



SOCIAL CONNECTEDNESS  
FELLOWSHIP PROGRAM



# **Special Olympics International: Supporting families of Special Olympics athletes during COVID- 19**

**An Inclusive Research Project**

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## EXECUTIVE SUMMARY

Special Olympics International (SOI) empowers individuals with intellectual disabilities (ID) through the inclusive power of sports. SOI views families as the “life force” of the movement as family participation remains central to building socially connected communities to enhance the athlete experience. To involve and celebrate families, SOI developed the Family Engagement Strategy, which was last expanded in 2013. This study fills a critical need to update the Family Engagement Strategy by exploring: **How can Special Olympics support families of Special Olympics athletes, and what are the expectations of the families from the organization, given the challenges of the COVID-19?**

Through an inclusive, mixed methods approach, Mohajeri and Turley surveyed 30 and interviewed three family members in Ireland, the United Arab Emirates, and the United States. The research process was adapted to ensure a participatory and emancipatory approach for Turley, Special Olympics Ireland Athlete Leader and individual with ID.

### **The following constraints were present during the research process:**

- **Literature Review:** lack of intersectionality, focusing on disability as the sole experience, instead of as a form of diversity.
- **Adapted Literature Review:** lack of Easy Read outputs.
- **Survey and interviews:** virtual medium excluded those without access.
- **Survey:** lack of demographic data collected from respondents.

### **The survey and interviews revealed the following key findings:**

- Double the percentage of family members felt that informal services continued without change during the pandemic as formal services.
- Family members placed social connectedness as their most urgent need with an average ranking of 1.96, on a scale of one as the most important and seven as the least important need.
- When families noted their COVID-19 concerns, 40% worried about their socio-emotional connections, 42% worried about their mental health, and 67% worried about socio-emotional connections for the athlete.

### **Recommendations:**

1. Prioritize social connectedness through further funded outreach.
2. Expand inclusive research methodology.
3. Conduct family research on a larger scale.
4. Expand intersectional research.
5. Continue temporal research post COVID-19.

## INTRODUCTION

Special Olympics International (SOI) responded to COVID-19 by transforming in-person programming to virtual formats for Special Olympics athletes and families in 201 countries and jurisdictions.<sup>1</sup> SOI is a non-profit organization founded in 1968 that fosters inclusion through year-round sports training and community programming for people with intellectual disabilities (ID). The minimum age requirement to participate in Special Olympics competitions is eight years of age, and there is no maximum age limit for competitions. Children are eligible to participate in the Young Athletes Program from the age of two.<sup>2</sup> Although ID manifests differently in each individual, standard criteria for diagnosis include: intellectual functioning level below 70-75 IQ, significant limitation in two or more adaptive skill areas, and exhibiting the former two criteria before the age of 18.<sup>3</sup>

At the peak of the COVID-19 pandemic, SOI empowered community members with easy to understand information on the prevention of COVID-19, and provided virtual fitness and mental health resources to promote the health, safety, well-being, and social connectedness of the community.<sup>4</sup> This strategy was essential, as people with intellectual disabilities (ID) are considered a high-risk group for COVID-19 due to the lack of equitable health access and higher rates of

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<sup>1</sup> "About." Special Olympics. <https://www.specialolympics.org/about>

<sup>2</sup> "Mission." Special Olympics. <https://www.specialolympics.org/about/mission>

<sup>3</sup> "What is Intellectual Disability?" Special Olympics. <https://www.specialolympics.org/about/intellectual-disabilities/what-is-intellectual-disability>

<sup>4</sup> "COVID-19 Information & Resources." Special Olympics. <https://www.specialolympics.org/our-work/covid19>

chronic health conditions.<sup>5</sup> As restrictions loosen globally, SOI has transitioned to in-person programming, with supplemental guidance above local levels where and when mandates allow.<sup>6</sup> However, the new phase of COVID-19 continues to present challenges for families of Special Olympics athletes.

