



SAMUEL CENTRE  
FOR SOCIAL  
CONNECTEDNESS



*Special Olympics*

## **Social Connectedness, Self-Determination & Health at Home:**

An Examination of Special Olympics Athletes and Their Families'  
Experiences During the COVID-19 Pandemic

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## EXECUTIVE SUMMARY

As a vital health resource to individuals with an Intellectual disability, the loss of in-person Special Olympics programming due to the COVID-19 pandemic was felt throughout the Special Olympics community. In response to this loss, Special Olympics International (SOI) launched a series of online resources for athletes and their families. This study conducted open-ended interviews with five athletes and five parents to assess online resources and gain insight into the way that household dynamics can positively and negatively influence an athlete's health journey. This report draws conclusions on the needs of athletes and their families in the home, and during the return to in-person play. Moreover, it lays out recommendations for how SOI can support athletes off the field.

### *Key Terms:*

- In this report, there are several key terms used to describe Special Olympics athletes' healthy choices. These terms are **self-determination** and **self-motivation**. In the context of this report, these terms are used to discuss how the personal motivations and decision-making processes of individuals with an intellectual disability intersect with the decisions that are made, often on their behalf, by their families and other carers.
- In the context of this report, an **individual with an Intellectual disability (ID)** has a diagnosis consisting of (i) cognitive impairment to adaptive and intellectual functioning, and (ii) an IQ of less than 70-75 points.

### *Recent Literature:*

- There is a general lack of access to and / or awareness of financial, emotional, or social support for individuals with ID and their families.
- The health, wellbeing, and social connectedness of individuals with ID is directly related to that of their family members.
- Some studies have shown that when individuals with ID are involved in the decision making-processes, stressors are reduced, and healthier decisions are made.<sup>1</sup>

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<sup>1</sup> Simone A Onrust, et al., "Family Group Conferences within the Integrated Care System for Young People with ID: A Controlled Study of Effects and Costs." *BMC Health Services Research* 15, no. 1 (2015): 392., S Koritsas et al., "Weight, Nutrition, Food Choice, and Physical Activity in Adults with Intellectual Disability." *Journal of Intellectual Disability Research* 60, no. 4 (2016): 355-64.

## INTRODUCTION

In March of 2020, Special Olympics International (SOI) and their respective State and Local Programs canceled all in-person programming in response to the emerging COVID-19 virus. To mitigate the loss of these programs, SOI launched a series of online resources to engage athletes (individuals with Intellectual disability [ID]) and their families. In partnership with the Samuel Centre for Social Connectedness (SCSC), SOI launched this study to understand and assess how Special Olympics (SO) athletes and their families have used online resources to maintain their health, wellbeing, and social connectedness together during the COVID-19 pandemic.

SOI is an international non-governmental organization that offers year-round health and active lifestyle-based programming, competitive sporting opportunities, and community to individuals with ID.<sup>2</sup> ID is defined as a cognitive impairment that affects adaptive and intellectual functioning. While the specific qualities of each individual's ID are different, there are several standard classifiers. Individuals with ID experience limitations in adaptive functioning (social, practical, and functional areas) before age 18 years and have an IQ of less than 70-75 points.<sup>3</sup>

Due to their unique social, functional, and practical needs, individuals with ID and their families are often unable to find health and social-related resources that fit their needs, wants, and schedules. This is a serious issue, considering that the ID population

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

<sup>3</sup> "What is Intellectual Disability?", <https://www.psychiatry.org/patients-families/intellectual-disability/what-is-intellectual-disability>

is particularly vulnerable to physical and mental health issues.<sup>4</sup> When compared to the general populations, individuals with ID have a greater risk of early death,<sup>5</sup> and are more prone to cancers, sensory impairments, epilepsy, and chronic diseases.<sup>6</sup> Further, studies have reported that individuals with ID are less likely to meet physical health and nutrition recommendations than the general population. This carries over to issues with nutrition and wellbeing, where recent studies have found that individuals with ID lack opportunities to exercise autonomy over their decisions.<sup>7</sup>

After the transition from school to community, there are not as many programs or supports that are inclusive of those with ID. For many, SO is the only program that fits into their life after they have graduated. Beyond serving primary health needs and wants, SO fosters an inclusive environment that allows athletes to express their voice, adopt leadership roles, and exercise autonomy over their health. The sense of confidence and self-advocacy skills gained from these opportunities extends beyond the official programming to have a real-world impact. One example of this is SO team-based sports. This programming offers athletes an opportunity to build practical social skills, learn about healthy choices, and to foster social connectedness so that they can overcome health barriers and facilitate healthy habits and lifestyles.

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<sup>4</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., S Koritsas et al., "Weight, Nutrition, Food Choice, and Physical Activity in Adults with Intellectual Disability." *Journal of Intellectual Disability Research* 60, no. 4 (2016): 355-64.

<sup>5</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

<sup>6</sup> S Koritsas et al., "Weight, Nutrition, Food Choice, and Physical Activity in Adults with Intellectual Disability." *Journal of Intellectual Disability Research* 60, no. 4 (2016): 355-64.

<sup>7</sup> Ibid.

