



SAMUEL CENTRE  
FOR SOCIAL  
CONNECTEDNESS

*Special  
Olympics*



**Intellectual Disability and Sibling Relationships:  
Perspectives of Individuals with ID**  
An Inclusive Research Project

By Olivia Najdovski  
Social Connectedness Fellow 2020  
Samuel Centre for Social Connectedness  
In Partnership with Special Olympics  
[www.socialconnectedness.org](http://www.socialconnectedness.org)

August 2020

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## EXECUTIVE SUMMARY

Special Olympics launched the Sibling Engagement Initiative in 2018 in partnership with The Samuel Family Foundation. This initiative aims to promote sibling involvement in Special Olympics events and activities, share their stories to make their experiences salient to others, create resources to support siblings' social and emotional wellbeing, and research the experiences of siblings of people with intellectual disabilities (ID). This research project is part of Special Olympics' Sibling Engagement Initiative, in partnership with the Samuel Centre for Social Connectedness (SCSC). The project seeks to explore the sibling relationship between Special Olympics athlete leaders and their siblings without ID.

This study aims to answer two main questions: How do Special Olympics athletes experience the sibling relationship? What supports are needed for siblings with and without ID?

A review of the current literature revealed the following key challenges for individuals with ID and their siblings:

- Some studies report that siblings of individuals with disabilities are more likely to have poor mental health outcomes
- Siblings of individuals with ID have challenges related to caregiving
- Support groups have proven to be a helpful resource for siblings of individuals with ID
- There is a lack of research including the perspectives of individuals with ID

The surveys and interviews revealed the following key findings:

- Athlete leaders have strong, positive relationships with their siblings
- Athlete leaders have positive parent-child relationships
- Siblings of athlete leaders are advocates for inclusion in their communities
- Special Olympics has positively impacted most athlete leaders' sibling relationships
- The majority of challenges that athlete leaders face are a result of negative attitudes towards disability in the community
- Athletes leaders and their siblings want more programming that facilitates sibling connection and collaboration

### ***Recommendations***

1. Conduct athlete-sibling research on a larger scale
2. Future research projects should be inclusive
3. Establish an international sibling network
4. Consider launching sibling support groups
5. Consider launching sibling education programs
6. Create sibling resources addressing areas of need

## INTRODUCTION

Special Olympics provides year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities (ID).<sup>1</sup> Intellectual disability is a condition defined by three criteria: (1) IQ is below 70-75, (2) there are significant limitations in two or more adaptive areas (skills needed to work and live in the community, like communication or self-care), and (3) the condition manifests itself before age 18.<sup>2</sup> Special Olympics supports people with ID by providing an inclusive space to demonstrate skill, courage, and to feel joy through sport. Special Olympics also provides support to families of people with ID in a variety of ways, including building communities and providing resources.<sup>3</sup>

Despite the many positive experiences associated with having a sibling with ID, there are also challenges imposed by the attitudes and structures of society. Although siblings face these challenges, there is a marked lack of support for siblings of people with ID. Most support for families is directed towards the parents of individuals with ID and do not address siblings. To address this gap in current programming, Special Olympics launched the Sibling Engagement Initiative in 2018 in partnership with The Samuel Family Foundation. This initiative aims to promote sibling involvement in Special Olympics events and activities, share their stories to make their experiences salient to others, create resources to support siblings' social and emotional wellbeing, and to research the experiences of siblings of people with ID.<sup>4</sup> This research project is part of Special Olympics' Sibling Engagement Initiative, in partnership with the Samuel

<sup>1</sup> "Our Mission," Special Olympics, <https://www.specialolympics.org/about/our-mission>.

<sup>2</sup> "What is Intellectual Disability?," Special Olympics, <https://www.specialolympics.org/about/intellectual-disabilities/what-is-intellectual-disability>.

<sup>3</sup> "Our Mission," Special Olympics.

<sup>4</sup> "Sibling Engagement," Special Olympics, <https://www.specialolympicsglobalyouth.org/sibling-engagement>.

Centre for Social Connectedness (SCSC). The project seeks to explore the sibling relationship between Special Olympics athlete leaders and their siblings without ID.

