Healthy Communities Evaluation: Executive Summary of Results

I. Background

The turn of the 21st century marked a new era in the understanding of disability. The United Nations created an international treaty on the rights of persons with disabilities; at the same time, the World Health Organization shifted the definition of disability from one of a medical issue or a deficit within individuals, to a social model that perceives disability as the interaction between a given impairment with social, cultural and environmental influences. These social and environmental factors are not only determinants of disability, but are also critical determinants of health and quality of life for all individuals. Studies demonstrate that individuals with disabilities often experience a variety of risk factors for poorer health, including: poverty, unemployment, and lack of education; social exclusion and isolation; barriers to health communication and literacy; poor access to and quality of healthcare; and lifestyle challenges such as poor diet and exercise[1-7].

As a result of these social determinants, individuals with disabilities face significant disparities in respiratory disease, cardiac and cardiovascular disease, diabetes, dementia, epilepsy, osteoporosis and many other health issues[1,3-6,8-10]. Moreover, people with disabilities are less likely to have access to preventive health screenings and health promotion, which contributes to disparities in hearing, vision, and oral health issues, mental health issues, obesity, and cancer. While research finds these patterns consistently in developed countries, additional health issues arise in low income countries, such as malnutrition, infectious diseases, and illnesses due to poor water and sanitation.

One of the most substantial contributors to these health problems are inequities in the availability and quality of healthcare[5,7,8,11]. Healthcare systems vary tremendously throughout the world, but one of the most common barriers to health for individuals with disabilities is the inadequate education and training of healthcare providers to work with people with disabilities. Without the necessary knowledge and skills to treat people with disabilities, healthcare experiences are often marked by communication difficulties, accessibility issues, misdiagnosis of health conditions, and discrimination or stigmatization. Another barrier to achieving health is the cost of care, which depends not only upon the services rendered, but also on the healthcare infrastructure of a given country.

Recognizing these health disparities among people with intellectual disabilities (ID) and the need for services to ameliorate them, Special Olympics International (SOI) launched the Healthy Athletes program in 1997, which provides free screenings in vision, hearing, oral health, podiatry, physical therapy, and health promotion (body mass index, bone density, and blood pressure), and recently, a pilot screening on education in stress management techniques. Additionally, these screenings provide education to both individuals with ID and the volunteer healthcare professionals who conduct them. The Healthy Athletes program has been enormously successful at identifying health issues and training providers, but Special Olympics realized that additional measures needed to be taken in order to ensure that Special Olympics athletes received proper treatment and follow-up care for these health issues. Hence, with the support of the Golisano Foundation, Special Olympics started the Healthy Communities initiative in 2012. Healthy Communities aims to bring about improved health and healthier lifestyles for persons with intellectual disabilities.

There were four pillars that guided the development of the Healthy Communities initiative. These strategic approaches were to:

1. Infuse expanded health services, including ones focused on diseases of extreme poverty, into all Special Olympics' worldwide, year round events & programming.
2. Create local Healthy Community networks for health providers engaged in Special Olympics' health work & committed to providing ongoing health resources & services to people with ID & their families outside of Special Olympics.
3. Develop world class bio-informatics capability to monitor longitudinal health outcomes for people with ID to measure progress, inform public policy leaders, and demand health justice worldwide.
4. Create global Healthy Communities coalition of leading businesses, NGOs & governments that support Special Olympics' health work & increase access to health resources & services through macro-level action.

Fourteen country or state Special Olympics Programs served as pilot sites for Healthy Communities: Arizona, Kansas, Florida, New Jersey, New York, Wisconsin, Mexico, Peru, Malaysia, Thailand, South Africa, Malawi, Kazakhstan, and Romania. Healthy Community pilot Programs reported to SOI on their activities from 2012 to 2015. A sample of results from the activities of pilot Programs includes:

- Conducted 88,785 Healthy Athletes screening exams in 697 clinics
- Provided training in health education to 20,213 athletes, 669 who were trained as peer health educators
- Trained 15,130 healthcare professionals and students to work with patients with ID, and received commitments from 46 universities to change curriculum for healthcare professionals
- Referred 10,487 athletes for follow-up care
- Engaged 248 local partners which generated $30,000,472.52 in cash and value-in-kind

