

Schools and neighborhoods are missing out on seeing what a blessing our kids are. They need to learn more about kids with Down syndrome, and the potential they have when we teach and support them properly.

When our daughter was born MSDC sent out a care package with a quilt inside that we still use and it reminds me of when she was born. Thank you, it was a small thing but it meant so much.

MASSACHUSETTS DOWN SYNDROME CONGRESS *2013 MEMBERSHIP SURVEY PROJECT*



We know that they are there for our family. We know that they are continuously and selflessly advocating for our loved ones with Down syndrome and setting the stage for amazing opportunities and well deserved ones at that. We know that if we need anything for our son that we can reach out to them and they will point us in the right direction.

We feel like we are accepted completely...we finally have somewhere we know people that understand us, and our child, and support us.

I LOVE attending the yearly conference in Worcester. It is over an hour ride for me, but totally worth it! There are always great speakers and vendors and it is so uplifting and inspiring.



Promoting Acceptance & Inclusion
The premiere resource for Down syndrome information, advocacy and networking in Massachusetts

About the MDSC and Current Needs

Nearly 28 years ago parents met in a living room to share information about their children, provide support for each other and strategize how to educate their families, schools and communities. Today the MDSC has over 3,600 members, an energetic Board of Directors, a dynamic management team, and a clear mission:

To ensure individuals with Down syndrome in Massachusetts are valued, included, and given the opportunities to pursue fulfilling lives by providing information, networking opportunities, and advocacy for people with Down syndrome and their families, educators, health care professionals, and the community-at-large.

Part of what has made the MDSC successful is always thinking about the future, and asking the tough questions. Who can we serve, and what do we want to provide in terms of programs and services? Should we focus on adult populations with Down syndrome or should we continue to focus on school age children with Down syndrome? In addition to our ongoing programs and interests, we are beginning to explore advocacy, information, and other supports for adults. We want to learn more from our membership and families about what is affecting them and how we can be most helpful.

One key strategy to solicit feedback and gauge community needs is a well-designed survey widely distributed to the parents/guardians and family members of individuals with Down syndrome, as well as individuals with Down syndrome who are 18 or over. This kind of invitation for thoughtful input can provide valuable information, involve our primary stakeholders in thinking and planning for the future, and increase overall investment in our program and organization.

Professional Support and Consultation

In September we began to develop a comprehensive survey tool with the help of Meridian Consulting, a Massachusetts-based consulting firm which specializes in non-profit evaluation projects. Marian Wolfsun, Senior Evaluation Consultant with Meridian Consulting, has over 11 years of experience providing organizational and management consulting with a focus on the design and delivery of culturally sensitive needs assessment, outcome and process evaluation, and participatory and community impact evaluation with non-profits. Ms. Wolfsun is included in U.S. Dept. of Education Registry of Outcome Evaluators, and in 2010, her work was commended as a “Best Practice in Evaluation” by the federal DHHS Office of Minority Health (OMH).

Survey Goals

- Our intention was to collect a large amount of basic data on what kinds of challenges families and individuals have experienced and where in their communities they have gone to get support, advice, and advocacy.
- We wanted to thoroughly investigate what specific MDSC services or programs families and individuals have used or participated in, as well as gather feedback on their experiences and what has been helpful.
- We were interested in member priorities and what kinds of services/future directions might be needed or wanted. As part of the data analysis, we planned to analyze responses according to children's ages in order to deepen our understanding of how needs and perception change as individuals with Down syndrome mature and reach adulthood.
- We wanted to make the survey comprehensive, but still keep it from being too long or time-consuming to complete.
- We wanted to circulate the survey to our membership, as well as to any interested individuals/ families that are not on the current membership list. This way we could get the broadest and most representative results possible, while taking advantage of an opportunity to reach people about MDSC and potentially build the membership list.
- We wanted our membership to be clear about why we were doing the survey – in particular, we did not want individuals to be confused or make assumptions about MDSC changing, growing, adding, or losing services. We wanted people to understand that MDSC will not be shifting direction suddenly, and that we will remain committed to our addressing our members' current needs.

With the participation and input of MDSC staff, board members, colleagues and other professionals, Meridian Consulting spent six months drafting questions, soliciting feedback and critiques, and conducting meticulous review and testing of survey questions.

