MDSS Membership Engagement Survey Final Report January 2019



Thank you to those who were able to participate in our member engagement

survey. The MDSS collected 29 responses, 82% of which were members. We appreciate the valuable input you have provided and have noted several clear themes as well as a wide range of suggestions for improvements and growth. With this report, we hope to share with the membership what we have learned.



First, we found that the most common way people heard about the MDSS, with 25% of respondents noting this, was through a friend, family member or another parent. This highlights a strength of our community- our ability to reach out to those around us to help us feel connected and supported. The second most noted response was that people heard of the MDSS through the new parent packages.

Notably, several respondents stated they heard of MDSS at the time of the birth of their child; it can be speculated that this too may fit with either hearing of MDSS from a new parent package or from a friend, family member or another parent.

We identified two barriers to membership including a lack of a PayPal account and lack of interest in available programming. We aim to continue to grow and develop our programming moving forward. In terms of PayPal being a barrier, we wish to let our members and prospective members know that membership can be also be activated via a credit card, online or over the phone, or via cheque mailed in to our office. You can find our contact information at the end of this report.

Unfortunately, there was a glitch in the question regarding what events respondents had attended. We apologize for this error! Despite this, **Walk with Us, Baby Love and the Dinner Dance appear to be the most frequently attended events.**

The **top three recommendations for changes at future MDSS events**, which each came up a minimum of 3 times, included:

- 1. Improve communications regarding upcoming events
- 2. Offer more programming and events for those under 18
 - 3. Offer regional events, outside of Winnipeg

In addition to these recommendations, respondents also recommended additional life skills development opportunities for our community members with Down syndrome. One notable response was someone wishing for less rain at our annual fundraising walk and we have to say, we wholeheartedly agree with you!



When asked to rate how well the MDSS is meeting its mandate, the overall average was 3.69 out of 5; 41% of respondents rated the MDSS a two or a three; 59% rated MDSS a four or a five.



When asked for suggestions on areas we can improve, there was a wide array of thoughtful responses. The most common theme identified was that the MDSS can improve by providing information to families about resources available. Relatedly, families want to see the MDSS provide information to schools and early childcare facilities.

More specifically, this included:

- Providing information on child to adult transition services;
- Providing information on funding available for families;
- Providing information on supports available through schools;
- Having guest speakers come present to members;
- And connecting families to resources outside the MDSS, to support families to fill needs not met by the MDSS.

The second most frequently mentioned suggestion related to improving communications.

Members want to ensure they are receiving emails and also want to see the MDSS better communicate and promote events. Related to communications, some members would like to see the MDSS better showcase the abilities of persons with Down syndrome from our community. The MDSS Board has officially added communications as an ongoing agenda line item, and will be reviewing communications procedures in order to begin to improve.

Additional suggestions included providing more advocacy, increasing financial transparency, and reaching communities outside of Winnipeg.



When asking about the age of community members with Down syndrome, 48% of respondents had a child 12 or under, 31% had a child in their teens, and 21% had a child 20 or over. 65.5% of these respondents felt that the MDSS is offering programs and supports for the children in their age range. Despite this, when asked about ideas for additional programs, the top theme was increased programming for children and youth under 18 years of age, with an emphasis on "middle aged" children.

In summary, we hear those of you who believe that we have room to improve and we agree. The MDSS will be working diligently to discuss and explore all of your suggestions and we appreciate the time everyone has taken to contributing to the discussions. If you are interested in seeing your suggestions come to life, please consider volunteering with the board or on a committee.

You can reach out to us through one of our many platforms.

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In response to some of the suggestions/concerns, here are a few additional resources:

CDSS Teaching Resources- Includes an educator's package which can be provided to your child's school: https://cdss.ca/resources/education-teaching/

Parent Supports-

The Manitoba Families of Children with Down Syndrome group provides an informal, supportive network of families to connect with. Search on Facebook "Manitoba Families of Children with Down Syndrome" and request to join.

Family Advocacy Network is a community of parents, family members and caregivers to people living with disabilities in Manitoba. There is a Facebook group and an email list.

Specialized Services for Children and Youth (SSCY) has an informative email list and website that details a variety of therapeutic and social supports, as well as opportunities for individuals with disabilities and their families. https://sscy.ca