These findings suggest that the Healthy Communities pilot Programs were successful in improving access to healthcare for persons with ID, training local health advocates and leaders, and enabling inclusive environments. However, SOI wanted to know more about how this change was achieved, in order to identify the successes and challenges of implementing Healthy Communities programming in a variety of real-world settings. Hence, SOI commissioned the University of Cape Town (UCT) to conduct a qualitative evaluation of Healthy Communities. The evaluation was steered by principal investigators Professor Theresa Lorenzo and Honorary Professor Roy McConkey (Ulster University) with the support of the evaluation team based at Disability Studies, UCT. The lessons from this evaluation will enable SOI to create evidence-based recommendations around efficacy and effectiveness as the Healthy Communities initiative is expanded to other SO Programs. This executive summary, based on a report from the UCT, reviews the results of this qualitative study on the impact of Healthy Communities. For the full report, please click here.

II. Methodology of Qualitative Evaluation

Seven of the 14 pilot Programs participated in the qualitative evaluation; the participating sites were Florida, New York, Wisconsin, Peru, Malawi, Thailand and Romania. UCT staff shared expectations for participation with all 14 sites, and SO Programs then nominated themselves for participation in the evaluation. The final sample was selected to be a cross-cultural representation of the Healthy Communities pilot Programs. Further, UCT collaborated with universities and ministries from each pilot Program, termed local evaluation partners (LEP). The table below details these partnerships by SO pilot Program.

Special Olympics Program	Local Evaluation Partner
Florida	Florida International University
Peru	CRONICAS Center of Excellence in Chronic Diseases
Romania	Bucharest University of Physical Education and Sports
Malawi	Ministry of Gender, Children, Disability and Social Welfare
Wisconsin	University of Wisconsin-Madison
New York	University of Rochester
Thailand	Healthy Community Asian Institute of Technology (AIT)

Information was gathered using a combination of interviews and focus groups, with open-ended questions. Interviews and focus groups were conducted with SO athletes, family members, community and health volunteers, and Healthy Communities staff. Participating sites transcribed interviews verbatim, and UCT then analyzed the data to identify specific categories, patterns, and the emerging higher-level themes.

Before participation, each individual provided informed consent. To obtain informed consent from people with ID, UCT and local evaluation partners created an easy-read, visual consent form and read this form aloud to each potential participant. The Institutional Review Board of SOI provided approval to conduct the evaluation across all sites. In addition, approval for local data collection was obtained from Human Research ethics committees at the University of Cape Town, as well as in Malawi, New York, and Wisconsin.

When possible, co-evaluators with ID were recruited, trained and supported to work alongside the LEPs. Malawi, Wisconsin, and Thailand used local athletes for data collection. Co-evaluators acknowledged that they felt very strongly about being included in this evaluation, as essentially research about them should not be done without them.

III. Results

The evaluation demonstrated three core themes that reflected the successful strategies Healthy Communities pilot Programs utilized to improve access to healthcare for people with ID, train advocates, and enable healthier environments:

1. Improving access to health promotion, healthcare and treatments
2. Creating and mobilizing community partnerships
3. Effectiveness and sustainability of Healthy Communities activities

This summary will provide examples of each of these core themes, and how these activities translated into success for pilot Programs.

1. Improving access to health promotion, healthcare and treatments

Pilot Programs detailed several elements used to improve access to health and healthcare, such as creating supportive environments, reorienting health services, and fostering the development of personal skills. Examples of activities focused on creating supportive environments include:

- Changing attitudes and perceptions
- Athlete leadership and advocacy in health promotion
- Building relationships and friendships for athletes

Many interviews highlighted the importance of supportive environments for people with ID. In Malawi, a staff member described how Healthy Communities built relationships within families:

> "*We have strengthened the bond between parents and their children with intellectual disabilities. Parents are able to understand their children with ID, which was difficult before we had the expertise to counsel them."*

The reorientation of health services was also critical to improving access. Examples of activities centered on the reorientation of health services include:

- Engaging with healthcare providers, both professionals and students
- Facilitating education and training around health and ID
- Enabling health promotion and prevention
- Creating networks for referral and follow-up care
- Partnering with universities to change curricula for health professionals

Through these activities, Healthy Communities pilot Programs were able to reorient health services via improved provider knowledge, attitudes, and interactions with patients with ID. A community member in Romania summarized the reorientation of health services as follows:

> *"FMR[1] contributed in this partnership through integration of Healthy Communities program in our joint project of this year, so now the young people with intellectual disabilities from poor and isolated areas can receive health evaluations and recommendations to improve their health condition."*

[1] FMR is the Motivation Romania Foundation, which provides programs that focus on social, educational and professional inclusion through consultancy for accessibility, by facilitating employment of people with disabilities, through day center services or leisure activities such as adapted sports or cultural events.

The final strategy utilized by pilot Programs to improve access to health and healthcare was the development of personal skills. Examples of activities that enabled development of personal skills include:

- Training athletes, families, and coaches on healthy eating, physical activity, and oral health
- Training athletes to be peer health educators for other people with ID

These activities served to both improve self-confidence and enhance well-being. An athlete from New York praised the benefits they experienced from participating in Healthy Communities:

> *"…So when we first started this, coach said your goal is 10,000 steps a day, so …I'm like, oh my god I've got to go for a walk at night…we came back the next Thursday and you know she's recording all our data, …he had like 35,000, like every single day."*

Likewise, in Peru, a parent described the skills their child gained from educational materials made by Healthy Communities:

> "*Now, with the introduction of a health program the kids learn… we made a booklet showing them how to brush their teeth. My son has this booklet in our bathroom and he follows each step to brush his teeth."*

2. Creation and mobilization of community partnerships

In order to create and mobilize community partnerships, pilot Programs relied on collaborative planning, fostering action among local community leaders, and building capacity within the community. Examples of activities used to generate collaborative planning include:

- Identifying potential partners
- Engaging partners at the beginning of the project and throughout the planning stages
- Lobbying and advocacy at the level of the individual and the group or organization
- Cross-sector involvement from both informal sources (e.g., parent group) and formal sources (e.g., transportation services)

For example, Special Olympics Thailand engaged UNICEF as a partner and collaboratively planned their project with UNICEF:

> *"UNICEF is now working on a ministerial level officially, because UNICEF can also do you know, public advocacy, that's what they do very, very well. And so they're just exploring ways on how they can use this, to leverage, changes in policy, so that it is another, subject all together that, this move, was just the start of this meeting of the 3 ministries with UNICEF and us uh huh, and there'll be many more meetings."*

In New York, community members described the importance of cross-sector involvement in collaborative planning:

> *"The majority of our students [with ID] are impoverished so a lot of them receive their health services through social service. Without the assistance of social services, we know they wouldn't be able to afford any type of health care, there's no doubt about it."*

For some pilot Programs, a partner was instrumental in mobilizing other partners and opening new doors. In Peru, the Healthy Communities Coordinator reflected on relationships with influential international organizations:

"Secondly, partnerships at the institutional level, such as those with UNICEF, are one of our big strengths. Finally we signed a memorandum of maintenance, and this gave us a different vision. We already had a partnership with Save the Children and then with other institutions such as CEPEC, CONADIS, which came along the way."

Fostering action among leaders and members of the existing communities was another strategy used to create and mobilize community partnerships. Examples of activities that fostered community action include:

- Engagement and consultation with community leaders
- Recruitment of community volunteers

In Malawi, local leaders were the foundation of community mobilization:

"You need to engage traditional leaders …and let them know what you are trying implement, who is involved; the community awareness has to be there, you tell them what you are trying to do and make sure that they understand because if they do not understand then they will not patronize it, you will be having few getting involved, so they have to embrace it."

Building capacity for community mobilization involved increasing knowledge, resources, and partnerships within the community so that members are better able to reach their chosen goals. Examples of activities that built capacity include:

- Leveraging technology, such as social media
- Expanding partnerships to develop additional resources
- Maintaining open lines of communication during project implementation.

