A Qualitative Evaluation of the Healthy Communities Initiative of Special Olympics International:

Summary Report

July, 2016

Preface

This report has been prepared primarily for Special Olympics personnel involved with Healthy Communities Initiatives at present and in the future. It should also prove helpful to Special Olympics Programs worldwide as the organization moves to a greater linking of sports and health within the new Strategic Plan. Healthy Communities Initiatives is the most ambitious trans-national project to date aimed at improving the health and wellbeing of persons with intellectual disabilities. As such, it provides insights for health service planners and commissioners both nationally and internationally as to how the needs of this subpopulation can be better met in the years to come.

The evaluation used both the United National Convention on the Rights of Persons with Disabilities (UNCRPD) and Sustainable Development Goals (SDGs)[1] as guiding frameworks to interpret some of the global summative trends within Healthy Communities Initiatives in terms of the human rights perspective and the achievement of sustainable development goals.

This report consists of an extended summary of the evaluation that was undertaken in seven pilot sites in the USA and across four continents. The summary is supported by a series of Appendices that provides technical information and more detailed exposition of the findings. Hence, readers can choose the amount of detail they wish to obtain from reading the report.

Acknowledgements

This evaluation was conducted with funding from the Golisano Foundation awarded to Special Olympics International, Washington DC, USA. Our thanks as well, to all participating Healthy Community sites and stakeholders. Healthy Community sites, and the authors, supplied photos.

We are particularly grateful to our Local Evaluation Partners:

1. Florida
2. Malawi

[1] The Sustainable Development Goals (SDGs) are, build on the Millennium Development Goals MDGs focused on working in partnership and making global progress on poverty, education, health, hunger and the environment. At the United Nations Sustainable Development Summit on 25 September 2015, world leaders adopted the 2030 Agenda for Sustainable Development, which includes a set of 17 Sustainable Development Goals (SDGs) to end poverty, fight inequality and injustice, and tackle climate change by 2030.

3. New York
4. Peru
5. Romania
6. Thailand
7. Wisconsin

Disclaimer

The views contained in this report are those of the authors and should not be taken to represent those of Special Olympics International. Correspondence regarding this report should be sent to Amy Shellard, Director of Research, ashellard@specialolympics.org

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Glossary

CBR	Community Based Rehabilitation
DPOs	Disabled People Organization
ID	Intellectual Disabilities
HC	Healthy Communities
L-MIC	low- to middle-income country
HIC	High-income country
SO	Special Olympics
SOI	Special Olympics International
ToC	Theory of Change
HREC	Human Research Ethics Committee
IRB	Institutional Review Board
UCT	University of Cape Town
UN	United Nations
UNCRPD	United Nations Conventions on the Rights of Persons with Disabilities

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The Appendices can be downloaded at:

(Amy to insert link)

Executive Summary

Internationally, people with intellectual disability have poorer physical and mental health. Special Olympics International has started to address this disparity through their Healthy Athletes Program and a recently launched Healthy Communities Initiative in 14 sites across four continents during 2012-2015. The primary aim was to ensure people with intellectual disabilities have better access to health services and to health-promoting actions through both Special Olympics sports and by mobilizing local community networks.

This evaluation of the Health Communities Initiatives was undertaken in seven locations worldwide and involved interviews with over 500 participants, including athletes, family members and community personnel. The focus was on how the programs brought about improved health and healthier lifestyles for persons with intellectual disabilities. In addition, literature and document reviews, alongside interviews with Program personnel, enabled a critical examination to be made of the theory of change underpinning the programs and an evaluation of the processes they had implemented.

The findings of the evaluation were grouped around three core questions. They were benchmarked against internationally agreed strategies for improving the health and wellbeing of the world's citizens.

How was improved access to health promotion, healthcare and treatments achieved?