When the COVID-19 pandemic emerged, SO programming and resources were forced to move online, and it was unclear to what degree athletes would be able to maintain healthy habits, wellbeing, self-confidence, and social connectedness. This is a major concern, not only because of the previously noted health vulnerabilities and lack of alternative resources, but also because these deterrents were heightened by the COVID-19 pandemic. The pandemic led to the cancellation of vital SO in-person programming and created a situation wherein athletes needed more support than ever. This has raised numerous concerns. Indeed, studies have shown that individuals with ID have a higher susceptibility to COVID-19, and exhibit more serious symptoms and outcomes if they become ill.<sup>8</sup> Further, the loss of regular in-person events raised concerns for the wellbeing of athletes, who are often quite dependent upon routine. Generally, the heightened sense of uncertainty and need for adaptability caused by the pandemic led to significant challenges for mental health and wellbeing for individuals with ID.<sup>9</sup> Moreover, the lack of in-person contact with other athletes and coaches made it unclear whether athletes would continue exercising autonomy over their healthy choices at home.

This project was launched not only to assess whether athletes and their family's health needs were being met through online resources, but also to understand if the inclusive environment, self-advocacy health skills, and social connectedness fostered

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<sup>8</sup> Coleen Boyle et al., "The Public Health Response to the COVID-19 Pandemic for People with Disabilities." *Disability and Health Journal* 13, no. 3 (2020): 100943.

<sup>9</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., Coleen Boyle et al., "The Public Health Response to the COVID-19 Pandemic for People with Disabilities." *Disability and Health Journal* 13, no. 3 (2020): 100943.

by in-person events had effectively translated to an online platform. From qualitative and open-ended conversation with Special Olympics athletes and their families, it became clear that the online resources filled a necessary void during the pandemic. Though a certain magic of in-person events was lost, (e.g., the ability to be on the field with one's team) new value was found in the form of global social connectedness. This report presents the insights of SO athletes and their families into the loss of in-person programming during the COVID-19 pandemic. As well, it highlights the value of online resources to understand what athletes will require as they return to in-person play, and how in-person play can benefit from online resources.

Additionally, what emerged through this analysis was insight into SO athletes' autonomy over their health choices at home. While assessing the use of online health programming in the home, it became clear that household and familial dynamics can positively and negatively affect the ability of the athletes to exercise their autonomy, make healthy choices, and maintain wellbeing. When athletes are aligned with their families and friends on health issues, they are more motivated to exercise and prioritize wellbeing. This particular insight is relevant far beyond the context of the COVID-19 pandemic. The home is the place where one comes to eat, rest, grow, and seek shelter. As such, it should be a place where health, wellbeing, and social connectedness are prioritized, even after the pandemic. Therefore, beyond drawing insight into the return to in-person play, this report draws conclusions and recommendations on how SOI can support the ongoing healthy journeys of athletes at home.

## METHODOLOGY

This study was launched as an inclusive research project between SCSC Fellow, Adrianna Vanos, and Justin Hunsinger, a SO athlete, Health Messenger, and Health Engagement Coordinator. The inclusive research format has been carried out successfully in past SCSC research projects (e.g., 2020 fellow Olivia Najdovski's report on Intellectual Disability & Sibling Relationships).<sup>10</sup> Hunsinger's extensive knowledge on SO programs, resources, and operations lent itself to the research design and execution. His lived experiences meant that he was able to relate to the participants on an emotional level when discussing health and the loss of in-person programs. The value of Hunsinger's contribution is particularly evident in the research methodology and execution of this study.

Our experiences of health, wellbeing, and social connectedness are unique to us as individuals. This is especially true for individuals with ID who face barriers to health, wellbeing, and social connectedness. Several relevant studies examining the health and wellbeing of individuals with ID have adopted a quantitative survey-based approach. While these studies have mitigated geographical and scheduling restrictions, they may not account for lived experiences beyond their predetermined survey questions.<sup>11</sup> Further, it should be noted that the majority of these studies were conducted by

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<sup>10</sup> Olivia Najdovski. "Intellectual Disability & Sibling Relationships". Samuel Centre for Social Connectedness, 2020.

<sup>11</sup> Paul Willner et al., "Effect of the COVID-19 Pandemic on the Mental Health of Carers of People with Intellectual Disabilities." *Journal of Applied Research in Intellectual Disabilities* 33, no. 6 (2020): 1523-533. S Koritsas et al., "Weight, Nutrition, Food Choice, and Physical Activity in Adults with Intellectual Disability." *Journal of Intellectual Disability Research* 60, no. 4 (2016): 355-64.



neurotypical individuals who cannot account for the lived experiences of individuals with ID.

This raises questions about the integrity and authenticity of knowledge collected on individuals with ID. If we choose to create research designs through an able-minded and privileged perspective, we may fail to create research that holds meaning to the community it affects. The Disability and Health Journal emphasized this point. In their 2021 edition, they highlighted the need for empirical research – observation and interviews – that focuses on individuals with ID. They pointed out that there is a lack of reliable data that prioritizes the voices of individuals with ID, and stressed that to better understand areas of concern, such as health and wellbeing during the pandemic, this type of data is vital.<sup>12</sup>

To prioritize and respect the unique lived experience of athletes, this study adopted a qualitative interview-based methodology. While this study was limited to 10 participants, it ensured that the voices and experiences of these individuals were prioritized and not taken for granted. Hunsinger's involvement in the research design ensured that the primary questions we asked athletes were rooted in lived experiences. Beyond these initial questions, athletes had room to guide and sculpt the conversation. Their heartfelt reflections, stories, and insight came together to reveal an authentic image of their health experiences.

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<sup>12</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., Coleen Boyle et al., "The Public Health Response to the COVID-19 Pandemic for People with Disabilities." *Disability and Health Journal* 13, no. 3 (2020): 100943.