The current literature on family engagement, individuals with ID, and COVID-19 concurs that family members have taken on compound caregiving roles during the pandemic in order to provide for their family members with ID.<sup>7</sup> Due to the lack of in-person support, equitable healthcare, and necessary accommodations, parents, and mothers in particular, have stepped in as multifaceted support systems. These additional responsibilities on primary caretakers have exasperated extant obstacles to inclusion, such as physical, educational, policy, transportation, pragmatic, attitudinal, and social barriers.<sup>8</sup>

Although intersectional research on families of persons with disabilities (PWD) remains scarce, existing literature and lived experiences recognize that oppression intersects with varying identities. PWD and their families from indigenous and minority communities face oppression, amplified by COVID-19,

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<sup>5</sup> “COVID-19 Risk for People With Intellectual Disabilities.” Special Olympics. <https://www.specialolympics.org/our-work/covid19/covid-19-risk-for-people-with-intellectual-disabilities>

<sup>6</sup> “Return to Activities during COVID-19.” Special Olympics. <https://resources.specialolympics.org/resources-to-help-during-the-crisis/return-to-activities-during-covid-19>

<sup>7</sup> Navas, Patricia, Miguel Ángel Verdugo, Sergio Martínez, Antonio M. Amor, Manuela Crespo, and Madalin M. Deliu. “Impact of COVID -19 on the Burden of Care of Families of People with Intellectual and Developmental Disabilities.” *Journal of Applied Research in Intellectual Disabilities* 35, no. 2 (March 2022): 577–86. <https://doi.org/10.1111/jar.12969>; Baumer, Nicole. “The Pandemic Isn’t over — Particularly for People with Disabilities.” Harvard Medical School. Harvard Health Publishing (blog), May 25, 2021.

<sup>8</sup> “Disability Barriers to Inclusion.” Center for Disease Control. <https://www.cdc.gov/ncbddd/disabilityandhealth/disability-barriers.html>

such as racial discrimination and violence.<sup>9</sup> Furthermore, families of PWD who are older, identify as LGBTQ2S+, and from lower socioeconomic status, often face lack of critical services, combined with increased social isolation during the pandemic, resulting in greater odds of physical and mental health distress.<sup>10</sup>

## OUR PROJECT

In partnership with the Samuel Centre for Social Connectedness, this project seeks to address the challenges that families of Special Olympics athletes face. This research will fill a critical need for SOI to update their Family Engagement Strategy, which was last expanded in 2013. Family engagement remains at the center of building socially connected communities to enhance the athlete experience. The overall strategic plan is to “create trained, empowered, and involved families at all levels of the organization.”<sup>11</sup> The plan focuses on four areas: Family Volunteers, Healthy Families, Young Athlete Leaders, and Community Builders. To achieve this goal, SOI implemented Family Support Networks to connect families, enhance families’ views of athletes’ capabilities, provide peer support, and enable a structure for ongoing communication. SOI views families as the “life force” of the movement, and the organization

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<sup>9</sup> “Statement on the Impact of the Global COVID-19 Pandemic on Persons with Disabilities from Minority, Indigenous and Other Marginalised Communities,” 2020.

<sup>10</sup> Nolan, Syreeta L. “The Compounded Burden of Being a Black and Disabled Student during the Age of COVID-19.” *Disability & Society* 37, no. 1 (January 2, 2022): 148–53.

<https://doi.org/10.1080/09687599.2021.1916889>; “Disability, Queerness and COVID-19: Living Proud in a Quiet World.” Web log. *Archer Magazine* (blog), August 25, 2020.; Kuper, Hannah, and Tom Shakespeare. “Are Older People with Disabilities Neglected in the COVID-19 Pandemic?” *The Lancet Public Health* 6, no. 6 (June 2021): e347–48.

[https://doi.org/10.1016/S2468-2667\(21\)00077-3](https://doi.org/10.1016/S2468-2667(21)00077-3).

<sup>11</sup> Family Toolkit.” Special Olympics. <https://resources.specialolympics.org/community-building/families/family-toolkit>

emphasizes family engagement in trainings, competitions, health screenings, and fundraising events.<sup>12</sup>

This study aims to inform the organization's Family Engagement strategy by focusing on families of athletes and assessing how SOI can support these athletes during COVID-19, and what the expectations of the families are from the organization. This research may guide the expansion of the Family Toolkit resource as well as protocols for global Special Olympics regions, employees, and volunteers. Although this study is designed to address the needs of Special Olympics families, it may also be relevant for understanding the needs of families of individuals with ID outside of SOI. Specifically, this research may help equip governments, non-government organizations, other non-profits, and the general public to assess resources and support for families of individuals with ID in the new phase and aftermath of COVID-19.