The Survey Tool

The final tool was put on line using Survey Monkey, and it went live on May 20, 2013. The membership was notified several times through e-mail about the survey and encouraged to participate with an incentive offer of a free year of membership in the MDSC (a \$50 value). Those families and individuals who did not have e-mail addresses on file received postcards in the mail instead.

When the on-line survey was formally closed on June 3, 2013, there were 483 responses with 416 respondents completing the entire tool. This outstanding response rate was due

to the clear investment of families, and concerted and effective outreach efforts on the part of the MDSC staff. The vast majority of the incomplete surveys were started by individuals who were neither family/guardians nor self-reports and who stopped completing questions once they realized the survey was not geared for them.

This report includes:

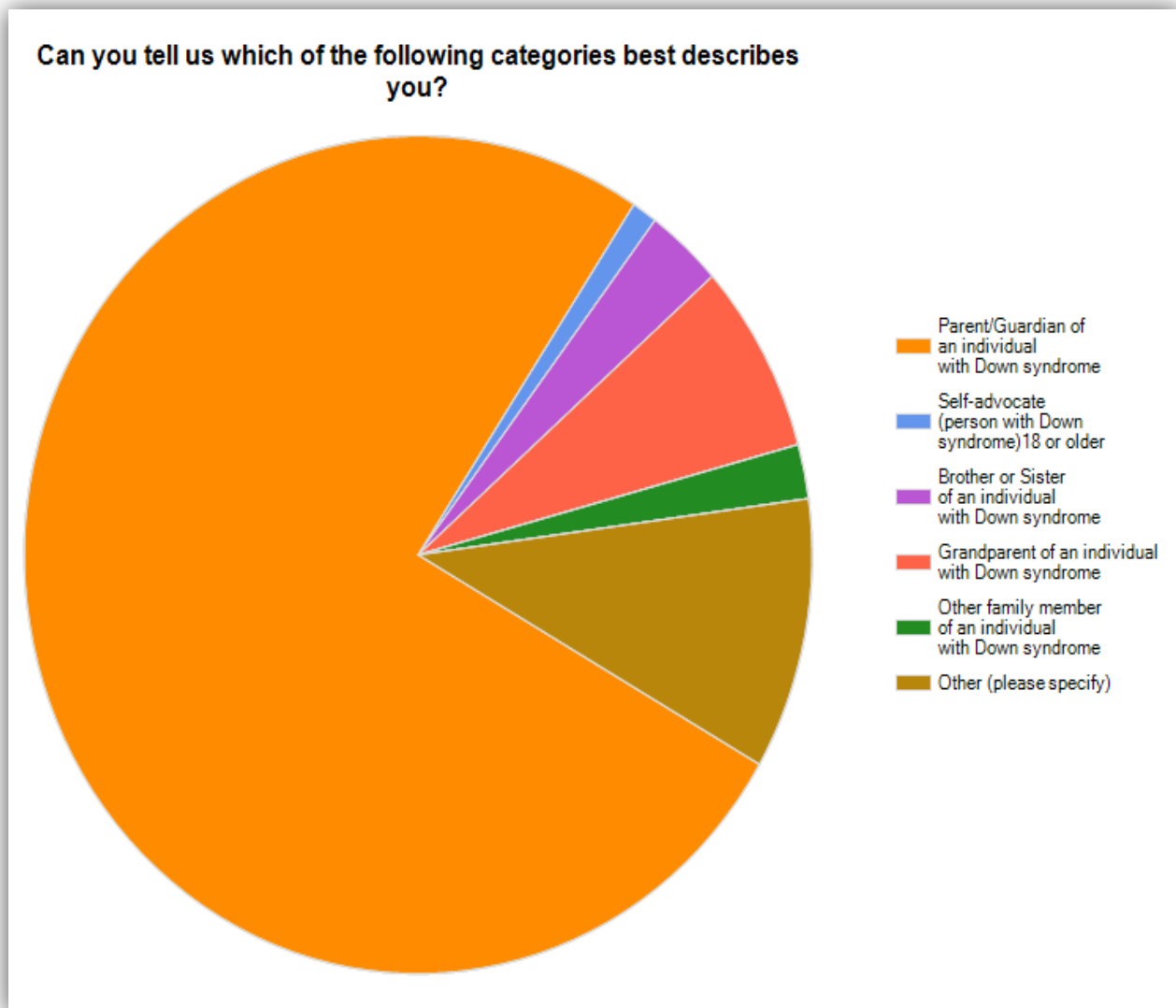
1. Summary report of all results
2. Filtered reports which examine results by age of child and level of involvement with the MDSC
3. Demographics of the respondents
4. Highlights and notable findings.