A staff member from Wisconsin described how health messaging on social media raised awareness and helped to build capacity for Healthy Communities:

"Overall, I think social media is a huge engagement for our followers and people who are part of our organization … social media is very easy and very user friendly so I think when people are looking for information that's a very good resource to use, where you can get the information out pretty quickly."

In Peru, having an ongoing dialogue with partners enhanced collaboration and capacity:

"We have had close communication, as much from their side as from mine. They [Government partners] are very direct and they always put their cards on the table."

3. Effectiveness and Sustainability of Healthy Communities initiatives

An important aspect of understanding how change was achieved by Healthy Communities is to examine whether this change can be sustained moving forward. Examples of activities that pilot Programs undertook to improve sustainability include:

- Integrating disability and health within the appropriate cultural and policy contexts in a given country
- Aligning with governmental priorities, both national and international, as well as interests of other public and private organizations
- Engaging with a variety of professional and family networks, which in turn enabled the training of leaders and champions for change
- Creating a common goal of inclusion of people with ID

A community member from Peru reported the value of embedding the work of Healthy Communities within existing cultural paradigms:

> *"We worked around the status of indigenous children, the status of indigenous children in Peru, and we have also done a study on Afro-descendant children. So we have been trying to reach to the most vulnerable population and in some way we have also been touching the topic of disabilities."*

In Romania, the Program expressed the effects of aligning with national priorities and integrating sports and health:

> *"We attended a meeting organized by the Prime Minister about people with disabilities in Romania as part of their anti-poverty policy and this is how we promote ourselves. Because if we say look, Special Olympics is an organization that creates sports opportunities… in this kind of environment, many will think that sport is a luxury for people with disabilities because their needs are different than sports. They would say they have basic needs, people are still living in institutions and so on, but we try to promote ourselves as a sports organization and sports for improving health."*

A parent from Thailand emphasized the contribution that engaging with family networks can make towards sustainability:

> *"In order to make sure that the future continuation of this project is tangible we have to look after the network of the parents and the families and these are the important mechanisms that this project can be continued by having a strong contribution, a strong participation of the family networks in, in every province."*

In Wisconsin, a coach described how the community rallied around their common goal of being a Healthy Community:

> *"In term of the expansion of the organization, this project has effect the, the collaboration among the concerned agencies especially the social welfare department and, and the parents networks, or family networks that, that work together. Apart from the, apart from the local NGOs or specific people with disabilities associations that they are very, very strong, these 2 networks, I mean the family network and also the department of social welfare have added into the system so they can help the, the projects a lot in term of the expansion of the activities and also helping the project."*

IV. Challenges and Solutions

The diversity of the Healthy Communities pilot Programs and the work they accomplished, with respect to location and activities implemented, represents a major strength because the results here may be generalizable to many other countries. However, pilot Programs reported a number of challenges in implementing the Healthy Communities model. These challenges comprised difficulties related not only to the activities and sustainability of Healthy Communities, but also to broader community-level barriers to accessing healthcare and creating healthy environments.

For example, community-level challenges include:

- Attitudes and behaviors of athletes, family members and coaches that influence healthy lifestyles
- Stigma associated with ID and cultural differences in perceptions about people with ID
- Funding for health services within the state or country of the SO Program

Challenges related to the Healthy Communities project include:

- Implementation of technology for Healthy Communities activities, especially for low-income countries, and evaluation of impact of these activities:
    - Communication with athletes, families, and partner organizations via social media, email, or phone was challenging. In particular, sending text message reminders for referrals after Healthy Athletes or social media updates to promote healthy habits was often more difficult to implement than expected.
    - Development of systems to capture data on Program activities and outcomes was identified as a challenge for many Programs. For example, the tracking of health indicators (like weight and blood pressure) as part of wellness opportunities was difficult.
    - Digital data entry for Healthy Athletes screenings was another difficult area for Programs. This challenge could include things like having the resources or infrastructure to implement digital data entry, as well as sufficient volunteer training.
- Programs expressed challenges in getting support for Healthy Communities from SO Program staff members in other SO departments, and retaining staff members who support or work on Healthy Communities during the 3-year pilot phase and beyond.
- Tracking whether follow-up care was obtained after Healthy Athletes events for individuals who receive a referral for a health issue
    - Many Programs were able to leverage partnerships to connect an athlete to a healthcare provider, but Programs experienced difficulty in capturing the outcome of the referral (whether the athlete had received treatment and what treatment had been performed).
- A narrow focus on specific health issues arising from the Healthy Athletes screening
    - Health screenings identify current problems but there may still be underlying issues that are not identified, such as chronic infectious diseases, or are not followed up sufficiently due to difficulties accessing community or primary care services.
- A frequent challenge that Programs shared was being able to sustain partnerships and funding from partners after Healthy Communities funding from SOI ceases, as well as leveraging partnerships for additional support.