## ***Methodology***

### **Inclusive, Mixed Methods Approach**

This study centers an inclusive research design by involving Margaret Turley, an individual with ID and Special Olympics Ireland Athlete Leader, throughout the research process. Inclusive research embraces and models the "Nothing Without Us!" demand for the full and equitable inclusion of PWD, with participatory and emancipatory approaches to research.<sup>13</sup> Inclusive research is

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<sup>12</sup> "Family Toolkit." Special Olympics.; Pfeifer, Whitney. "From 'Nothing About Us Without Us' to 'Nothing Without Us.'" National Democratic Institute (NDI). NDI, March 28, 2022. <https://www.ndi.org/our-stories/nothing-about-us-without-us-nothing-without-us>.

<sup>13</sup> "Athlete Leadership." Special Olympics

collaborative, furthers the interests of PWD, and produces accessible outputs.<sup>14</sup> Conversely, research that excludes PWD also excludes the lived experiences and first-hand demands of the largest global minority. Studies that contemplate disabilities and advocate for inclusion but forgo inclusive methodology, specifically, risk harming the community by removing agency, speaking for the community, and perpetuating ableism.<sup>15</sup> Inclusive research design has been centered in SCSC and SOI collaborations since 2020.<sup>16</sup>

During this study, Turley was an invaluable and equal team member. To ensure inclusivity and empower participation, standard practices were adapted during each phase of the project. Mohajeri and Turley created a connection as co-researchers via Zoom as Mohajeri lived in the United Arab Emirates and the United States, while Turley remained in Ireland during the fellowship. During weekly meetings, Mohajeri and Turley shared their lived experiences, learned knowledge, and updates or questions about the study. They also updated each other via email and used shared documents to draft outputs.

During secondary research, Mohajeri and Turley chose Easy Read documents for the literature review process, which Turley read, summarized, and discussed. Easy Read documents state information in clear, easy to read and understand language and display relevant images alongside words. These

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<sup>14</sup> Walmsley J and Johnson K (2003) *Inclusive research with people with learning disabilities: Past, present and futures*. London: Jessica Kingsley Publishers

<sup>15</sup> Rios, Dianne, Susan Magasi, Catherine Novak, and Mark Harniss. "Conducting accessible research: including people with disabilities in public health, epidemiological, and outcomes studies." *American journal of public health* 106, no. 12 (2016): 2137-2144.

<sup>16</sup> Najdovski, Olivia. "Intellectual Disability & Sibling Relationships." Samuel Centre for Social Connectedness, 2020.; Vanos, Adrianna. "Social Connectedness, Self-Determination & Health at Home." Samuel Centre for Social Connectedness, 2021.



accessible documents support people who have a learning disability, low literacy level, or use English as a second language to understand written information better.<sup>17</sup> Where Easy Read documents were unavailable, Mohajeri chose key pages or sections of literature to review together.

This research also utilizes a mixed methods approach. During primary research, Turley and Mohajeri collaborated to obtain and analyze data. In qualitative inquiry, Turley chose an interviewee, conducted outreach, assisted in question creation, and co-interviewed the participant. Mohajeri and Turley co-interviewed three family members of PWD overall: a mother living in the US, a sibling living in Ireland, and a mother living in the UAE. To overcome geographical restrictions and ensure COVID-19 safety, interviews took place over Zoom and phone calls. The participants were chosen through purposive sampling. None of the participants identified with other intersectionality marginalized communities. The interviews provided nuanced perspectives on cultural considerations, COVID-19 realities, and regional Special Olympics programming that informed our creation of a quantitative survey. Mohajeri and Turley also co-created an Easy Read output that featured the interview.