It is generally true that survey results can indicate a need/benefit for some additional targeted research into specific areas, and this holds true for the MDSC survey results as well. The vast majority of respondents were parents/guardians, with only 5 responses from self-care 18+ individuals. At this point it would make sense to follow up with additional evaluation activities including individual interviews and/or focus groups to reach out to this important part of the membership. Staff are already considering a focus group with the Advisory Council of self-care 18+ members.

DEMOGRAPHICS

Category of Respondent

The vast majority of respondents identified themselves as a parent or guardian of an individual with Down syndrome and completed 76% of the surveys. Family members accounted for an additional 13%, with most of the remaining respondents falling into the “other” category. This category includes friends, teachers, neighbors, educators, politicians, health care providers, and volunteers.



Languages spoken

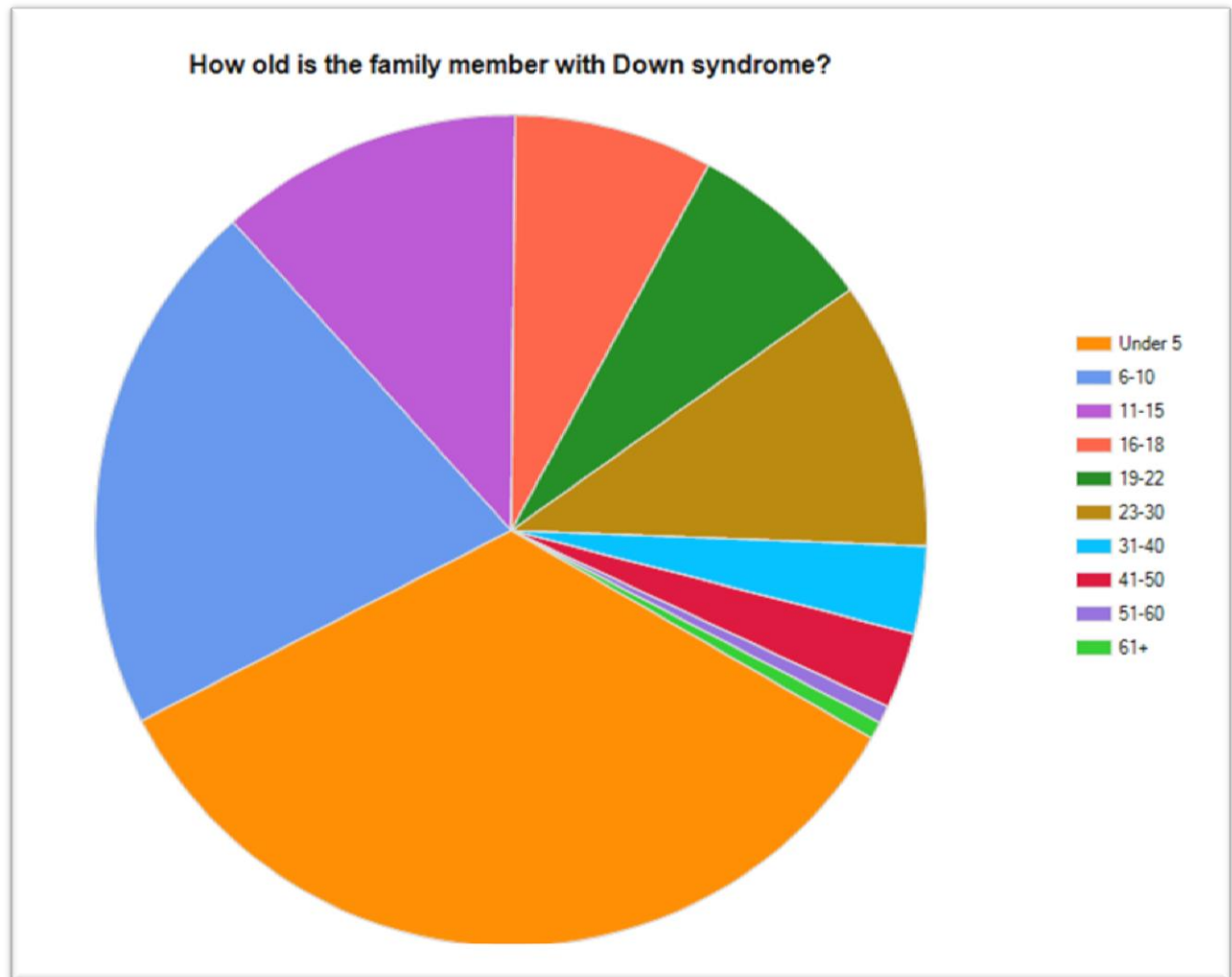
Close to 99% of respondents stated that their primary language spoken in the home is English. Only 15 individuals identified their primary language as anything other than English. The top “other” primary language was Spanish, with one respondent each for the remaining 9 primary languages: Portuguese, Arabic, Polish, Indonesian, Arabic, Telugu, Danish, Mandarin, and Indonesian.