Moreover, from Hunsinger's lived experience and recent literature, we were armed with the knowledge that the health experiences of individuals with ID are intertwined with that of their family members. Family members, particularly parents, often take on the responsibility of a caregiver or support person, and are frequently incredibly involved in the daily routines and health decisions of individuals with ID. To truly capture a full image of the health experiences of SO athletes, it was essential that we understood the experience of the family members who have lived with the SO athlete during the COVID-19 pandemic.

To authentically capture the perspectives of athletes and their families, the interviews were divided into three sections: (i) athlete & family, (ii) athlete, and (iii) family. To overcome COVID-19 and geographical restrictions, interviews took place over Zoom. During these interviews, we asked athletes and their families questions about their experiences with online SO programming, the healthy choices made in their homes, and the return to in-person play. The first interview between athletes and their families allowed us to gain insight into the household's collective experiences with SO in-person and online programming, as well as household dynamics. Beyond this initial interview, hosting individual conversations with athletes and their family members allowed us to understand each person's subjective experiences, and specific roles and responsibilities within the home.

To ensure that all athletes were given an opportunity to express their voice, the study had very limited eligibility requirements. Beyond being a Special Olympics athlete and family member, each aged over 18 years, the only requirement was that the pair

had lived together for at least one month during the COVID-19 pandemic. Even though the interviews were open to any family member, it was unanimously the athlete's parents who participated. This could be reflective of the particularly involved role that parents play in athletes' lives.

The following findings and analysis are based on interviews from 10 participants: five Special Olympics athletes and five family members. To ensure that participants felt comfortable sharing their authentic, and often vulnerable, experiences, their identities are anonymized throughout this report. In the following analysis, the letter A is used to represent an athlete, and P is used for parent/guardian. The corresponding number, such as 'A1' or 'P1' is used to distinguish between the five athletes and parents. Athletes and parents with a corresponding number are matched within the same household. For instance, A1 and P1 are an athlete and parent from the same household.

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

### ***Defining Social Connectedness:***

Social connectedness resides at the forefront of this report to reflect its outstanding role in the stories, insights, and reflections of athletes and their parents. Traditionally, social connectedness is a term used to describe the feeling of belonging

and closeness within one's relationships.<sup>13</sup> While participants' interviews moved beyond social connectedness into the topics of health and wellbeing, underlying each of their interviews was a distinct link to social connectedness, highlighting its central role. Participants described social connectedness on the field, at home, and in anticipation of their return to in-person play. Social connectedness not only helped to shape motivation, focus, and use of online resources during the pandemic, but it also sculpted overall health experiences. To fully appreciate participants' insights into their health and wellbeing during the COVID-19 pandemic, it was essential to grasp their unique and nuanced definitions of social connectedness.

While each participant's understanding of social connectedness varied slightly, they were unanimously rooted in experiences of learning and growth. Participants described the value of social connectedness as the ability to share their voice and be heard and respected. Generally, these experiences were described in two ways: (i) in relation to the SO community, and (ii) through the SO community in relation to the greater community. In both settings, athletes and parents cited experiences wherein they faced social stigma and discrimination and did not feel included. They spoke of how meaningful the authentic social connectedness of SO was to them.

The athletes who discussed social connectedness in relation to the greater community beyond SO emphasized the pride they felt when they spoke on behalf of the

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<sup>13</sup> "What is Social Connectedness?" Greater Good Magazine, 2021, [https://greatergood.berkeley.edu/topic/social\\_connection/definition](https://greatergood.berkeley.edu/topic/social_connection/definition)

SO community. Participant A1 described how “as an athlete, social community means that we are actually out in the community... it enables the community to see us not just as individuals with ID, but as human beings.”<sup>14</sup> A1’s role as an athlete created opportunity for her to be seen beyond her disability, as an individual who is passionate about sports and health. When athletes discussed SO, they knew they were being listened to as knowledgeable representatives of a respected community they are passionate about. This sentiment was echoed by participant A2, who said: “I was talking to my hairdresser about Special Olympics, because she has an autistic boy... I could tell her that he could start at eight years old. So that was like, cool for me.”<sup>15</sup> For both A1 and A2, social connectedness presented a valuable opportunity to share knowledge, pride, and a sense of accomplishment with others.

The same experiences of pride and community advocacy translated into athletes’ understanding of social connectedness within the SO community. Athletes explained that the SO community held a special place in their lives, and that to be part of that community made them feel proud and accomplished. Participant A3 explained that her role within the SO community is “everything to her.” More than a group of friends, SO was a “collaborative family.”<sup>16</sup> For A3, holding membership in the SO community meant: “...listening to one another. And that's the whole piece of connection as to be accepted

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<sup>14</sup> Anonymous Zoom interview by the author, Toronto, ON, August 6<sup>th</sup>, 2021

<sup>15</sup> Anonymous Zoom interview by the author, Toronto, ON, August 8<sup>th</sup>, 2021

<sup>16</sup> Anonymous Zoom interview by the author, Toronto, ON, August 9<sup>th</sup>, 2021

and listened to, and not just listened to but also seen as human beings.”<sup>17</sup> Similar to athletes who described social connectedness in relation to the greater community, these athletes valued the opportunity to be seen as individuals. They gained confidence knowing they were accepted into a community of peers who viewed them as unique individuals, not just individuals with ID.

The social connectedness that accompanies being a SO athlete is an authentic opportunity to escape the prejudice and social stigma that individuals with ID often face. This sentiment was especially relevant for athletes who held leadership positions within SO. Four out of five athletes interviewed were certified Global Health Messengers. Global Health Messengers receive additional health training and responsibilities within the SO community. These athletes found pride in being viewed as capable leaders who were not limited by their disability. They felt a responsibility to foster and maintain social connectedness within the SO community and in relation to the greater community, where athletes always found a place to belong.