For quantitative inquiry, Turley participated in survey research, design, and dissemination. Mohajeri and Turley created a pilot survey that was distributed to three programs: Special Olympics Pennsylvania, Special Olympics Ireland, and Special Olympics United Arab Emirates. These programs were purposefully

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<sup>17</sup> “Office for Disability Issues. “A Guide to Making Easy Read Information.” Office for Disability Issues. New Zealand Government Ministry of Social Development, n.d. <https://www.odi.govt.nz/guidance-and-resources/a-guide-to-making-easy-read-information/>.

chosen due to Mohajeri and Turley's connections with leadership and their understanding of cultural and geographical particularities. For instance, Mohajeri created an outreach template, and Turley led and personalized the process of reaching out to participants in Ireland. The survey items were piloted for clarity, ease of response, and thoroughness. In the future, the survey will be updated based on recommendations from families submitted at the conclusion of the survey and analysis of submitted responses. SOI will then launch the survey across four regions: North America, Latin America, Africa, and Asia Pacific. Mohajeri and Turley also co-created an Easy Read output of this study for the use and implementation of the community. During every phase, Turley drew from her personal experiences to ensure that questions and recommendations were relevant and useful for families of PWD.

### **Survey Participants**

The participants in the study were randomly selected by the local Special Olympics leaders from active family rosters. Eligible participants were either a father, mother, or sibling of a Special Olympics athlete who has been actively involved with programming in the past year. The survey incorporated demographic, multiple choice, matrix, likert scale, ranking, and open-ended questions. Items were created by the research team following interviews, review of literature, and discussions about Turley's experiences. Select questions were adapted from

previous Special Olympics surveys to ensure inter-item reliability.<sup>18</sup> Themes from “Parents of Children with Disabilities in the Early Months of COVID-19: Knowledge, Attitudes, and Needs” were also incorporated to assess temporal impact.<sup>19</sup> The survey explored the impact of COVID-19 on families of individuals with ID, how families experience support provided by Special Olympics, and what needs families hold that the organization can fulfill.

The final sample for the survey included 30 family members of Special Olympics athletes. Within these 30 family members, 25 mothers, five fathers, and zero siblings completed the survey. Participants were located in three geographical locations: 18 in Ireland, four in the UAE, and eight in the US. Most respondents were involved as volunteers or chaperones for the organization, followed by involvement as coaches. The majority of the family members were highly engaged with Special Olympics within the last year, with 63% attending competitions always or most of the time.

To understand the experience of the family unit, the survey also inquired about athletes in these families. The athletes ranged in age from seven to 45, with a mean of 23.5. An overwhelming number of the athletes (87%) participated in unified or traditional sports practices or competitions, and the majority of the others

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<sup>18</sup> Kersh, Joanne, Gary N. Siperstein, and S. O. G. C. Center. "The positive contributions of Special Olympics to the family." Special Olympics (2012).; "Socio-Economic, Health and Psychosocial Impact of the COVID-19 Pandemic on Children with Intellectual Disabilities and Their Families in Sabah, Malaysia." Internal. Special Olympics Asia Pacific and UNICEF, February 2022.; "Serving Athletes, Families and the Community: The Universal Impact of Special Olympics: Challenging the Barriers for People with Intellectual Disability." Policy brief. Special Olympics and U.S. Centers for Disease Control, 2009.; "Best Stats for Families." Easy Read Families Research Overview. Special Olympics, n.d.

<sup>19</sup> Bruder PhD, Mary Beth, Tara M. Lutz PhD, and Kelly E. Ferreira PhD. "Parents of Children with Disabilities in the Early Months of COVID-19: Knowledge, Beliefs and Needs." *Developmental Disabilities Network Journal* 1, no. 2, 2021: 8.

participated in athlete leadership and/or health and fitness programming. Of the athletes who participated in sports practices or competitions, almost all (96%) participated once or more per week. Socially, about 63% of athletes connected with teammates or others between once a month to once a week. However, 20% of athletes never or rarely experienced social interactions.