Pilot Programs were highly resourceful, suggesting a number of solutions to these various challenges, including:

- More involvement of and support for the families and caregivers of athletes to enable healthier lifestyles for athletes
- Increased development of and cooperation with professional networks, especially organizations of healthcare providers
- Increased education around the health and wellbeing of persons with ID for the community, as well as individuals with ID and those who influence and impact the health of people with ID
- Increased athlete leadership training within SO Programs, including opportunities for peer education and mentorship
- Expansion of partnerships and enhanced collaboration with partners
- Effective communication and improved coordination across services, especially across government and service-provider organizations

There were some slight differences relating to activities in SO Programs in the US and SO Programs in Peru, Romania, Thailand, and Malawi. Programs based in the US were more likely than non-US sites to engage with partners and healthcare professionals, while non-US Programs were more likely to hold family, coach, and athlete health trainings and were more successful in enabling follow-up care after Healthy Athletes screenings. Further, non-US Programs expressed difficulties recruiting volunteers when individual resources are often limited. As a result of limited resources, partnerships became even more critical in these low and middle income countries that participated in Healthy Communities.

V. The Future of Healthy Communities

This evaluation, across five continents, seven Healthy Communities Pilot Programs, and involving over 578 informants, has provided a unique opportunity to reflect on why and how the Healthy Communities program is working, the impact it has had, and the implications for future action. It has shown what is possible when there is a coherent vision and committed staff who collaborate with athletes, their families, coaches and health service providers, as well as businesses, universities and international organizations. The successful strategies and lessons learned should be shared widely to promote the inclusion of all people with disabilities and improved health outcomes and quality of life for all.

In 2015, the Golisano Foundation committed an additional $25 million to expand Healthy Communities. These funds enabled SOI to provide grants to 36 new Programs for Healthy Communities in 2016. Also in 2016, SOI re-launched Healthy Communities as a recognition program, which recognizes SO Programs that achieve certain criteria: one main criterion is ensuring that athletes who receive referrals at Healthy Athletes have a place to go to get that follow-up care, the second main criterion for recognition as a Healthy Community is that athletes have access to year-round prevention and wellness programming. Programs working towards this criteria will learn from pilot Programs and each other, as well as this evaluation, about the strategies that have been successful to improve access to healthcare and enable healthier environments within local communities. While more Programs work towards Healthy Communities recognition, SOI will continue to evaluate this work to maximize impact and reduce health disparities.

SOI has set a goal to achieve 100 SO Programs meeting the Healthy Communities criteria by 2020. As SOI supports additional SO Programs in conducting health work, the regular reporting by the sites to SOI and the monthly webinar sessions will be an important component of monitoring progress, collecting qualitative data, and learning about best practices. In addition to reaching 100 Healthy Communities, the 2016-2020 SOI Strategic Plan focuses on building on this foundation of health programming by working to normalize the inclusion of those with ID in mainstream health systems. Further, SOI has committed to creating a culture of "Fitness" within our movement, which utilizes year-round sports training to improve athlete fitness, health, and wellbeing. Finally, training athlete leaders to become self-advocates is a priority of the movement, and will help to create athlete health leaders in SO Programs around the world.

Healthy Communities has the potential to change lives for individuals with ID. As a parent in Romania states:

> *"If it wasn't for the Special Olympics movement, she would have been in a depression; she has changed enormously since she entered Special Olympics events. Therapists no longer recommend any treatment for her, her mental and physical health is maintained through sports activities that she follows; therefore Special Olympics meant true health for my daughter."*

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