with a co-diagnosis, with 93 of the 146 who completed the survey responding. A variety of comments were shared through the survey with multiple themes. These themes are grouped into four categories: awareness, education, support, and medical concerns.

#### Awareness about co-diagnoses

The need for awareness education surrounding a co-diagnosis such as autism spectrum disorder is clearly represented in the 100 parent comments. There is a perception that, without the second diagnostic label, professionals will not consider all teaching and support strategies for children with Down syndrome. Parent comments highlight the need for the focus to move away from whether it is possible to have another diagnosis to how to effectively diagnose, teach, and support the person with Down syndrome who has an additional diagnosis.

*“More support for dual diagnosis and more information available to both parents and professionals. We often feel that no one recognises a dual diagnosis*

|   | 0-5 yrs        | 6-10 yrs      | 11-15 yrs     | 16-18 yrs    | 19-21 yrs   | 21-30 yrs   | 30+ yrs     |
|---|----------------|---------------|---------------|--------------|-------------|-------------|-------------|
| Age of your child   | 26<br>(18.1%)  | 55<br>(38.2%) | 38<br>(26.4%) | 10<br>(6.9%) | 8<br>(5.6%) | 6<br>(4.2%) | 1<br>(0.7%) |
| How old was your child when you knew something was “different”? | 120<br>(83.3%) | 20<br>(13.9%) | 4<br>(2.8%)   | 0            | 0           | 0           | 0           |
| If your child has a diagnosis, what age was that obtained?      | 80<br>(62.0%)  | 37<br>(28.7%) | 11<br>(8.5%)  | 1<br>(0.8%)  | 0           | 0           | 0           |
| Skipped question: 1   |                |               |               |              |             |             |             |

Table 2 | Replies to question 2

|                                       | Greatest challenge |               |               | No challenge  |
|---------------------------------------|--------------------|---------------|---------------|---------------|
|                                       | 1                  | 2             | 3             | 4             |
| Educational placement                 | 41<br>(28.5%)      | 43<br>(29.9%) | 46<br>(33.3%) | 12<br>(8.3%)  |
| Teaching strategies                   | 57<br>(39.6%)      | 52<br>(36.1%) | 28<br>(19.4%) | 7<br>(4.9%)   |
| In-home support                       | 37<br>(26.1%)      | 30<br>(21.1%) | 56<br>(39.4%) | 19<br>(13.4%) |
| Community and recreation activities   | 38<br>(26.6%)      | 63<br>(44.1%) | 31<br>(21.7%) | 11<br>(7.7%)  |
| Adult living opportunities            | 37<br>(27.6%)      | 19<br>(14.2%) | 48<br>(35.8%) | 30<br>(22.4%) |
| Medical care                          | 20 (14.1%)         | 25 (17.6%)    | 70 (49.3%)    | 27 (19.0%)    |
| Lowered expectations by professionals | 35<br>(24.5%)      | 47<br>(32.9%) | 51<br>(35.7%) | 10<br>(7.0%)  |
| Positive behaviour supports           | 44<br>(30.8%)      | 47<br>(32.9%) | 39<br>(27.3%) | 13<br>(9.1%)  |

Table 3 | Replies to question 3

*and puts it down to our child being low functioning! Internet support and info is good as it is easily accessible. Would love more programmes to help our children reach their potential.”*

*“More information needs to be shared with the Down syndrome community that it is possible for a child to have a dual diagnosis - I was not aware of it and neither was my child’s doctor ( who is a very good doctor) and so we were out there on our own for so long and more help could have been provided to her at a younger age that may have helped her had I known that this was possible. I just thought I was a bad parent because she is so not like the other kids with Down syndrome. So parents need to know what to look for in their kids at a younger age and need to be aware of the possibility of this occurring”*

*“At the adult level, most agencies absolutely refuse to look at mental health issues combined with MR; combined with OCD and ongoing health issues. ... There must be a way to present Down syndrome as one component not the component.*

*“My son was diagnosed with PDD at around age 11 (suspected but ruled out at*

*age 8). In addition, he has Celiac Disease, diagnosed around age 7. I’ve since learned that many kids with DS have autistic-like issues but it’s all hearsay. I’ve seen very little written, and professionals don’t seem to know how to address the two simultaneously. Parents are left with piecing together therapies or educational resources for both separately, rather than being able to address the way the two diagnoses relate, how their effects interact.”*

*“... awareness on the dual dx. So many of my daughters therapists do not agree with the diagnosis and therefore we worry some teaching methods might not be used. I think people need to know that the two conditions can co-exist, so for me it would be getting the word out as much as possible. Doctors, schools etc. ...”*

*“Until I went to the last NDSC [National Down Syndrome Congress] conference I never knew there were other children out there like my son. I have felt so isolated because of his disabilities, others couldn’t relate. There needs to be a way for us to access one another. The only doctor I have found that is educable in my son’s problems is in another state near the east coast; I live in Michigan. How do I pay for*

getting him there and convincing insurance to cover it? That is the kind of help we need. Information and programs for our kids with these unique needs."

## Education concerns

A common motif regarding education is accessing and implementing effective teaching strategies whether individually or through programming.

"Our experience has shown us that educational professionals don't know what to do with a multi-diagnosed individual. Our daughter has mosaic DS, autism, and other various mental health diagnoses - there just is no "program" for her in the public schools. There needs to be so much more information provided to the educators about behavior in children with multiple diagnoses."