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

### ***Key Challenges***

Key challenges were present in the review of current literature on the experiences of families of individuals with ID, as well as during the study. Most academic literature lacked intersectionality, focusing on disability as the sole experience, instead of as a form of diversity within the family. The majority of participants in studies and interviews were mothers who had children or young adults with ID. Most research excluded the experiences of families with older individuals with disabilities and the experiences of fathers and guardians as family members.<sup>20</sup> Few studies considered socioeconomic status (SES), and key findings generally lacked evidence and analysis of varying resources for those experiencing low SES. Additionally, studies taking place during COVID-19 were conducted virtually due to restrictions, limiting the inclusion of individuals in rural

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<sup>20</sup> Kuper, Hannah, and Tom Shakespeare. "Are Older People with Disabilities Neglected in the COVID-19 Pandemic?" *The Lancet Public Health* 6, no. 6 (June 2021): e347–48. [https://doi.org/10.1016/S2468-2667\(21\)00077-3](https://doi.org/10.1016/S2468-2667(21)00077-3).

locations or individuals without internet access.<sup>21</sup> Current literature also held limited representation of Indigenous and minority communities.

However, minorities families and communities who experienced disabilities, including people living in poverty; immigrants; and Black, Latinx, Indigenous, and queer folks suffered disproportionately during the pandemic. For instance, one statement from PWD who are from Indigenous and other minority communities, emphasized that their communities faced increased racial discrimination and violence during COVID-19. These signatories called for inclusive response strategies, quality collected and reported data, and accessible information during public health emergencies.<sup>22</sup> Further, the majority of the literature did not include PWD in the research process, lacking inclusivity by speaking **for** the community instead of **with** the community. Due to the lack of existing inclusive research, Easy Read and accessible material were also largely unavailable for the use of current and future inclusive research. Where accessible information was not available, Mohajeri emphasized and discussed key information and conclusions.

Although this study centered inclusive research methodology, other key challenges as current literature persisted. While fathers had low representation in the study, siblings chose not to participate. Further research is needed to analyze the higher participation of mothers as respondents. However, some studies conclude that mothers are often the primary caretakers for individuals with ID across cultures, facing increased risk of stress, along with poorer health and

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<sup>21</sup> Vanos, Adrianna. "Social Connectedness, Self-Determination & Health at Home." Samuel Centre for Social Connectedness, 2021.

<sup>22</sup> "Statement on the Impact of the Global COVID-19 Pandemic on Persons with Disabilities from Minority, Indigenous and Other Marginalised Communities," 2020.

weakened family relationships, justifying a need to continue research on the experiences of mothers.<sup>23</sup>

Due to geographical restrictions and COVID-19 safety, the survey and interviews occurred virtually. Respondents in rural areas or without means to virtual access were excluded. Some survey participants reaffirmed this exclusion by observing that the lack of internet access led to further isolation for families in their local Special Olympics program during COVID-19. Furthermore, the survey was distributed to three geographically diverse locations, but it is not evident whether minority communities within each region participated. From the limited demographic information collected, there were no respondents who identified as gender non-conforming.

## ***Evidence and Key Findings***

### **Impact of COVID-19**

The survey assessed the impact of COVID-19 on families of Special Olympics athletes by asking about the formal and informal services available during the pandemic. Formal support was defined as services and support provided by the government, a non-governmental organization, or other professionals, such as doctors and therapists. Informal support referred to support that families received from social networks, family members, or community members.

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<sup>23</sup> McConkey, Roy, Maria Truesdale-Kennedy, Mei-Ying Chang, Samiha Jarrah, and Raghda Shukri. "The Impact on Mothers of Bringing up a Child with Intellectual Disabilities: A Cross-Cultural Study." *International Journal of Nursing Studies* 45, no. 1 (January 2008): 65–74. <https://doi.org/10.1016/j.ijnurstu.2006.08.007>.

Families were nearly equally split on whether there was less, more, the same, or no formal support during COVID-19. However, 43% of families felt that informal services continued the same as prior to the pandemic, whereas almost a quarter (20%) felt the same about formal services. These responses reaffirmed the narratives shared by family members in interviews: all three interviewees felt that family members had to continue providing support in the face of diminishing formal services.<sup>24</sup> Out of the respondents who believed less formal support was available, most experienced fewer resources directed towards social-emotional connections or opportunities, followed by in-person services. This result was echoed in the 2020 Tower Foundation COVID-19 Family Survey, which concluded that the COVID-19 pandemic had led to a decrease in opportunities for social-emotional connections and in-person support in the United Kingdom.<sup>25</sup>

When thinking about their own wellbeing during COVID-19, family members were least concerned about their physical health (30%), and more, almost equally, worried about socio-emotional connections and mental health (around 40%). The contrast was more evident when family members discussed the wellbeing of the athlete in their family: the majority (67%) were concerned about socio-emotional connections or opportunities for the athlete. All interviewees also emphasized the concern that their family members with ID were losing opportunities for social

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<sup>24</sup> Anonymous Zoom interview by the author, Canada/UAE, June 23, 2022.; Anonymous Zoom interview by the author and Margaret Turley, Canada/Ireland, July 1, 2022. Anonymous Zoom interview by the author, USA/USA, July 15, 2022.