These thoughts were shared by the athletes’ parents. Parents unanimously found the value of social connectedness in the friendships and opportunities fostered by the SO community. Unlike some of the athletes, who found pride in relation to the greater community beyond SO, parents related social connectedness exclusively to SO programming. This response could be explained by parents’ longstanding struggle to

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<sup>17</sup> Anonymous Zoom interview by the author, Toronto, ON, August 9<sup>th</sup>, 2021

find programming to meet their child's needs. Not only does SO programming fit into their lives, but it provided opportunities for growth and leadership that their children might otherwise not have experienced or enjoyed. P3 explained: "The benefits of social connectedness are having programs that actually foster that and create opportunities within the Down syndrome community."<sup>18</sup> On a similar note, P1 said: "We are social creatures that were designed to be connected, no matter your disability, your ability, or difference. The social connectedness that people don't experience is crucial. It can be crippling, and it can be devastating for isolated people across the globe with ID and other things."<sup>19</sup> These parents shared a collective sense of relief and enthusiasm that their children were included in the SO social community.

### ***Social Connectedness & Motivation:***

Athlete and parent definitions of social connectedness revealed how they placed value on SO programming. Beyond health programs and resources, SO is a lifestyle that provides opportunity for all-encompassing personal growth and connectedness. In addition to these initial reflections, athlete and parent definitions revealed what motivated their dedication to healthy lifestyles, each other, and the greater SO community. Specifically, the importance of social connectedness was increasingly relevant during athlete discussions of health and wellbeing at home. Athletes' motivation

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<sup>18</sup> Anonymous Zoom interview by the author, Toronto, ON, August 9<sup>th</sup>, 2021

<sup>19</sup> Anonymous Zoom interview by the author, Toronto, ON, August 6<sup>th</sup>, 2021

to exercise, make healthy choices, and maintain wellbeing was directly related to their perspective on social connectedness. To fully understand both athlete and family health and wellbeing during the COVID-19 pandemic, we begin with an analysis of athletes' personal motivations. Subsequently, we move into an analysis of athletes' household dynamics and their use of online resources.

Four out of five athletes described feelings of heightened anxiety, sadness, and boredom due to the loss of in-person activities, and an exaggerated need for adaptability due to the COVID-19 pandemic. The athlete who did not experience these feelings was able to participate in in-person practices and programming within her community. The four athletes who lost in-person programming expressed that their motivation and excitement for health and wellbeing was negatively affected by this loss.

For example, participant A5 described how he dealt with feelings of anxiety and distress throughout the pandemic. The loss of routine and schedule that accompanied his SO in-person activities (e.g., team practices and competition) led to unpredictability and a decreased sense of control. Specifically, he found both the idea and act of leaving the house to be an especially difficult part of his day. His parent reported: "You don't know when [in-person] will come back or what, and that makes [him] nervous."<sup>20</sup>

These thoughts were shared by the three other participants who lost out on the majority of their in-person events. Participants A1 and A4 echoed the negative

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<sup>20</sup> Anonymous Zoom interview by the author, Toronto, ON, August 13<sup>th</sup>, 2021



implications associated with the pandemic's unpredictability described by A5. Further, they stressed that the inability to see friends and extended family was a barrier to their motivation and health during the pandemic. Without the social motivation or the promise of in-person events, their feelings of anxiety and stress made it difficult to exercise, make healthy choices, and maintain wellbeing. Likewise, A2 described a sense of boredom that overcame her life and made it difficult to find interest in remote events or her normal health routine.

These thoughts were reflective of recent literature and were an anticipated consequence of the loss of in-person play.<sup>21</sup> However, aside from the initial barriers to motivation, athlete reflections spoke to the importance and power of social connectedness. The athletes' pride and dedication to their social community motivated them to continue working toward their health goals despite unexpected challenges. While A5 encountered heightened anxiety, his passion and pride in being a part of the SO community restored his initial motivation and allowed him to persevere. He noted that the thought of a return to in-person practice and competition pushed him to stay on top of his health and fitness goals, which eventually led to a decrease in anxiety. A5 wanted to be ready and confident to join his peers when able. This may be attributed to the increase in self-confidence that accompanies in-person competition and the ability

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<sup>21</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., Coleen Boyle et al., "The Public Health Response to the COVID-19 Pandemic for People with Disabilities." *Disability and Health Journal* 13, no. 3 (2020): 100943.

to present improvement and new skills. Even so, these feelings are contextualized within the love and appreciation of the positive atmosphere created by SO programming and events.

Social connectedness as a fuel for motivation was especially relevant for the four athletes who held leadership responsibilities as Health Messengers. These athletes discussed a responsibility to the greater SO community that allowed them to persevere despite barriers created by the COVID-19 pandemic. That is, these athletes were able to overcome personal barriers because of their determination and desire to serve as positive role-models to the SO community. For example, participant A2 described how she found the motivation to interact with virtual challenges when she thought about the athletes in her community who needed assistance or role models. A2 sought out and participated in online physical, nutrition, and wellbeing challenges. She then shared photos and advice to her fellow athletes to prove that despite COVID-19 barriers and loss of in-person programming, it was possible to stay healthy at home. She explained: “I used my role and responsibility as a Health Messenger to do videos and teach the other athletes’ different things to see about what I can do and motivate them, while at the same time, motivating myself.” A2 went on to explain the way this sense of responsibility positively impacted her own health journey: “I’m not the type of person

that doesn't like to exercise or do anything by myself.”<sup>22</sup> By reaching out to friends and family to help work out, she fulfilled her sense of duty and mitigated personal barriers.