Individuals were also asked about a second language spoken in the home. The most common “other” or second language was ASL, used by 17 respondents. Below are all of the second languages mentioned.

American Sign Language (17)	Greek (2)	Japanese
ASL/PSE	Arabic	Turkish.
Spanish (6)	Navajo	TAMIL
Spanish	Hindi (2)	Polish
Dutch	Gujarati	French (2)
Danish	Armenian (2)	Portuguese (1)
Cantonese	Albanian	Hebrew (3)

Age of Individuals with Down syndrome

Slightly more than a third of respondents identified their child as under 5 years old. The second largest population was families with children ages 6-10; the third population in terms of size was children 11-15, and with a slightly lower percentage; the next largest group was “children” 23-30.

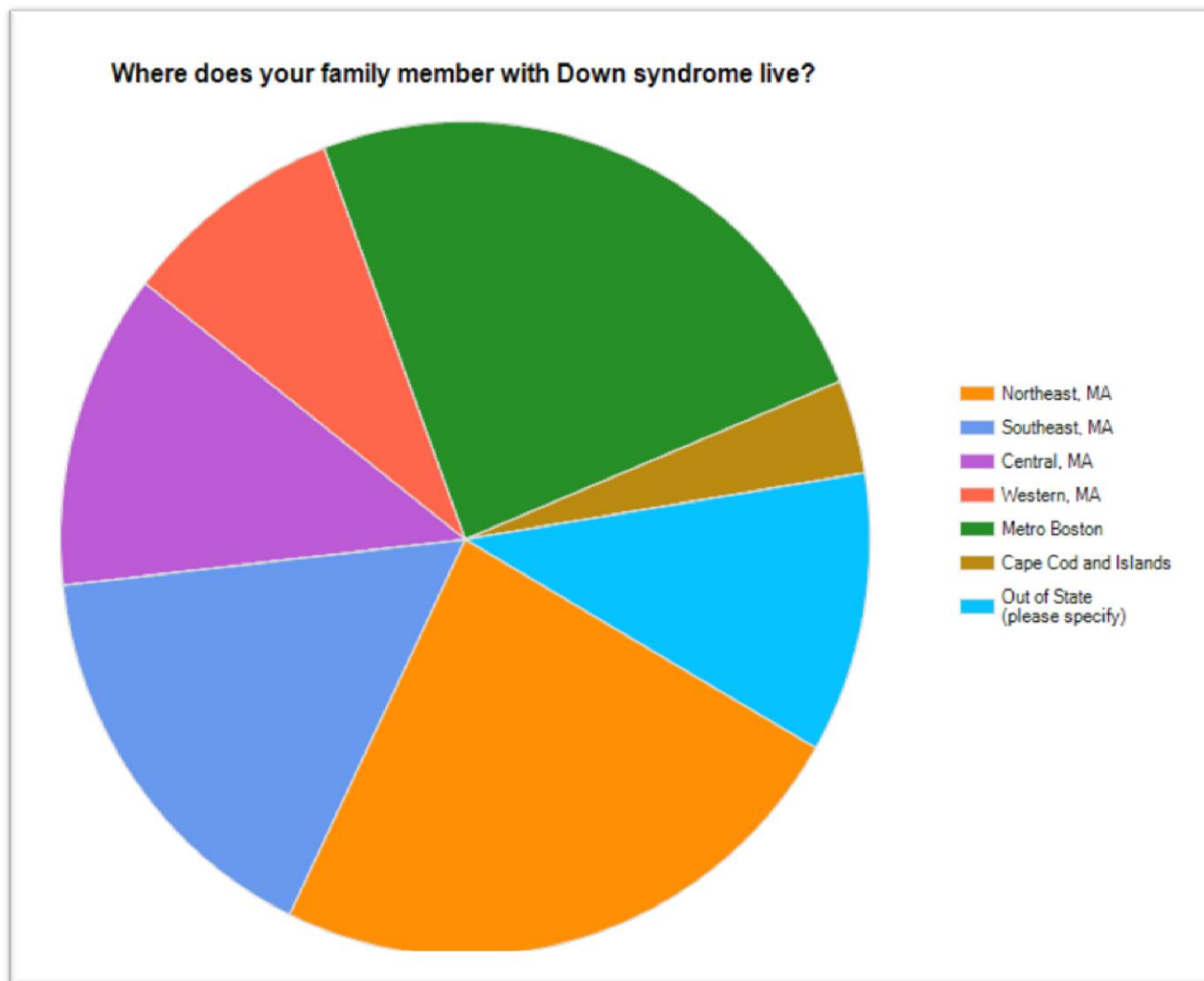


Gender of Respondents

A slightly larger percentage of men than women took the survey. The difference was small, however, with men representing about 52 percent of respondents, and women slightly over 47 percent.

Geographical Location of Respondents

Individuals across Massachusetts participated in this project. The largest number of respondents was from the northeast part of the state and Metro Boston. The smallest number of respondents was from Western Massachusetts and the Cape and Islands.



Approximately 11 percent of respondents identified themselves as living “out of state.”

New Hampshire (17)
Maine (5)
Connecticut (4)
New York (3)
Vermont (3)
Rhode Island (3)

New Jersey (2)
Massachusetts (2)
California (2)
Arizona
Indiana

West Virginia
Virginia
Bahamas
Ohio
Minnesota

Living Situation

The vast majority (90%) of respondents confirmed that their family member with Down syndrome lives with parents or another family member. Approximately 5% live in a group home or independently with supports. Only 2 respondents live alone and without built in supports.

OVERALL SURVEY AND NOTABLE RESULTS

When was the Diagnosis made and by whom?

Three quarters of the diagnosis were definitely made after birth. Pediatricians were the most common sources of diagnosis at 31%, with OB/GYN's following closely behind at 27%. Genetic counselors and geneticists represented an additional 19% of diagnosis confirmations.