<sup>25</sup> Dillon, Kristin. "Tower Foundation COVID-19 Family Survey Learning Disabilities Parent Results: Essex, Dukes, Barnstable, and Nantucket Counties." Peter and Elizabeth C. Tower Foundation, 2020.

connections due to the lack of in-person programming, such as Special Olympics. As one interviewee noted, “I can’t talk about COVID-19 without getting anxious about [the individual with ID in my family]. I’m worried about their mental health. I’m worried that they have no opportunities to socialize outside the family. Their stress is my stress.” These concerns were compounded for survey respondents as more than half (53%) were struggling with the change from in-person to virtual services or schooling, followed by loss of community-based services, loss of employment, access to quality healthcare services, loss of income, and loss of childcare.

### **Support from Special Olympics**

The majority of families looked favorably upon almost all of the support that they received from their Special Olympics chapter during the COVID-19 pandemic. Most (between 57-70%) either agreed or strongly agreed that Special Olympics has devoted enough resources and programming to support their family during COVID-19, and provided easy to understand information about resources and programming. The family members also used virtual resources provided by the organization during the pandemic and believed that their family’s physical health benefited from this community during COVID-19. An overwhelming majority (between 77-84%) agreed or strongly agreed that Special Olympics sent information on available resources during the pandemic, and has worked towards the return to in-person programming where and when appropriate. Families also felt comfortable with the guidelines for the return to in-person activities.



Participants had less agreement regarding mental health and social connectedness opportunities: 50% strongly agreed or agreed that the Special Olympics community benefited their family mentally or socially during the pandemic. This discrepancy was also described in interviews and open-ended responses in the survey: One respondent described how some families in their program did not have access to the internet. Others described accessibility needs that were not accommodated during virtual programming, resulting in feelings of social isolation for their family unit. For example, one family member felt guilty when they did not have the capacity to guide the athlete through a Zoom session, but the athlete could not participate in the live practice without their help due to the lack of subtitles.

This data aligned with the needs that families have and believe Special Olympics can fulfill. Families ranked their needs from one to seven, with one as the most important need and seven as the least. Respondents placed social connectedness as the most urgent need that their family has with a 1.96 average ranking. Physical health followed as the second most important need, with an average ranking of 3.08. Mental health needs, access to information/resources, and routine/stability were all ranked equally as third highest, with an average ranking of around 3.5. Overall, family members long for opportunities to connect with others and find community after the challenges that the COVID-19 pandemic has presented.

## RECOMMENDATIONS AND DISCUSSION

Addressing the continuous impact of COVID-19 on families of individuals with ID and providing support requires a positive shift towards social inclusion of the family unit. The following recommendations are viable for Special Olympics, as well as other NGOs, government entities, and researchers positioned to address such guidance.

- 1. Prioritize social connectedness through intentional outreach:** In both the theme explorations of “Impact of COVID-19” and “Support from Special Olympics,” family members longed primarily for socio-emotional connections or opportunities for their family unit. Global research prior to COVID-19 indicated that families of PWD experienced higher rates of social isolation due to the lack of inclusive communities and emotional support available, which often led to depression and anxiety.<sup>26</sup> This reality has been exacerbated due to the effects of COVID-19 and loss of connection to a sense of belonging.<sup>27</sup>

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<sup>26</sup> M.B Olsson, C.P Hwang. “Depression in Mothers and Fathers of Children with Intellectual Disability.” *Journal of Intellectual Disability Research*, Vol. 45, Part 6 (2021): 535-543.; Salehi and colleagues. “Review of Depression in Children with Disorders.” *Thought and Behaviour Quarterly*, Vol. 10 (2004): No. 37-38.