Likewise, participant A1 explained that her position as a Health Messenger motivated her to stay active and assist the greater SO community. In addition to participating in programming, she explained that her responsibility to the community prompted her to learn about the unique health barriers facing individuals with ID. A1 felt compelled to share this knowledge with her fellow athletes so that everyone could stay informed and understand the importance of health, especially during the COVID-19 pandemic. She explained: “I became more aware of the horrific health statistics that individuals with ID face without proper health care... and I was really like, well, what can we do to change this?”<sup>23</sup> Being equipped with this knowledge motivated A1 to be a strong self and community-advocate. This was especially relevant during the COVID-19 pandemic as A1 witnessed first-hand the barriers that her peers faced. She used her knowledge and motivation to take on additional leadership activities that provided localized resources to her community.<sup>24</sup>

While the athletes who participated in this study had the resources and sense of responsibility to overcome barriers presented by the COVID-19 pandemic, this may not be representative of all athletes' experiences. Unaccounted for in this study are the athletes who have not been able to find motivation or did not have the resources to

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<sup>22</sup> Anonymous Zoom interview by the author, Toronto, ON, August 8<sup>th</sup>, 2021

<sup>23</sup> Anonymous Zoom interview by the author, Toronto, ON, August 6<sup>th</sup>, 2021

<sup>24</sup> Anonymous Zoom interview by the author, Toronto, ON, August 6<sup>th</sup>, 2021

attend online programming or remote interviews. Even though this left a considerable gap in the research, we know some elements of their perspective through parent interviews, many of whom held leadership positions in the SO community as a coach or volunteer. These parents noted that many athletes have “fallen under the radar” because they do not have leadership positions or resources that can motivate them to overcome the barriers created by the COVID-19 pandemic. Parents noted that many athletes had nothing holding them accountable to maintaining their health and wellbeing. Therefore, even if they found motivation, they may not have had the extra push that the interviewed athletes had. For example, P5, who was a coach and volunteer for several years, noted that “there are athletes who are slipping a little bit because of COVID they don't have that, you know, weekly, biweekly, you know, daily contact with their peers, with their group and with their coaches,”<sup>25</sup> that would allow them to stay motivated.

### ***Social Connectedness, Health, & Wellbeing at Home:***

To fully capture the athletes’ experiences of health and wellbeing at home, and subsequently assess their use of online resources, it is important to understand their personal motivations, and the conditions under which their healthy choices were carried out. During the loss of in-person play, athletes lost the traditional structure and accountability that nurtured their motivation and pushed them to succeed. This environment was replaced with isolation at home. While some athletes were used to

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<sup>25</sup> Anonymous Zoom interview by the author, Toronto, ON, August 13<sup>th</sup>, 2021

working-out and making healthy choices at home, the extent to which they were there without in-person contact was a universally new experience.

In addition to impacting motivation, social connectedness determined the extent to which an athlete was able to act on their motivation and exercise healthy choices at home. More specifically, social connectedness between parents and athletes played an important role in boosting athlete motivation. This chapter explores the important role that home life played in athletes' ability to carry out healthy choices and maintain health and wellbeing at home during the COVID-19 pandemic.

While athletes who participated in this study were able to overcome barriers posed by the COVID-19 pandemic by maintaining their motivation, this did not account for their ability to carry out healthy choices at home. Many athletes — and all athletes interviewed — depended upon parents for support when carrying out healthy choices. No matter the level of support needed, this need grew during the COVID-19 lockdowns. Without in-person contact with coaches and mentors, athletes' motivation to be healthy and maintain their wellbeing depended upon the support of family members and friends.

However, while familial support was required most during the COVID-19 pandemic, recent literature revealed that social isolation and stressors brought on by the pandemic also negatively affected the mental health and wellbeing of parents. The two main stressors that contributed to parent's negative experiences of health and wellbeing during the pandemic were reported as: (i) less available social, financial, and

health resources for families that include an individual with ID,<sup>26</sup> and (ii) a general lack of consideration from global public health authorities for the position of individuals with ID during the pandemic.<sup>27</sup>

In general, this led to a rise in reported feelings of defeat, depression, and anxiety as parents struggled to find much-needed supports. Further, recent literature found that parents were isolated from supports they would normally use to ground them in situations of crisis. This created a situation wherein parents were struggling and generally unable to recreate lost in-person programming within the home. Parents were preoccupied with finding resources and staying afloat. These findings were reflected in four parent interviews. Parents described feelings of burnout and anxiety from the added stress of the COVID-19 pandemic. For these parents, the pandemic re-wrote the 'norm' of working out at home and required them to make major adjustments to their routines. Without in-person programs and alternative resources, parents were left to assume the role of coach and mentor.

For example, participant P5 noted, "burnout, completely, completely... I must say I'm sort of lost. We are like a tanker and we're out on the open seas, constantly driven with like, the next exhibition, the next regionals, the next provincials, the whole thing. And the whole system has come to a complete halt."<sup>28</sup> This analogy was used not only

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<sup>26</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., S Koritsas et al., "Weight, Nutrition, Food Choice, and Physical Activity in Adults with Intellectual Disability." *Journal of Intellectual Disability Research* 60, no. 4 (2016): 355-64.

<sup>27</sup> Paul Willner et al., "Effect of the COVID-19 Pandemic on the Mental Health of Carers of People with Intellectual Disabilities." *Journal of Applied Research in Intellectual Disabilities* 33, no. 6 (2020): 1523-533.