Three strategies were seen as crucial. First, by creating environments supportive to health and wellbeing. Healthy Communities did this by creating health awareness among families and SO programs; through health promotion activities and relationship building for athletes; and, by using sport to promote health. Second, by seeking to re-orientate existing health services through increasing athletes' access to local healthcare services after health screening; the recruitment and training of local health personnel; and, engaging with universities to better prepare their students to meet the needs of people with intellectual disability. Third, by building the personal skills of athletes and families through workshops, family forums and the development of educational resources, so that they take responsibility for their health and follow healthier lifestyles.

Unresolved challenges faced by the Healthy Community Programs were the environmental barriers to health that exist for persons with intellectual disabilities and families, such as finance and travel, as well as the cultural, linguistic and resource issues encountered by health professionals.

How were community partnerships mobilized and created?

Again, three strategies had proved successful. First, the Programs sought out and engaged with a range of partners to plan collaboratively in order to improve the health of people with intellectual disability. Second, they aimed to stimulate action by the community to take responsibility for the health of all their members: a strategy that was particularly necessary in low- and middle-income countries. Third, the Programs started to build the capacity of community partners to bring about change through ongoing dialogue, knowledge transfer and resource sharing. Nevertheless, the strong impression was that Healthy Communities largely "owned the problem" rather than the communities in which the initiatives took place. This perception is not unexpected given the newness of the programs and the limited resources at their disposal. Community ownership will require sustained advocacy and engagement.

To what extent are Healthy Communities initiatives effective and sustainable?

Participants in the evaluation, who attributed its effectiveness mostly to the strategies noted above, confirmed the positive impact on athletes, families and Special Olympics personnel. However, only limited knowledge was gained as to the sustainability of the Programs. In assessing this, greater reliance had to be placed on current thinking in health promotion. Core strategies are the implementation of international rights statement into national policy and practice; the building of strategic partnerships, especially with NGOs and advocacy organizations of disabled persons, and the creation of a shared consensus around the vision for achieving better health for persons with intellectual disabilities. Also, to have a primary focus on leadership development and a more effective use of information technology.

The Future for Healthy Communities

Healthy Communities Initiatives is the most ambitious, trans-national project to date, aimed at improving the health and wellbeing of persons with an intellectual disability. As such, it provides insights for health service planners and commissioners, both nationally and internationally, as to how the health needs of people with intellectual disability can be better met in the years to come. In particular, recommendations are made for the better integration of health promoting activities within Special Olympics Sports programs; for reaching out to the wider population of persons with intellectual disability beyond Special Olympics, and for influencing national policies and practices. An impressive start has been made, albeit that it is the end of the beginning.

Summary Report

The Health of Persons with Intellectual Disabilities

The health disparities of persons with intellectual disabilities are well evidenced internationally. As Appendix 1 to this report details:

- Persons with intellectual disabilities experience poorer health and are at higher risk of chronic illnesses and diseases.
- Access to healthcare that is attuned to their needs is likely to be diminished internationally but especially in low- and middle-income countries.
- Social influences play a major part in perpetuating their poorer health and reduced quality of life.

Nonetheless, there is an international consensus on the rights of persons with disabilities to better health and recognition that the social and environmental factors that influence poorer health must be addressed in order to produce healthier lives and lifestyles for persons with disabilities. Increasingly it is recognized that health gains for populations for all persons with intellectual disability are more likely to come through mainstream health provision rather trying to extend specialist disability services that reach only smaller numbers of persons (Krahn & Fox, 2014)[2]. This point is further addressed in Appendix 1.

Figure 1: Ecological model of health promotion

An ecological model has been proposed for sustainable health promotion strategies with subpopulations of persons, such as those with intellectual disability (see Figure 1)[3]. This embeds health interventions targeted at individuals and their support persons within the broader ethos and practices of support services provided for this population. Moreover the development, mobilization and adaptation of environmental and community resources is

[2] Krahn and Fox

[3] Marks, B. & Sisirak, J. (2014) Health promotion and people with intellectual disabilities. In L Taggart & W. Cousins (eds). *Health Promotion for People with Intellectual and Developmental Disabilities*. Open University Press, Maidenhead.

essential for sustained health gains, especially in countries where health resources are scarce.