Much of the current literature on the topic of ID lacks the input of people with ID themselves. Research on ID typically only includes the perspectives of people without ID, like parents, teachers, or medical experts, for example. Although these perspectives have value, those of the population being studied are notably missing. Individuals with ID have lived experience of the barriers to inclusion in society, including stigma, bullying and discrimination. Individuals with ID can provide the most pertinent insights into the supports and services that may be beneficial to this group. As such, this research project intentionally includes the perspectives of individuals with ID to address this gap in the literature.

This study aims to answer two main questions: (1) How do Special Olympics athletes experience the sibling relationship? (2) What supports are needed for siblings with and without ID? These questions were designed to address the needs of Special Olympics athletes and their siblings but may also be relevant to individuals with ID and their siblings not involved in Special Olympics. In addition, this research may also guide recommendations for Special Olympics regional offices, local programs, as well as employees and volunteers.

### ***Methodology***

This research project methodology was inclusive, meaning that the project was developed and conducted by a team that included both individuals with ID and siblings

of people with ID. The purpose of adopting this approach was to learn from the knowledge, experiences and insights of people with ID and their siblings to produce research that is representative of and relevant to the population it pertains to.

The researchers utilized a mixed methods approach, combining both quantitative and qualitative techniques. For the quantitative component, the researchers distributed a survey to Special Olympic Athlete Leaders across four regions: North America, Latin America, Africa, and Asia Pacific. Athlete leaders are Special Olympics athletes that are advocates for inclusion on a larger scale, through channels like public speaking, governance, and media. The survey included both likert-type scale questions and open-ended free response questions. Sibling relationships were assessed using selected items from the Adult Sibling Relationship Questionnaire<sup>5</sup> and the Instrumental Aid section of the Network of Relationships Questionnaire.<sup>6</sup> The relationship between the athlete and their primary caregiver was also assessed as parent-child relationships have been known to affect sibling relationships.<sup>7</sup> These relationships were measured using selected items from the Parent-Child Communication Scale.<sup>8</sup> The phrasing of all survey items were modified to easy-to-read language to be more accessible to individuals with ID. The survey items were piloted for clarity and ease of response with a group of Special Olympics athletes. After being piloted and edited based on athlete recommendations, the survey was launched to the wider group of athlete leaders.

<sup>5</sup> Clare M. Stocker et al., "Sibling relationships in early adulthood," *Journal of Family Psychology* 11, no. 2 (1997): 210-221, <https://doi.org/10.1037/0893-3200.11.2.210>.

<sup>6</sup> Wyndol Furman and Duane Buhrmester, "Children's perception of the personal relationships in their social networks," *Developmental Psychology* 21, no. 6 (1985): 1016-1024, <https://psycnet.apa.org/doi/10.1037/0012-1649.21.6.1016>.

<sup>7</sup> Susanne O. Roper et al., "Caregiver burden and sibling relationships in families raising children with disabilities and typically developing children," *Families, Systems, & Health* 32, no. 2 (2014): 241-246, <https://psycnet.apa.org/doi/10.1037/fsh0000047>.

<sup>8</sup> Rolf Loeber et al. "Antisocial behavior and mental health problems: Explanatory factors in childhood and adolescence," Lawrence Erlbaum Associates Publishers (1998), <https://psycnet.apa.org/record/1998-06025-000>.

For the qualitative component, Ben Haack, Board Member and Athlete Leader for Special Olympics International and the author of this report interviewed two sibling pairs consisting of Special Olympics athletes and their siblings from the Latin America and Africa regions. The purpose of these interviews was to gain a more in-depth understanding of athletes' sibling relationships from the regions of interest. Athletes and their siblings were asked a series of questions about their relationships and the supports and services that they feel would be most beneficial to them. The interviews were semi-structured, which allowed for more in-depth and comprehensive information compared to the survey.

## **ISSUE, EVIDENCE AND KEY FINDINGS**

### ***Key Challenges***

A review of the current literature on sibling relationships and ID revealed ambiguity in sibling experiences and areas of needed support. For instance, some studies report that siblings of individuals with ID tend to have positive mental health outcomes and are well-adjusted.<sup>9</sup> Other research indicates that siblings of individuals with ID may be more likely than siblings of individuals without ID to have poor mental health outcomes. This includes an increased likelihood for anxiety and depression. They may also be more likely to have lower life satisfaction compared to siblings of people without ID.<sup>10</sup> While results are mixed, these findings indicate that more mental health support and resources are needed for siblings of individuals with ID. Additionally, some studies suggest that siblings of individuals with ID tend to report less positive sibling relationships compared to siblings of people without ID, while other studies