<sup>28</sup> Anonymous Zoom interview by the author, Toronto, ON, August 13<sup>th</sup>, 2021

to discuss their motivation as a parent and coach, but also the dynamic between them and the athlete in their home. P5 continued: “[A5] has anxiety leaving the house anyway. So, to have got out of the rhythm of leaving the house is going to be huge. And I certainly have suffered from this.”<sup>29</sup> When it came to health, the relationship between A5 and P5 was altered by the COVID-19 pandemic. A reduction in services and non-SO programming made the transition especially difficult to navigate. P5 noted that: “It has definitely affected our family. We lost respite because there were no in-house visits. So, it has put a lot of strain back on the family.”<sup>30</sup>

However, despite these challenges, athletes and parents reported that they were able to connect on issues of health in the home because they had set up lines of communication and support before the pandemic. This meant that even though in-person activities were lost, and parents were experiencing their own barriers to health and wellbeing, athletes were able to practice self-determination and carry out healthy choices. This was in line with recent literature, which highlighted a strong correlation between an individual with ID’s self-determination surrounding healthy choices, and their home dynamic.<sup>31</sup> These studies found that when individuals with ID were involved in the process of making healthy choices at home, they were able to foster long-term self-determination over their healthy choices.<sup>32</sup> In this study, athletes

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<sup>29</sup> Anonymous Zoom interview by the author, Toronto, ON, August 13<sup>th</sup>, 2021

<sup>30</sup> Anonymous Zoom interview by the author, Toronto, ON, August 13<sup>th</sup>, 2021

<sup>31</sup> Simone A Onrust, et al., "Family Group Conferences within the Integrated Care System for Young People with ID: A Controlled Study of Effects and Costs." *BMC Health Services Research* 15, no. 1 (2015): 392.

<sup>32</sup> Paul Willner et al., "Effect of the COVID-19 Pandemic on the Mental Health of Carers of People with Intellectual Disabilities." *Journal of Applied Research in Intellectual Disabilities* 33, no. 6 (2020): 1523-533. S Koritsas et al., "Weight, Nutrition, Food Choice, and Physical Activity in Adults with Intellectual Disability." *Journal of Intellectual Disability Research* 60, no. 4 (2016): 355-64.

who came from supportive households were able to develop a passion, enthusiasm, and accountability for their health and wellbeing that pushed them to follow through on their healthy motivations during the pandemic.

Even though P5 and A5 experienced stress and personal burdens during the pandemic, their social connectedness within the home helped them come together and ensured that A5 could carry out his healthy choices. P5 described how she started Special Olympics with her athlete and have since become more involved as a family. Even though they lost out on resources and alternative care during the pandemic, staying connected in the home allowed them to persevere. A5 was provided with an environment where he was equipped with the tools to make health decisions, and the pride, accountability, and passion to self-motivate and execute his choices. P5 noted that A5: “became vegan about 18 months ago and is now vegan vegetarian. He does all his own cooking. He reads all the labels of everything that he buys. He's very creative and full of vegetables. He's very aware of the health of the world. No plastic, when we go shopping, he takes a cardboard box.”<sup>33</sup> A5's passion for health and wellbeing inspired his entire family to make healthier nutritional and physical exercise choices.

The same experience occurred for P4 and A4. When asked if increased mental health problems influenced their health dynamic in the home, P4 noted that despite the challenges caused by the pandemic: “not really, because we've always had health and healthy behaviors as a habit. So, you know, in terms of food and nutrition and exercise, even at the height of the pandemic we were, you know, doing exercise videos together

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<sup>33</sup> Anonymous Zoom interview by the author, Toronto, ON, August 13<sup>th</sup>, 2021



because it's just a habit that we've instilled with us.”<sup>34</sup> Even though the pandemic created a situation where she felt health and wellbeing were difficult, she was able to stay socially connected with family members in the home and work alongside her athlete to overcome barriers and challenges because they had a solid and established line of communication and support. In addition, the positive health dynamic in A4’s home provided him with an environment where he was able to develop passion, enthusiasm, and accountability for his health and wellbeing. A4 described how he would print off a weekly list of resources and materials to stay on top of his health and ensure he had an action plan for carrying out his motivations. Not only did this plan help him regain a sense of normalcy over his routine, but it also motivated his family to join him and be accountable for their health.

Similarly, A3 and P3 worked together to prioritize mental health and wellbeing throughout the pandemic. A3 and P3 described how their home dynamic was characterized by connection surrounding health and wellbeing before the COVID-19 pandemic. P3 noted that “[we] are very involved in [A3’s] activities... Special Olympics. It's sort of a second family for all of us. spend a lot of time working with [A3] there.”<sup>35</sup>

During the pandemic, A3 took on the responsibility of creating a ‘mental health weekend’ in which the whole family could partake. A3 was provided with an environment where she felt supported at home and was able to foster passion and self-motivation for executing healthy decisions. She explained: “So I have started a mental health weekend. And I do like a lot of different activities that make me feel more

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<sup>34</sup> Anonymous Zoom interview by the author, Toronto, ON, August 11<sup>th</sup>, 2021

<sup>35</sup> Anonymous Zoom interview by the author, Toronto, ON, August 13<sup>th</sup>, 2021

relaxed. And I just like, you know, finding peace, and I'm very insightful, as well. I can also be your Wikipedia if you want me to.”<sup>36</sup>