Received Accurate Information at the Time of Diagnosis?

Respondents were fairly equally split on whether or not they believed they had received accurate and up-to-date information at the time of diagnosis. A substantial percentage (19%) were not sure whether they had or not.

Level of school Individual with Down syndrome is in (or completed)

The largest population is currently in elementary school (23%), with an additional 21% in early intervention. Current preschool enrollment makes up just fewer than 16% of families, and 13% are currently in High School. Eighteen percent of the individuals being researched have either completed High School, or received an equivalent certificate of completion or are currently (or were) enrolled in Post-secondary education.

Do Individuals with Down syndrome have Complex Needs and/or Challenging Behavior Problems?

Respondents were fairly evenly split on the issue of complex needs, with 13% not sure how to answer the question. Behavioral problems were a different issue with 60% of respondents saying "no" that they don't feel there are behavioral problems simply due to having Down syndrome. Just under 10% were unsure how to answer this second question either.

How included at school is (or was) the person with Down syndrome?

The largest percentage response was 25% stating that they were in substantially separated classrooms. Following that was full inclusion with 22%, and partial inclusion in a typical classroom with 20%.

Are you or were you happy with the education program?

Two-thirds of families said they were "very happy and satisfied" or "mostly happy and satisfied" with the education program. An additional 23% were "somewhat happy and satisfied", and 11% were "not happy or satisfied" at all.

Challenges to Inclusion

This question had eight answer options with various concerns families might have. All eight concerns were statistically significant to the membership. The greatest concerns were school administration not encouraging best practices and the need for modifications to the academic curriculum. This category also provoked 142 additional comments citing specific concerns.