<sup>9</sup> Hyunkyung Choi and Marcia Van Riper, "Maternal perceptions of sibling adaptation in Korean families of children with Down syndrome," *Journal of Intellectual Disability Research* 58, no. 10 (2014): <https://doi.org/10.1111/jir.12126>

<sup>10</sup> Lindsay E. Murray and Linda O'Neill, "Neuroticism and extraversion mediate the relationship between having a sibling with developmental disabilities and anxiety and depression symptoms," *Journal of Affective Disorders* 243 (2019): 232-240, <https://doi.org/10.1016/j.jad.2018.09.042>.

report that siblings have positive relationships and enjoy spending time together.<sup>11</sup> Positive sibling relationships are associated with higher levels of life satisfaction and lower levels of depression and anxiety. More frequent contact with the sibling with ID is associated with stronger sibling relationships.<sup>12</sup> As such, programming for siblings with and without ID to engage in activities together has the potential to improve sibling relationships. Mental health outcomes associated with these factors may also improve as a result. Alternatively, improving mental health outcomes for siblings without ID may also improve the sibling relationship.

In addition to the many positive experiences associated with having a sibling with ID, siblings of individuals with ID may also have distinct differences in personal growth compared to siblings of individuals without ID. For example, on average, siblings of individuals with ID demonstrate higher levels of empathy and engage in significantly more perspective-taking than individuals without ID.<sup>13</sup> Siblings of people with ID also tend to demonstrate greater social, spiritual, and personal growth than siblings of children without ID. Researchers attribute this growth among siblings of people with ID to positive perceptions of family dynamics, self-differentiation, and stress management.<sup>14</sup>

Siblings of individuals with ID may also have unique challenges related to caregiving. Some siblings may be responsible for providing care to their sibling with ID

<sup>11</sup> Zachary Rossetti et al., "Perspectives about adult sibling relationships: A dyadic analysis of siblings with and without intellectual and developmental disabilities," *Research in Developmental Disabilities* 96, (2020), <https://doi.org/10.1016/j.ridd.2019.103538>.

<sup>12</sup> Massimiliano Sommantico et al., "Adult siblings of people with and without intellectual and developmental disabilities: Sibling relationship attitudes and psychosocial outcomes," *Research in Developmental Disabilities* 99 (2020), <https://doi.org/10.1016/j.ridd.2020.103594>.

<sup>13</sup> Carolyn M. Shivers, "Empathy and perceptions of their brother or sister among adolescent siblings of individuals with and without autism spectrum disorder," *Research in Developmental Disabilities* 92, (2019), <https://doi.org/10.1016/j.ridd.2019.103451>.

<sup>14</sup> Liora Findler, Aya Vardi, and Steven J. Taylor, "Psychological Growth Among Siblings of Children With and Without Intellectual Disabilities," *Intellectual and Developmental Disabilities* 47, no. 1 (2009): 1-12, <https://doi.org/10.1352/2009.47:1-12>.



during childhood or throughout adulthood. Some siblings report difficulty transitioning and adapting to a caregiving role.<sup>15</sup> Decisions to provide care for a sibling with ID may be associated with feelings of guilt and resentment. Research on siblings and caregiving reveals that many siblings of individuals with ID struggle with self-compassion when it comes to making care-related decisions for their sibling with ID.<sup>16</sup> Additionally, some siblings report a struggle with competing relationships. Caregiving responsibilities are associated with strained relationships with partners and other family members.<sup>17</sup> Siblings require additional support to alleviate the stress and negative emotions that may be associated with caring for a sibling with ID. For example, families can provide social support for individuals with ID and their siblings by engaging in a consistent flow of communication, including their children in major family discussions, and providing a safe space for sharing feelings. Through a family-centered approach siblings' satisfaction with family functioning has been found to be strongly related to sibling relationship quality. Additionally, more positive sibling relationships are associated with siblings feeling supported by their family.<sup>18</sup> Improving family functioning may also improve sibling relationships

Research on experiences of siblings of individuals with ID reveals a phenomenon coined *disability by association*. This term is used to describe when someone experiences discrimination due to their connection to a person with disability. As a

<sup>15</sup> Yeh-chen Kuo, "Brothers' Experiences Caring for a Sibling with Down Syndrome," *Qualitative Health Research* 24, no. 8 (2014): 1102-1113, <https://doi.org/10.1177%2F1049732314543110>.