As was revealed in the previous sections, the athletes who signed up for interviews were, in general, highly motivated leaders in the SO community. This left the aforementioned gap in the research population, which was subsidized by parent's second-hand testimony. This gap was also evident in relation to athlete home life but will continue to be mitigated by parent interviews. For many athletes, a dynamic and involved home life may not have been possible. Many athletes did not have the resources to stay active and healthy. P5 noted: “we are also dealing with a low-income community... and a lot of our athletes are probably in a lower socioeconomic, less educated community, not all, but many of them. So therefore, their choices are obviously less educated.”<sup>37</sup> These individuals may not have had the same access to resources, or parents who were able to cultivate social connectedness within the home. P5 continued: “As a coach, you know, I'm fully aware of supportive families and non-supportive families. And I certainly noticed that supportive families, the athletes do things, they do go for them... and [non-supportive families], that's where I see, you know, the athletes who are slipping a little bit because of COVID.”<sup>38</sup>

This was echoed by P4 and P1, both of whom took on leadership responsibilities for athletes whose parents were not able to be as involved at home, due to the demands of work or personal struggles. P4 observed that while these athletes were potentially motivated, they did not have the environment or support to fully carry out

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<sup>36</sup> Anonymous Zoom interview by the author, Toronto, ON, August 6<sup>th</sup>, 2021

<sup>37</sup> Anonymous Zoom interview by the author, Toronto, ON, August 13<sup>th</sup>, 2021

<sup>38</sup> Anonymous Zoom interview by the author, Toronto, ON, August 13<sup>th</sup>, 2021

their ambitions. P4 explained: “[these athletes] don’t have us pushing him to say you could go a bit faster, just get a bit out of breath on that hill, just you know.”<sup>39</sup> The same thought was shared by P1, in discussing athletes who do not have family or friends around them. P1 said: “We know people whose programs were taken away. Special Olympics was the only thing ... and I kid you not.”<sup>40</sup> Without support, accountability, and place to work out these athletes were lost.

### ***Online Resources:***

As is clear from the previous two chapters, athletes and their families' faced barriers to their health and wellbeing throughout the COVID-19 pandemic. While they were able to overcome these barriers by fostering social connectedness in their community and at home, they were still dependent upon online resources to stay healthy and to maintain their connection to the SO community. Their insights into these resources reflected their definitions of social connectedness and home life. While these insights were based upon their individual experiences, they provided valuable insight into the general difficulties and successes of online programming.

Primarily, athletes and their families expressed gratitude to SO for pivoting its programming to an online format so quickly after the closure of in-person events. Participants noted that there was an abundance of virtual SO resources that began very quickly and have remained throughout the pandemic. Generally, these resources fit into three categories: physical health, mental wellbeing, and social connectedness. While

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<sup>39</sup> Anonymous Zoom interview by the author, Toronto, ON, August 11<sup>th</sup>, 2021

<sup>40</sup> Anonymous Zoom interview by the author, Toronto, ON, August 6<sup>th</sup>, 2021

athletes focused more on the physical and social connectedness resources, they noted that the mental health programming provide them with new skills and a break from their daily stress. Overall, athletes and their parents had no specific feedback on the content of online resources. Instead, they were focused on the short and long-term benefits that the programming had on their lives.

The first overall benefit gained from online programming was flexibility and availability. Since activities were being conducted remotely and around the world, they were ongoing at all times of the day. Athletes and their families reported a sense of relief that resources were available to them at all hours. These resources could fit into anyone's schedule, and in whatever capacity they wanted. The consistent availability of these resources in the home meant that family members could schedule time with their athletes and attend events together. This allowed athletes and their families to either begin or continue to build social connectedness within the home. Parents P2, P4, P3, and P5 were happy to take advantage of online resources and connect with their athletes.

Moreover, since athletes and their families participated in these resources together, they found that they were more open to conversations about health and wellbeing. For example, P2 remarked that the regional nutritional programming and cooking shows had benefited her whole family because they were engaging in a health-related topic together. She explained "[A2] was experimenting, some new recipes, quick recipes with us as a family, and some are good."<sup>41</sup> Therefore, in addition

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<sup>41</sup> Anonymous Zoom interview by the author, Toronto, ON, August 8<sup>th</sup>, 2021

to providing immediate access to programming, the online format had the long-term benefit of fostering social connectedness within the home.

While online resources could not re-create the “magic” of being on the field with one’s team, they prioritized and fostered a new kind of social community. Athletes and their families found the opportunity to connect with individuals all around the world to be a major benefit of online programming. A1 remarked that initially, she thought “Well, it wasn’t the same ... it enabled many of us to still stay connected... it may not be the same as actually talking to you face to face, but it is better than nothing.”<sup>42</sup> However, after getting an opportunity to connect with individuals around the world, she became committed to her online community. She explained, “I would think okay, this time we’re going to go to that dance party that’s happening in Illinois. This time we’re going to go to that dance party that’s happening in Maryland.” This sentiment was echoed by P4 who explained: “We get to meet somebody, an athlete, all the way across the country.”<sup>43</sup> The global community became the highlight of the online resources for many athletes.

Further, the online community was the reason that many athletes maintained interest and involvement in official SO programming. P1 explained that “you know, if you could draw a picture, you would see that life preserver around with this line, you know, to the virtual dance party that became a very big ... they can see all their friends.”<sup>44</sup> In this analogy, not only were athletes being kept afloat by online resources, but they were also being saved from the pandemic. The online social community created a refuge from the stress, worry, and the burden of the pandemic that allowed

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<sup>42</sup> Anonymous Zoom interview by the author, Toronto, ON, August 6<sup>th</sup>, 2021

<sup>43</sup> Anonymous Zoom interview by the author, Toronto, ON, August 13<sup>th</sup>, 2021

<sup>44</sup> Anonymous Zoom interview by the author, Toronto, ON, August 6<sup>th</sup>, 2021

athletes to reconnect with a cherished part of SO programming -- connecting with friends.