As yet, population-based strategies for improving the health of persons with intellectual disabilities have still to be implemented and evaluated.

Healthy Communities Initiative

In July 2012, Special Olympics International (SOI) partnered with the Golisano Foundation to expand health programming for people with intellectual disabilities in an effort to reduce the disparities that exist internationally in their health status and access to health services. Their vision is:

- *A world where every person with Intellectual Disability and their family understands what they need to do in order to optimize their health.*
- *A world where accessible information, resources, systems and policies exist at the individual, community, national and global levels that support them in realizing healthy and productive lives.*

The Strategic Approach of Healthy Communities

Four pillars (strategic approaches) were developed to guide this work, which would be taken forward by selected Special Olympics Programs. Details of activities undertaken by the pilot sites are contained in the final report of the Project[4] and summarized in Appendix 2:

1. *Infuse expanded health services, including ones focused on diseases of extreme poverty, into all Special Olympics' worldwide, year round events and programming.*

Examples include expanding the reach of Healthy Athletes clinics; including offering locally relevant health services into new areas; and, providing health education for family members, athlete leaders, coaches and others.

2. *Create local Healthy Community networks for health providers engaged in Special Olympics' health work and committed to providing ongoing health resources and services to people with Intellectual Disabilities and their families outside of Special Olympics.*

Examples include:

[4] Special Olympics International (2016) *Healthy Communities Pilot Final Results*. Washington DC

- recruiting and training healthcare workers to be better able to provide for the needs of persons with intellectual disabilities through the provision of health education sessions;
- improving the curriculum at educational institutions;
- identifying healthcare providers willing to treat persons with intellectual disabilities; and;
- providing wellness opportunities such as fitness and nutrition Programs for Special Olympics athletes and other persons with intellectual disabilities outside of Special Olympics.

3. Develop world-class bio-informatics capability to monitor longitudinal health outcomes for persons with intellectual disabilities to measure progress, inform public policy leaders, and demand health justice worldwide.

Examples include the creation of unique identifiers and personal and accessible electronic health records for athletes; sending text message/SMS reminders to athletes for follow-up care; and, athlete accessible fitness and nutrition apps.

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.

Examples include: leveraging support (cash, in kind services and policy changes) from government, NGOs and corporations leading to improved access to health resources for persons with intellectual disabilities; increased public awareness and knowledge through media campaigns and publications; and, sharing best health practices among the Special Olympics community.

Operations of Healthy Communities

In order to pilot this new initiative, 14 sites were identified: six Special Olympic Programs in the USA (Wisconsin, Arizona , Kansas, New York, Florida, New Jersey) and eight Special Olympic Programs across four continents (Thailand, Malaysia, Mexico, Peru, Romania, Kazakhstan, South Africa, Malawi).

Each Program was allocated funding from SOI to employ Healthy Community Coordinators. Each site reported to SOI bi-annually on their activities and outputs over the three years that the project ran. The main findings over the three years were as follows:

"Over the past three years, Special Olympics Programs participating in Healthy Communities have conducted

- *20,665 Healthy Athletes exams in*
- *156 new locations, reaching athletes that have not been reached by Healthy Athletes previously.*

Since the start of the pilot,

- *6,042 family members/caregivers,*
- *1,940 coaches/teachers and*
- *669 athlete leaders have been educated to become health educators for other athletes.*

Healthy Communities have also educated

- *20,213 athletes on health topics, ranging from HIV, malaria, sexual health to mental health, obesity and nutrition.*
- *Additionally, 21,825 healthcare professionals and students have been trained on how to work with people with ID and*
- *46 universities have committed to making changes to their curricula to better prepare medical professionals to provide care for people with ID.*
- *Healthy Communities have also developed 248 local partnerships providing a total of $30,000,472 in cash and value in kind (VIK). The results have shown significant increase throughout the three year period." (p.1).*