<sup>16</sup> Máire Leane, "Siblings caring for siblings with Intellectual Disabilities: Naming and negotiating emotional tensions," *Social Science & Medicine* 230 (2019): 264-270, <https://doi.org/10.1016/j.socscimed.2019.04.022>.

<sup>17</sup> Ngozi E. Chukwu et al., "Coping strategies of families of persons with learning disability in Imo state of Nigeria," *Journal of Health, Population and Nutrition* 38, no. 9 (2019), <https://jhpn.biomedcentral.com/articles/10.1186/s41043-019-0168-2>.

<sup>18</sup> Melissa H. Bellin and Karen M. Rice, "Individual, family, and peer factors associated with the quality of sibling relationships in families of youths with spina bifida," *Journal of Family Psychology* 23, no.1 (2009): 39-47, <https://psycnet.apa.org/doi/10.1037/a0014381>.

result, siblings of people with ID may feel a lack of belonging with their peers and experience feelings of loneliness and isolation.<sup>19</sup> In a study that investigated sibling support needs, siblings reported that they would like supports that provide a way to connect with one another.<sup>20</sup> Support groups are the most common and most heavily researched intervention for siblings of individuals with ID. Support groups provide a space for siblings of individuals with ID to connect with fellow siblings. Some support groups facilitate discussions about siblings' feelings and thoughts related to disability while others allow for free discussion on other topics. Research on sibling support groups demonstrates consistent positive effects. Support groups help to mitigate negative emotions, anxiety, and depression in siblings of people with ID.<sup>21</sup> They also facilitate feelings of sibling connectedness and empowerment. Many siblings also report wanting to see efforts to change their community's attitudes towards disability. Support groups have demonstrated the ability to inspire siblings to create systemic change in their community. Unfortunately, these efforts are often not carried out by siblings because of the demands and responsibilities that are often placed onto them.<sup>22</sup> It is necessary to implement more supports and services to relieve siblings of their responsibilities to give siblings the time and resources to be agents of change in their communities.

The literature review also revealed a small subset of research that includes the perspectives of siblings with ID. Studies including individuals with disabilities

<sup>19</sup> Alexandra Gregory et al., "Academic self-concept and sense of school belonging of adolescent siblings of autistic children," *Research in Developmental Disabilities* 96, (2020), <https://doi.org/10.1016/j.ridd.2019.103519>.

<sup>20</sup> Catherine K. Arnold et al., "Support Needs of Siblings of People with Developmental Disabilities," *Intellectual and Developmental Disabilities* 50, no. 5 (2012): 373-382, <https://doi.org/10.1352/1934-9556-50.5.373>.

<sup>21</sup> Emily A. Jones et al., "Randomized controlled trial of a sibling support group: Mental health outcomes for siblings of children," *Autism*, (2020), <https://doi.org/10.1177%2F1362361320908979>.

<sup>22</sup> Meghan M. Burke et al., "Exploring the preliminary outcomes of a sibling leadership program for adult siblings of individuals with intellectual and developmental disabilities," *International Journal of Developmental Disabilities* 66, no. 1 (2020): 82-89, <https://doi.org/10.1080/20473869.2018.1519632>.

demonstrate that siblings with a disability tend to report similar experiences of the sibling relationship when compared to siblings without a disability. Moreover, siblings with ID tend to de-emphasize disability when describing their relationship with their sibling without ID.<sup>23</sup> 70% of adult siblings with a disability consider their relationship with their sibling as a significant relationship in their lives. 50% of adult siblings report a supportive relationship with their sibling in which the sibling pair mutually supports each other.<sup>24</sup> This review of the literature demonstrates the need for further research which includes the perspectives of individuals with ID to better understand their experience of the sibling relationship.

### ***Key Findings***

The survey gathered 27 responses from Special Olympics athlete leaders, 70% of which were complete responses. Across the four regions of interest, approximately 34% of responses were from North America, 30% from Asia-Pacific, 18% from Africa, and 18% from Latin America. Respondents ranged from 22 to 50 years of age and were majority female (54%). 42% of respondents report living with their sibling.