Employment

Over 80% of children are not currently employed; the majority of whom are under 16. Concerns about work increased as children's ages increased. Fourteen percent of the individuals who are working are at a regular job with a salary, and another 9% working at a DSS support setting or a day program learning skills without pay. Three-quarters of those working are employed 10 hours or less a week. Half of the families responding were satisfied with the current employment situation, half were not.

Social and Recreational Experiences

Approximately one-third of respondents were "very satisfied" with this area, another third were fairly satisfied", and the remaining third had concerns. When asked what might help increase participation in these kinds of activities, the top two requests were for more information and notice about activities, and a support person or peer mentor to buddy with for new activities.

Level of Participation in the MDSC

Nineteen percent of respondents consider themselves "very active" or "active" in the MDSC. Close to half of respondents reported that they are "somewhat active." If an individual stated that they were "not active", the survey asked "why"? This follow-up question generated a very large response with 144 individual comments and explanations. The reasons ranged, but included not enough time, not aware of opportunities or how to get involved, geographical distance, that the focus seems to be on younger children, financial restrictions, still adjusting to diagnosis and learning about resources.

Specific Participation in the MDSC

The annual conference and Buddy Walk were the two most popular activities for the membership with over 60% of respondents participating in them. The next two most popular activities were the Educators Conference and support group meetings/activities in local areas. Other significant areas of participation included legislative advocacy, MDSC fundraising events, and DADS.

Top Priorities for the MDSC

High quality education and transition planning is the top priority for the membership with 63% selecting it as their number one choice. Other high priorities include receiving up to date information about Down syndrome and available supports, networking and direct supports, advocacy for community inclusion and employment, and educating the public about Down syndrome. All areas were of concern however.

Down syndrome clinics

The Boston Children's Hospital Program was by far the most frequent clinic individuals were seen at with 78% of the population surveyed. Mass General Hospital was cited 16% of the time, and a substantial 16% chose "other" with specific information provided in comments.

Areas of Greatest Need

There were twenty-four answer options for this question as well as an "other" category. Every single option was checked by respondents, but the top areas were social/recreation with 52% selecting this priority. The next most frequently checked option was education at 41%.

Organizations being turned to for Support

This question elicited hundreds of comments with acronyms and specific services. The MDSC was frequently cited along with many others.

Experience with Support Groups

Seven percent of respondents stated that they were not aware support groups existed or were available. The remainder of the responses were equally split between those who have or haven't participated in one.

MDSC's Biggest Impact

This was another question which elicited hundreds of detailed responses. Individuals repeatedly cited the support, information, acceptance, advocacy, a sense of community, and specific favorite program activities. Comments included statements like "It was a revelation and joy to discover that the MDSC existed."

Can the MDSC do a better job serving your needs?

This was fairly split with approximately half of respondents saying "no" and the other half saying "yes". Those who said yes were prompted to give specific comments, and 247 individuals did just that. Comments ranged across the spectrum from "more events

for younger children” to “more events for older children” and a myriad of “wishes and requests” on any aspect of living with Down syndrome that could be imagined.

Additional Comments

Again, there was a wide range of comments, suggestions and requests. Many respondents took this opportunity to express their pride in being a member of the MSDC, their gratitude and appreciation for all of the important work the MSDC has done on all of our behalf.

COMPARING RESPONSES BASED ON AGE OF CHILD WITH DOWN SYNDROME

Special reports were filtered to compare the responses by age of child. Each of these full reports follow this section. Age categories included:

- Under 5
- 6-15
- 16-22
- 23-30
- 31+

Who completed the survey

In most age categories approximately 85% of survey respondents identified themselves as parents or guardians. The exception to this shows in the category for individuals with Down syndrome who are 31 years old or older. Interestingly, only 62% of survey respondents in this category were parents or guardians, with 20% of the survey respondents identifying as brothers or sisters.

Gender

There was consistency in gender split across most groups, with a very slightly higher percentage of males in each category as well as overall. The group with a noticeably higher difference in gender was the 16-22 age category. This group identified 63.5% males vs. 38.5% females.

Geographic Location

Metro Boston was the most frequently identified location with approximately 30% of respondents in this category. The one group that stood out differently was the 16-22 age range with only half as many located in the metro Boston area.