"My child has the co-diagnosis of hearing loss -- which although is not mentioned above -- definitely contributes an additional impact to his DS. Educational planning is very difficult because the school district does not take his hearing impairment into account when assessing his needs and programming decisions. For a child with DS (in which there is an inherent auditory processing disorder), adding hearing loss makes communication and language development significantly more difficult. I wish the schools would incorporate auditory-oral methodology into their educational planning for young kids with DS when they have hearing loss -- the research shows this has an incredibly positive impact on language and communication development (in addition to preventing a host of behavioral problems that arise simply because the child has not been taught how to use his residual hearing)."

"What is most frustrating for me is that when 'supervisory' staff and professionals see how well my son can function when his special needs are accommodated, they try to 'wean' him from that support, and then express concern/ advice / threats about whether he will be able to continue in the program when new challenging behaviors come along."

## Support concerns

The comments shared related to support for individuals with a co-diagnosis and their families varied more than other thematic categories. This may be a sign of the family's resilience or the network of support in their community. Comments ranged from being happy with the level of

assistance and support to feeling isolated and in need of assistance.

"My child has a diagnosis of severe depression. We are lucky to have quality psychiatric care for him, but the rest of the system is not very well informed about an additional problem. People tend to view him as lower functioning because he is slow to respond or disinterested in what is going on around him. Our community is sorely lacking in recreational options, so if you don't want to go bowling, you're out of luck."

"I would like to see more support programs for kids w/dual diagnosis. She is like the square peg for the round hole. She doesn't fit in exactly w/DS kids or exactly w/autistic kids so treatment and therapies for those diagnosis don't quite cut it. Its like we aren't quite reaching her."

"As an adult, it is nearly impossible to find providers who will follow dietary restrictions, exercise, and emotional support requirements. Rather the emphasis is on MR.... I would like to see agencies who serve individuals with MR be required to learn about nutrition and the effects of good vs. poor nutrition upon emotional status; physical health and long-term health quality."

"Actually we were surprised at the number of additional programs that kicked in when we received the diagnosis of ASD. And the programs that were geared for Ds have still been welcoming of M. even with the additional difficulties created by the additional diagnosis. At this point our greatest concern is what will happen to M. if something happens to us."

"The difficulty this has caused, the huge amount of stress, the lack of supports, has ended my marriage after 16 years. We finally became one of the statistics I tried so hard to avoid. Having a dual diagnosis and no one to understand or help us with this living where we live has always been so hard. I am now a single parent struggling to find a way to hold my family together...."

## Medical concerns

A primary theme regarding medical care is the lack of knowledge or expertise of care providers – both medical and the support from medical to day-to-day providers – for individuals with Down syndrome and another diagnosis:

"With much of what my child is going through medically at this time, most physicians and specialist are not knowledgeable."

"My daughter's diagnoses are two totally different conditions that make her care very difficult. She has Down syndrome and cystic fibrosis. Two genetic conditions that rarely occur in the same person. Right now our biggest challenge is not having one physician that oversees her care."

## Next steps

Perhaps the greatest lesson from this survey is the willingness of families who are living with a child with Down syndrome who has a co-diagnosis to respond to an online survey. Like any research method, online surveys have limitations. However, they are easy for families of children with difficult behaviours to access and complete. This survey, done through Survey-Monkey.com, collected 169 responses in 7 days. This indicates a desire of parents of children with a co-diagnosis to share what is important to them with those who design research and programmes, and the ease of participation over the Internet. Use of the Internet, however, does pose problems with regard to who is able to respond. Given how little is known about families who deal with children with Down syndrome who have another diagnosis, it is a reasonable and viable first step.

Co-diagnosis is an under-researched area and one that likely contributes to family stress over and beyond that of families with children who have a child with Down syndrome alone. One parent commented, "Some days I don't know how to help him, and I don't know how I am going to get through the rest of our lives!"

Recommended next steps include improved diagnostic tools, teaching strategies, support strategies and systems, and awareness programmes. Given the limited funding for a small percentage of the population, it is important to design efficacious research, strategies, and programmes. It could be argued that by understanding and supporting those with the greatest behavioural needs, more people can be impacted, as it is easier to modify strategies and programmes from the most to least difficult situation rather than the reverse. The following quote from one participant illustrates this point:

"It seems those with Down syndrome alone are making great strides and doors are opening. When autism or other behavioral problems are also diagnosed, people run the other way. Society needs to be educated that these children can succeed

*and be an integral part of society as long as we know how to deal with them. Their cause is not hopeless."*

Families of children with Down syndrome who have another diagnostic label seek more effective and purposeful information and support for quality lives for their child and their family. Creating solutions for a quality life requires a community vision that includes everyone.

1. Rasmussen P, Borjesson O, Wentz E, Gillberg C. Autistic disorders in Down Syndrome: Background factors and clinical correlates. *Developmental Medicine and Child Neurology*. 2001;43:750-54.
2. Rutter M. Autism: Its recognition, early diagnosis, and service implications. *Journal of Developmental and Behavioral Pediatrics*. 2006;27(2):54-58.

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### FURTHER INFORMATION

The Down Syndrome-Autism Information Center: <http://www.Creating-Solutions.Info/dsaic/index.htm>

Creating Solutions: [www.Creating-Solutions.Info](http://www.Creating-Solutions.Info)

Disability Solutions, "Special Edition: Down Syndrome and Autistic Spectrum Disorder," Volume 3, Issue 5 and 6, 1998. <http://disabilitysolutions.org/newsletters/files/three/3-5-6.pdf>