### ***Sibling Relationship***

Responses from athlete leaders indicate that most have strong, positive relationships with their sibling. 81% of respondents report considering their sibling as a good friend. 86% of respondents feel as though their sibling accepts them for who they are. Interview responses also pointed to strong sibling relationships. A sibling of an athlete leader from South Africa described her relationship with her brother:

<sup>23</sup> Ariella Meltzer, "Comparative life experiences: young adult siblings with and without disabilities' different understandings of their respective life experiences during young adulthood," *Families, Relationships and Societies* 8, no. 1 (2019): 89-104, <https://doi.org/10.1332/096278917X15015139344438>.

<sup>24</sup> Sanne A. H. Giesbers et al., "Social Capital and the Reciprocal Nature of Family Relationships: The Perspectives of Individuals with Mild Intellectual Disability," *American Journal on Intellectual and Developmental Disabilities* 125, no. 3 (2020): 170-185, <https://doi.org/10.1352/1944-7558-125.3.170>.

“The relationship between me and my brother, it’s strong... our bond is strong. Growing up, you have those people who underestimate you, but my brother would stand up for me, so he is forever there... he is always protecting me.”<sup>25</sup> The majority of athletes report receiving instrumental aid from their siblings. For instance, 55% of athletes report that their siblings teach them things they do not know, and 35% of athletes report sometimes receiving this support. Half of respondents report spending a lot of time with their siblings. In addition, most athlete leaders’ siblings advocate for them either often (55%) or sometimes (30%). Athlete leaders also provide support to their siblings. In an interview, an athlete leader described the support he gives to his sister. He said “if someone bothers her, I cannot let it happen because we are siblings. She loves me and I love her so there is a connection.”<sup>26</sup> Moreover, the parent-child relationship has been known to affect sibling relationships. In line with this, the majority of athlete leaders have generally positive communication with their primary caregivers. When asked if athlete leaders feel comfortable letting their primary caregivers know what is bothering them, 68% responded yes, and 21% responded sometimes. In addition to the strong relationships athletes leaders report having with their siblings, siblings of athlete leaders are also advocates for inclusion. 60% of athlete leaders report their siblings advocating for inclusion in the community either often or sometimes.

### *Special Olympics’ Impact on Sibling Relationships*

Additionally, 93% of athlete leaders reported that Special Olympics has been helpful for them and their siblings. Furthermore, 45% of siblings of athlete leaders are regularly involved in Special Olympics. When asked what in particular has been helpful,

<sup>25</sup> Anonymous Zoom interview by the author, Toronto/Johannesburg, ON/RSA, July 31, 2020.

<sup>26</sup> Anonymous Zoom interview by the author, Toronto/Santiago, ON/CHL, July 31, 2020.

athlete leaders described a variety of benefits. Some athlete leaders highlighted that Special Olympics has made their relationship stronger with their siblings. Athlete leaders report that they bond with their siblings and spend more time together because of Special Olympics activities. For example, some siblings of athlete leaders volunteer in Special Olympics, including as a coach, while others take their siblings to and from Special Olympics events. Some siblings have gone on to start Special Olympics Programs in previously unserved areas. Athlete leaders also highlighted that Special Olympics has educated their siblings about inclusion. A sibling of an athlete leader reports that “Special Olympics has taught [her] that we are different people with different characters... we have different specialities.” As a result, “We understand each other better and our relationship is growing stronger and stronger everyday.”<sup>27</sup> Some athlete leaders report that Special Olympics has given their siblings an opportunity to cheer for them and celebrate their achievements. An athlete leader highlights that “growing up, [their family] didn’t expect [they] were going to achieve some of these things but Special Olympics is able to change mindsets.”<sup>28</sup> The athlete leaders who reported that Special Olympics has not helped themselves and their siblings did not elaborate in the follow-up question. Overall, athlete leaders enjoy positive relationships with their siblings, in which many siblings are advocates for inclusion and are involved in Special Olympics.

### *Challenges within the Community*

The interviews also revealed some of the challenges that athlete leaders and their siblings face. These challenges are often a product of stigma surrounding ID in the community. A sibling of an athlete leader reports that “the biggest challenge... are the limiting beliefs of all those that do not experience inclusion and how difficult it is to make

<sup>27</sup> Anonymous Zoom interview by the author, Toronto/Johannesburg, ON/RSA, July 31, 2020.