<sup>27</sup> Bruder PhD, Mary Beth, Tara M. Lutz PhD, and Kelly E. Ferreira PhD. "Parents of Children with Disabilities in the Early Months of COVID-19: Knowledge, Beliefs and Needs."; Arim, Rubab, Leanne Findlay, and Dafna Kohen. *The impact of the COVID-19 pandemic on Canadian families of Children with Disabilities*. Statistics Canada=Statistique Canada, 2020.; Charlotte Leach, Christopher Wigfield. “Coronavirus and the Social Impacts on Disabled People in Great Britain: March 2020 to December 2021.” *Coronavirus and the social impacts on disabled people in Great Britain*. Office for National Statistics, February 2, 2022.  
<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/coronavirusandthesocialimpactsondisabledpeopleingreatbritain/march2020todecember2021>.

Within this study, most family members felt a lack of connection to people and purpose. With the lack of in-person programming for athletes, families of individuals with ID lost social connections to their communities as well. For instance, interviews and survey responses suggested that in-person Special Olympics programming provided a weekly social outlet for family members to meet, connect, and share with one another while the athletes trained prior to the pandemic. These opportunities for social connectedness seldom occurred during COVID-19 as only athletes participated virtually.

Further, although family units who experience disability generally have an increased sense of purpose, the impact of COVID-19, and its associated uncertainties, created a sense of purposelessness.<sup>28</sup> As noted in the “Impact of COVID-19” key findings, some of these uncertainties included economic precarity, access to virtual programming, lack of human support systems, multitasking for household needs, and lack of access to equitable healthcare for the household. As one family member described, the amalgamation of these factors resulted in feeling that “our world became narrower, and our level of motivation decreased significantly.” An interviewee described her depression as “overwhelming guilt that I could not do it all on my own when nothing was certain: support my child, support myself, support my entire family.”

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<sup>28</sup> Catherine Okoro et al., “Indicators of Poor Mental Health and Stressors during the COVID-19 Pandemic, by Disability Status: A Cross-sectional Analysis.” *Disability and Health Journal*, 2021, 101110.; Jacques, Ray. “Family Issues.” *Intellectual Disability and Health*. University of Hertfordshire, May 24, 2019. <http://www.intellectualdisability.info/family/articles/family-issues>.

In the future, increased funding and focus on intentional outreach through established networks may help to alleviate social isolation. For instance, an audit of local programs can illuminate what needs local programs must meet through in-person or virtual programming. For virtual methods, providing technology such as loaner laptops, tablets, and a wireless connection, or providing accessible options, such as through radio, TV, and print, may prove valuable for families to connect externally. Additionally, organizing virtual or in-person weekly social events for families of Special Olympics during athlete practices will encourage the entire family unit to connect with the community. Further, as family networks expand, leaders in the community must undergo formal mental health training. This preparation will prepare community members to recognize symptoms of social isolation within Special Olympics families and either provide support or connect with external resources when necessary. Generally, increasing formal and informal services for families and individuals with ID remains necessary.

- 2. Expand inclusive research methodology:** Inclusive research has been conducted successfully in the past and must continue in the future.<sup>29</sup> To overcome the present barriers to inclusion in policy and practice, all research must include PWD in its development and conduct. Research on topics about or surrounding individuals with ID, specifically, must center the

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<sup>29</sup> Najdovski, Olivia. "Intellectual Disability & Sibling Relationships." (2020).; Vanos, Adrianna. "Social Connectedness, Self-Determination & Health at Home." (2021).

voices of individuals with ID throughout every phase of the project to ensure accurate and relevant studies. Research that is not inclusive excludes the demand of the community: “Nothing Without Us!” Exclusionary practices propagate ableism in academia, public policy, and daily life. Individuals with lived experiences are willing to offer their insights, skills, and time, and academia must include and support these voices.