Living Situation

As expected, the percentage of individuals who live with parents and guardians diminished as their ages increased. In the youngest category all children lived with parents/guardians, from 6-15, it was close to 99%. In the 16-22 age range it still was very high with approximately 94% living with parents or guardians. By age 23-30 that percentage shrank to 74% with another 13% living independently with supports. By age 31+, only 30% still lived with parents or guardians. In this category the responses were split across most of the options provided. It is worth noting that only 6% (or two individuals) were identified as living independently without supports.

Who Made the Diagnosis?

All categories identified OB/GYN's and pediatricians as the most frequent providers of the diagnosis, however there was a noticeably larger spread across categories with younger children with 45% of families with children under 5 selecting options other than these two. By the ages of 23 and above these other categories shrank to approximately 10% of families.

Received Accurate Information at the Time of Diagnosis?

All age categories reported similar experiences with anywhere from 41 to 46 percent saying "yes" to receiving accurate information. However, for individuals aged 31+, that "yes" percentage diminished to 31%.

Do Individuals with Down syndrome Have Complex Needs?

Of the five age categories, four had comparable reports in this category with anywhere from 41 to 44 percent selecting "no" as their response. The one group that had a marked difference in response was the 23-30 year old group where 63% of survey respondents selected "no" as their answer.

Do Individuals with Down syndrome Have Challenging Behavior Problems?

Three of the five age categories had comparable response rates to this question. The under 5, 16-22, and 31+ were within a few percentage points of each other ranging from 62 to 70 percent. However, the 6-15 year old group is apparently the most challenging group in terms of behavior with a 46% "no" response, and the 23-30 age group had the least challenging assessment with a 80% "no" response.

How included at school is (or was) the person with Down syndrome?

In examining results for age categories 6 and higher, the survey results show close agreement with three of the categories (16-22, 23-30, 31+), but a 15% or higher rate of inclusion for children ages 6-15.

Are you or were you happy with the education program?

Families with the youngest children were the most happy with education programs, with over 90% selecting either very happy or mostly happy. Other groups were not as pleased with the sum of those two categories close to 60% for each.

Is your family member with Down syndrome currently working?

The two highest age categories indicated between 18 and 23 percent of individuals were not working. However, for the group aged 16-22, that number was 70%.

Job Satisfaction

For individuals aged 23-30, job satisfaction was low, with close to half saying they were not satisfied. For individuals aged 31 or older, job satisfaction was slightly better with approximately 40% not satisfied.

How satisfied you are with your family member's social and recreational experiences?

All categories expressed moderate to severe concerns in this area. About a quarter of the youngest and oldest categories stated concerns, but the highest categories were for ages 16-22 and 23-30 where percentages grew to 41% and 37% respectively.

What might help increase participation in social and recreational activities?

Several things stood out in this category. First, older individuals with Down syndrome are more in need of transportation than other categories with 41% choosing this as a priority. The most frequently chosen options were information, and a peer mentor or support person to accompany them to activities. Information was most critical to families with the youngest children, and peer mentors or support buddies were most critical to ages 6-30.

Level of Participation in the MDSC

The age category that chose "very active" the most was for ages 16-22. Not active was increasingly chosen as child age increased with 25% selecting "not active" for children under 5, all the way to 74% for "children" ages 31 or older. The reasons ranged, but included not enough time, not aware of opportunities or how to get involved, geographical distance, that the focus seems to be on younger children, financial restrictions, still adjusting to diagnosis and learning about resources.

Specific Participation in the MDSC

The two most commonly chosen categories were the same for all age groups; the annual conference and the Buddy Walk. For 16-22 year olds the AIM program was very popular and for 31+ individuals legislative advocacy was a top choice.

Top Priorities for the MDSC

All age categories chose options 1 and 3 as priorities (receiving up-to-date info, and enable networking and direct supports). For ages 23-30, a third priority was advocating for systemic change on issues such as community inclusion and employment. For ages 31+, two additional priorities were advocating for systemic change on issues such as community inclusion and employment, and advocating for high quality education including transition planning.