<sup>28</sup> Anonymous Zoom interview by the author, Toronto/Johannesburg, ON/RSA, July 31, 2020.

them see the value of inclusion. Sometimes these barriers are so strong that it's hard to break."<sup>29</sup> An athlete leader recounts "the names that they use when they want to tease me... That's when most of my siblings would try and stop them."<sup>30</sup> Another sibling reports that "in the community... it's not easy... We are at a point that we don't even care what the community says. If [my brother] is happy, we are also happy."<sup>31</sup> There also appears to be a lack of education within the community. For example, a sibling of an athlete leader emphasizes that "[the community] doesn't understand the disability [her brother] has because they only know physical disabilities."<sup>32</sup> Unfortunately, because of the negative attitudes in the community, an athlete leader highlights that "most athletes, they hide."<sup>33</sup>

### *Supports and Services*

The sibling interviews also addressed what supports and services could be helpful for sibling pairs. The most common theme was bringing siblings of athletes together. An athlete leader recommended that Special Olympics "create a space, get siblings, and give them time to speak about what they experience."<sup>34</sup> A sibling emphasized education in these groups, stating that "it would be nice for us to attend to be educated so that we can also go and educate other people [on ID]."<sup>35</sup> Another sibling stated that "it would be very powerful... to work towards more collaborative and network-styled work or leadership [for siblings]." She elaborated that "we could get more in contact with other organizations that have youth leadership programs and start collaborative work with them." Additionally, she emphasized that "collaboration and

<sup>29</sup> Anonymous Zoom interview by the author, Toronto/Santiago, ON/CHL, July 31, 2020.

<sup>30</sup> Anonymous Zoom interview by the author, Toronto/Johannesburg, ON/RSA, July 31, 2020.

<sup>31</sup> Ibid.

<sup>32</sup> Ibid.

<sup>33</sup> Ibid.

<sup>34</sup> Ibid.

<sup>35</sup> Anonymous Zoom interview by the author, Toronto/Santiago, ON/CHL, July 31, 2020.

networking would also be very cool with other youth leaders and other Special Olympics programs around the world.” She expressed her desire to have “Zoom meetings with other youth leaders around the world... and learn about their projects [to] create synergy.”<sup>36</sup>

## RECOMMENDATIONS

Based on the primary and secondary research outlined above, this section provides recommendations for supports and services for individuals with disabilities and their siblings. These recommendations are targeted to Special Olympics International (SOI), as well as other non-profit organizations and non-governmental organizations that provide support to individuals with disabilities and their families.

### **1. Conduct athlete-sibling research on a larger scale**

The main limitation of this research project was the sample of the athlete population. Firstly, the sample size was small for both the survey and interviews. As a result, statistical analysis of the survey responses and an in-depth qualitative analysis of the interview responses were not possible. The small sample size is partly a result of Special Olympics’ programming interruptions due to COVID-19. The survey was difficult to distribute to the broader athlete community because of the lack of in-person programming due to social distancing measures. There are a variety of challenges associated with administering a large-scale online survey, which were exacerbated by the short timeline of the project. For example, athletes may require assistance to complete the survey, and this can be more difficult to facilitate online. Furthermore, some athletes may not have access to a stable internet connection during COVID-19. A larger sample size is necessary to understand the correlates of the athlete-sibling

<sup>36</sup> Ibid.

relationship and to gain a more in-depth understanding of the support needs of athletes and their siblings. Additionally, the sample consisted only of athlete leaders. This is another significant constraint. Although athlete leaders provided excellent insights, as they are deeply involved in Special Olympics, athlete leaders and their families are also likely to reap the most benefits from Special Olympics' services and programming compared to other athletes. The athlete leaders sampled in this research project tend to have excellent sibling relationships and their siblings are often involved in Special Olympics. Despite this, these findings are not likely to extend to the broader athlete community and their siblings, who may not be as deeply involved in Special Olympics, on average. As a result, the broader athlete community may require more support than athlete leaders. Athletes and their siblings may also require different kinds of support because their needs are significantly different than the needs of athlete leaders and their siblings. Overall, a large scale research project is necessary to assess athlete-sibling relationships and the supports and services necessary for this population.