However, even though online resources benefited many athletes and families, it is important to note that they were not universally accessible. Parents noted that there was clear digital divide that left many athletes behind. This divide referred to a lack of accessibility to the internet, a computer, or a lack of knowledge about online programming. P1 explained: "Athletes' family members don't know how to [get online]. And you couldn't go to their house at home and say, look, it's just this simple, you know, click the Zoom link. So, out of a team of say, 70, towards the end we had like half of the people on our Zoom calls."<sup>45</sup> The COVID-19 pandemic created the need for online resources, but it also built the barriers that prevented so many athletes from accessing these programs. P1 continued: "I see that the digital divide has been like an ark. Right? Those of us that are on the ark, are moving forward. And those of us that don't know how to be on the ark, are not." While a lack of motivation or difficult home life may have played a role in creating the digital divide, the concern around accessibility and knowledge was particularly alarming. It was no longer a matter of whether athletes would like to access resources, but a concern that athletes were being helplessly left behind without any available support.

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<sup>45</sup> Anonymous Zoom interview by the author, Toronto, ON, August 6<sup>th</sup>, 2021

## **RECOMMENDATIONS**

### **1.) *Future Research***

As has become evident throughout this report, the main limitation of this study is that the athletes who were unable to access the internet and online resources during the COVID-19 pandemic were unaccounted for. As this study used the internet for recruitment, interviews, and communication, these individuals were unintentionally excluded from the entire research process. At the same time, these are the athletes most in need of additional focus and resources, having undergone an extended period without participating in the SO community. While we can review the second-hand testimony of participants to get a rough idea of these athlete's experiences, we will never truly understand their narrative, or have access to their insights until we interview them directly. Although this population is currently difficult to get in contact with, it is recommended that SOI conduct a research study that has the necessary resources and timeline to interview and understand the needs of these athletes.

### **2.) *The Return to In-Person Play***

A pivotal part of the return to in-person play will be facilitated by coaches and volunteers. However, as is clear from parent's testimony, many of whom are coaches and volunteers, these individuals are dealing with burnout, stress, and burdens caused by the COVID-19 pandemic. To ensure there is a smooth return to in-person play, it is recommended that these individuals are provided mental health training and resources that they can apply to their personal situations and share with athletes.

### **3.) *Social Connectedness at Home***

This report has shown the importance of staying connected to health and wellbeing within the home. However, it has also been revealed that due to socioeconomic and accessibility issues, many families did not have the capacity to maintain their health and wellbeing together within the home environment. To mitigate this issue, the parents who were interviewed used their privilege to assist families in need by providing resources, support, and care. These parents demonstrate the valuable possibility of not only fostering connectedness at home, but also within the greater SO community. SOI should consider creating a support network that matches community leaders and parents to families who need assistance accessing resources and supporting health in the home. This type of support may reduce the stress of families in need and ensure that no athlete is left behind. This online platform could have channels for athletes and parents to discuss their problems, find solutions, and work together to create a community where everyone has the resources they need to succeed.

#### **4.) *Online Resources***

While online programmes have not been able to account for certain aspects of in-person play, like being together with a team, they created new benefits that can assist athletes and their families beyond the context of the COVID-19 pandemic. When SOI transitions back into in-person programming, it is recommended that it maintains asynchronous online events that can be adapted to each family's schedules and needs. Further, we recommend that SOI maintain international Zoom social events so athletes can continue to partake in a global online community.

#### **5.) *Create Opportunities for Self Determination***



The report has shown that athletes with leadership positions have increased motivation and responsibility over their health. While all athletes may not have the desire or capacity to take on a leadership position, providing optional Health Messenger training might help athletes boost their motivation. It is recommended that SOI consider hosting training sessions on responsibility and social connectedness without any need for athletes to commit to a leadership position.

## **IMPACT**

This project was launched as an inclusive research project that included and prioritized the perspective of SO athlete and Health Messenger, Justin Hunsinger, throughout the research process and creation of the final report. In return for sharing his perspectives and insight, Hunsinger gained valuable knowledge and experience in creating and implementing a research plan. Inclusive research creates projects that are rooted in lived experience and which allow for comprehensive recruitment, interview questions, and analysis. Hunsinger's insight into this project allowed us to impact the individuals we interviewed by asking meaningful and self-reflective questions. Further, it allowed us to gain insight and formulate recommendations that can be directly applied to the experiences of individuals with ID. SOI will be able to use this data to create programming that positively affects SO athlete experiences of health, wellbeing, and social connectedness on the field and at home. Further, SCSC and SO can use the positive results of this inclusive research project to fund and justify future projects that adopt a similar inclusive format.

## CONCLUSION

As a vital health resource to individuals with ID, the loss of in-person SO programming due to the COVID-19 pandemic was felt throughout the Special Olympics community. In response to this loss, SO launched a series of online resources for athletes and their families. This study used qualitative research methods to understand how athletes and their families used online resources and maintained their health, wellbeing, and social connectedness. Further, alongside this analysis, the study provided insight into the way that household dynamics positively and negatively influence the health journey of athletes. By drawing conclusions on the needs of athletes and their families in the home, and during the return to in-person play, this report may benefit the lives of SO athletes. Finally, this study has identified a major gap in the research population, as athletes without access to a computer or internet may be most in need of added support but are difficult to recruit for interviews. This insight can help to inform future SO studies so that all athletes can be equipped with the tools they need.

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