Areas of Greatest Need

This area varied according to age. For ages 5 and under, education was the most frequently identified need. For ages 5-15 the two most significant needs were education and social/recreational support. For ages 16-22, the two most significant areas of need were transition and social/recreational support. For ages 23-30 the greatest concerns were housing, employment and social/recreational support. For ages 31+ the top priority was social and recreational support.

Can the MDSC do a better job serving your needs?

The highest percentage of people saying “yes” the MDSC could do a better job was families with children under the age of five with slightly over 68% choosing this option. The interesting thing about this response is that a number of individuals commented (in different parts of the survey) that they perceived the MDSC as focusing too much on their youngest population.

COMPARING RESULTS BASED ON LEVEL OF PARTICIPATION IN THE MDSC

Special reports were filtered to compare the responses by level of participation in the MSDC.

Categories included:

- Very Active and Active
- Somewhat Active
- Not Active

Age of Family Member with Down syndrome

Families with children ages 6-15 selected “very active or active” 17% of the time, which is 3x the frequency chosen for the other two activity levels. All categories showed a concentration in the youngest ages, but the survey has a much higher number of overall respondents who fit these age categories.

Geographic Location

Not surprisingly, the most active MDSC members live within Massachusetts. While all categories show a concentration of population in Metro Boston, the most active families also show a concentration in the Northeast and the smallest percentage of families in Western Mass.

Living Situation

The vast majority of respondents in all categories selected “living with parent/guardian or family member” at an average of 94%; however, this percentage was 10 points lower for the least active families.

Level of School Completed

The largest category for active members was elementary school at 26%. The percentage of individuals who have obtained a High School Diploma (or the equivalent) was double for active members vs. the other two categories.

Do Individuals with Down syndrome Have Complex Needs?

Those members who identified as “not active” expressed the highest percentage of agreement with this question with 55% saying “yes” vs. 36% and 27% for the other levels of engagement.

How included at school is (or was) the person with Down syndrome?

Those members who identified as “not active” selected “substantially separated classroom” almost twice as often as the other two categories of involvement.

Are you or were you happy with the education program?

Those members who identified as “not active” selected “not happy” three times as often as the other two categories of involvement.

Job Satisfaction

The most active families showed the highest degree of satisfaction with employment with 59% saying “yes.” The least active families showed the lowest degree of satisfaction with employment with 45% saying “yes.”

How satisfied you are with your family member’s social and recreational experiences?

The least active families chose “this is a real problem” close to 4x as often as other families who have greater levels of participation in the MDSC.

Top Priorities for the MDSC

The most active MDSC members are not experiencing the same level of need as other members around information, resources, advocacy and transition planning. This group selected that option 5% of the time vs. the other two groups selecting it 16-18% of the time.

Have you participated in any support groups at any point during the past five years?

The most active members said “yes” 65% of the time. The members who said they were “somewhat active” said “yes” 47% of the time. The least active members only said “yes” 28% of the time.

COMPARING RESPONSES FROM SELF-REPORTING 18+ INDIVIDUALS TO OTHERS

With only 5 responses from individuals about their own experiences, it is impossible to draw any conclusions or even make any assumptions.

We can describe the population that did respond as entirely English speaking, three males and two females. Three of the respondents live with their parents or guardians, the other two with roommates. Two are currently in high school, one is in college and 1 has finished college. Their greatest needs were in money and planning for the future, as well as advocating for themselves and others with Down syndrome. Their ages ranged from 19 to 60.

Individuals with Down syndrome are one of the key stakeholder groups in the organization, but their participation in this survey was extremely limited. It is important to obtain feedback and thoughts from this group of self-advocates. One effective approach could be a series of small focus groups to allow for brainstorming and feedback. Not only would this yield important information, but would have a secondary benefit in terms of networking and building connections between MSDC members. Another option might be individual interviews with individuals representing different ages, regions and backgrounds.

FINAL NOTE

It is worth noting that membership in the MSDC seems to result in families having improved outcomes and experiences in their lives. For example, in the section of this report which compares responses by “level of participation” in the organization, the results show that the less active experienced “substantially separated classrooms” twice as often as the other group. In addition, the least active members are “not happy” with the education program three times as often as the other categories of involvement. And the least active families were less satisfied with employment, social and recreational experiences. While it is important not to draw hard and fast conclusions from one survey, these results seem to indicate that actively participating in the MDSC can have a marked impact on perspective and experience.