## **2. Future research projects should be inclusive**

Future research projects pertaining to individuals with ID should include them throughout the research process whenever possible. Inclusive research means including individuals with ID in the development of the research in addition to surveying the perspectives of individuals with ID. Often, research is conducted *for* marginalized communities, rather than *with* them. Research that is not inclusive risks propagating the assumption that these populations do not have valuable insights to offer. As such, the main benefit of inclusive research projects is that it ensures that research is relevant and accurate to the population it pertains to by learning from the knowledge and insights



of the population being studied. The researchers strongly recommend that research projects be inclusive whenever possible going forward.

### **3. Establish an international sibling network**

Research on siblings of individuals with ID demonstrates that some siblings have an expressed interest in connecting with fellow siblings. In interviews, siblings of athlete leaders emphasized that they would like to network and collaborate with other siblings around the world both virtually and in-person. Special Olympics has focused primarily on distributing information and resources. Moving forward, Special Olympics should consider putting greater emphasis on social networks. Siblings of individuals with a disability are more likely to feel isolated and different from their peers. This sibling network could allow for siblings to meet other like-minded individuals with similar experiences and create a stronger sense of belonging and connectedness. This network could also provide siblings with opportunities to be more involved in Special Olympics and to act as inclusion ambassadors in their community.

### **4. Consider launching sibling support groups**

Support groups for siblings of individuals with disabilities have a demonstrated ability to improve outcomes for siblings. This includes improving rates of anxiety and depression, and increasing feelings of sibling connectedness, empowerment and the desire to create change in their communities. In interviews, athlete leaders and their siblings also expressed the desire for a space for siblings to come together and share their experiences. Support groups not only have the potential to improve the lives of siblings, but also empower siblings to be more involved in Special Olympics and be agents of change in their communities. Virtual support groups may be an effective way

to administer these sessions, particularly during COVID-19 when physical distancing measures are in place. Local Special Olympics programs may also benefit by connecting with local organizations that are already conducting support groups, if available.

#### **5. Consider launching sibling education programs**

In the interviews, athlete leaders and their siblings expressed a desire for more educational resources for siblings of individuals with ID and their families. More specifically, siblings would like more education about ID for the purposes of educating their communities to reduce stigma. Educational programming has the potential to benefit sibling relationships by improving their understanding of ID, but could also provide siblings with the opportunity to be better ambassadors for inclusion in their communities.

#### **6. Create sibling resources addressing areas of need**

Siblings of individuals with ID are more likely to experience mental health difficulties and feelings of isolation compared to siblings of people without disabilities. As such, Special Olympics should make targeted resources to siblings of athletes addressing these concerns. For example, creating resources with coping strategies and suggestions for where to reach out for support could make a significant impact on siblings who may be struggling with negative emotions, anxiety, or depression as a consequence of the challenges imposed by the attitudes and structures of society surrounding disability. Additionally, resources targeted to siblings providing tips and strategies related to caregiving could also be beneficial.

## **IMPACT**

This Fellowship supported a pilot study on Special Olympics athletes' experiences of their sibling relationships. This project also ignited an inclusive research initiative within Special Olympics, as the team of researchers included individuals with ID throughout the research process. It also amplified the voices of individuals with ID in terms of understanding the sibling relationship. This resulted in a series of recommendations that are relevant to the needs of athletes and their siblings. Special Olympics can use these recommendations to inform SOI initiatives as well as to inform local Program recommendations, with the goal of creating additional support for athletes and their siblings. SCSC can assist Special Olympics to achieve these goals by supporting the Sibling Engagement Initiative. Additionally, SCSC can support the initiative for inclusive research by including the members of the population being studied in the research process when possible.

## **CONCLUSION**

This research project sought to answer two main questions: How do Special Olympics athletes experience the sibling relationship? What supports are needed for siblings with and without ID? A review of the literature on the topics of siblings and disability revealed that siblings of individuals with disability face a variety of unique challenges that require further support. To better understand sibling relationships from the perspective of individuals with ID, the researchers used a mixed methods approach, utilizing both surveys and interviews. Athlete leaders tended to have strong relationships with their siblings. The majority of siblings were advocates for inclusion in their community, and many were involved in Special Olympics. The majority of

challenges faced by athletes and their siblings were related to negative attitudes surrounding disability in the community. Recommendations included programming, which facilitates feelings of belongingness among siblings. The major constraint of this research project was the small sample size which only included athlete leaders. As a result, only limited analysis was possible. Additionally, the findings from this sample may not generalize to the broader community of athletes. Future research should investigate sibling relationships utilizing a larger sample which better represents the broader population of individuals with ID.

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