- 3. Conduct family research on a larger scale:** One limitation of this pilot study was the limited sample size of families of Special Olympics athletes. For both surveys and interviews, qualitative and statistical analysis did not yield conclusive results. As a pilot, this survey was difficult to distribute due to the short timeline of the project, lack of incentive, and additional obstacles present for families of individuals with ID during the ongoing pandemic. A larger sample size is necessary to establish correlation between various demographics, the impact of COVID-19 on families, and support from Special Olympics. With additional time, outreach via mail and phone will allow participants without access to virtual methods to contribute. Furthermore, the chosen respondents already held extensive connections to Special Olympics. For example, the majority of families had leadership roles within Special Olympics. Therefore, participants who have not been able to gain from the support of Special Olympics were excluded and should be considered in future research. The survey feedback section will be useful to transform this pilot to a large-scale study that includes more narratives.

- 4. Expand intersectional research:** Future research on disabilities should consider that disability is experienced alongside social class, race, age, sex, gender and 2SLGBTQ+ identity, religion, and rural and urban divides both globally and within country. Due to the lack of existing intersectional research, families whose identities privilege access to resources continue to represent the loudest voices within disability research. Current studies deprioritize the needs of minority communities, creating a cycle of demand without supply. As Special Olympics programs expand and as existing participants age, intersectional research will continue to prove valuable in meeting future needs..
  
- 5. Continue temporal research post COVID-19:** Due to the risks and limitations present, participants without internet access have been excluded from research on COVID-19, as it has largely taken place virtually. For instance, some respondents noted that families in their program were not able to access virtual programming due to lack of internet. These same families would not have been able to participate in this survey due to its virtual nature. Once safe to do so, field studies should represent the voices of those who were not represented due to restrictions. Further, a temporal study can analyze the length and depth of the impact of COVID-19 on families of individuals with ID. Such research can provide insights and prepare relevant entities for future public health emergencies.

## **IMPACT**

This inclusive research project centered the “Nothing Without Us!” demand of PWD through an equitable research partnership. This project exemplified how research, policies, and programming can implement inclusive practices: include PWD in every phase of the process, build a connection and understand differing needs, ask questions, adapt practices to empower participation, and offer support. The process also modeled that inclusion results in accurate, relevant, and accessible questions, results, and discussions for both communities with and without disabilities.

The results of this study will be relevant for NGOs, governments, researchers, and the general population who serve families of individuals with ID. The research results provide further ground to prioritize opportunities for social connectedness for families of PWD in the new phase of COVID-19. Additionally, the results and recommendations can prepare relevant entities for future public health emergencies, when PWD and their families face ancillary challenges.

In the future, the pilot survey will be improved based on current results and open-ended feedback provided at the conclusion of the survey. Afterwards, the survey will be distributed to four additional regions on a larger scale: Latin America, Africa, and Asia Pacific. The conglomerate of results will fill a critical need to assess the successes of SOI and where new efforts remain necessary to meet the needs of families in the community. This analysis will be used to update SOI’s Family Engagement Strategy.

## CONCLUSION

This inclusive research project sought to inform the Family Engagement Strategy by exploring two main questions: How Special Olympics can support families of athletes during COVID-19, and what the expectations of the families are from the organization. Current literature largely lacks intersectionality, excluding the voices of minorities. Furthermore, virtual research due to COVID-19 is not an accessible format for all families.

Based on a mixed methods approach, general conclusions were drawn surrounding the impact of COVID-19 and support from Special Olympics. Special Olympics families felt that informal services continued in relatively the same manner during COVID-19, whereas their access to formal services differed. Families were primarily concerned about socio-emotional connections and opportunities for the athletes in their family during COVID-19, while simultaneously worrying about their own mental health and social isolation. The majority of families positively viewed Special Olympics resources during COVID-19. However, families continue to urgently ask for opportunities for social connectedness for their family unit, which they believe Special Olympics can fulfill.

Recommendations are applicable to not only Special Olympics, but other NGOs, governments, researchers, and the general community. This guidance includes prioritizing social connectedness through further funding intentional outreach, expanding inclusive research, conducting research on families on a larger scale, expanding intersectional research, and continuing temporal research post COVID-19. Future research should expand the sample size and ensure the



inclusion of individuals with ID throughout the research process. These recommendations are centered on the belief that disability is a form of diversity, and more authentic and expansive inclusion of people with disabilities and their families at all levels of research, policy, and programming will result in stronger communities that celebrate difference.

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