Full details of the quantitative evaluation are available at:

(SOI Please insert electronic link to the quantitative report)

Qualitative Evaluation

An agreement was signed on May 2014 between Special Olympics Inc. (SOI) and the Disability Studies Program at the University of Cape Town (UCT) to conduct a qualitative evaluation on the Healthy Communities initiative. This evaluation is 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 purpose of the evaluation was to collect qualitative data on the implementation of the Healthy Communities initiative over the three-year project period. For the purpose of the evaluation, seven of the 14 pilot locations were chosen to give a good global representation as well as coverage from the USA (see Figure 2). A participatory approach was followed to choose the evaluation sites. UCT staff participated in monthly webinars over a period of four months and shared with all 14 sites the expectations for participating and the parameters of the evaluation. Sites participating were expected to be well-developed initiatives that complemented each other rather than repeated each other's approaches and strategies. A process of self-nomination then followed and SOI and UCT finalized the seven chosen sites to ensure a cross-cultural representation of the Healthy Community Initiatives in this pilot phase. more

Figure 2 Sites for Healthy Communities Evaluation

The chosen sites were Florida, New York, Wisconsin, Peru, Malawi, Thailand and Romania; with South Africa as a "pilot site" for the evaluation methodologies.

A comparison was undertaken of the activities carried out by the Programs selected for the evaluation with those who were not. There were few differences, which suggested that the chosen sites were broadly representative of all the pilot projects. However, there were more marked differences between the projects in the USA compared to the four low- and middle-income countries included in the evaluation[5] (See Appendix 2)

[5] The LMIC definition is constructed on the Work Bank classification of the world's economies based on estimates of gross national income (GNI) per capita for the previous year

Aims of the evaluation

The focus of the qualitative evaluation was on *HOW* the Healthy Community Initiatives operated. This formative evaluation will inform the future expansion of Healthy Communities projects to some 100 SO Programs from 2016 onwards and for which funding has recently been obtained. It would contribute to a greater understanding globally on how to promote and improve the health of persons with intellectual disabilities.

How do Healthy Community initiatives bring about improved health and healthier lifestyles for persons with intellectual disabilities?

The overarching question was:

Three sub-questions of particular interest were:

- How has improved access to health promotion, healthcare and treatments been achieved?
- How were community partnerships mobilized and created?
- To what extent are Healthy Communities initiatives effective and sustainable?

Three strands featured in the evaluation: 1) an analysis of the Theory of change underpinning the HC Initiatives, 2) an evaluation of the processes of implementing HC Initiatives based on the experiences of HC coordinators and staff, and 3) the experiences of athletes, families, health professionals and community personnel.

Theory of Change

The qualitative evaluation of Healthy Communities Initiatives needed to be located within a broader context than the activities, which individual sites had chosen, although that too is an important indicator of its impact. Hence, a documentary analysis was undertaken of the various reports from each of the participating sites over the past three years using a Theory of Change (ToC) Tool developed by the International Network on Strategic Philanthropy (2005).

At its most basic, a theory of change articulates the assumptions about the process through which change will occur, and specifies the ways in which all of the required early and intermediate outcomes related to achieving the desired long-term change will be brought about and documented as they occur. A ToC maps out five broad stages:

1. Identify long-term goals
2. Identify immediate outcomes

3. Identify activities
4. Show the casual links
5. Examine your assumptions and logic

A theory of change was drafted for each evaluation site and two collective theories of change were prepared for the three sites in the USA and the four sites in LMIC countries. The theories of change across the seven evaluation sites are fairly similar with the exception of the context of each site and a variation in the focus on activities within the four strategic approaches. Two ToC are developed for the project evaluation sites i.e. high-income sites (USA sites) and L-MIC (Malawi, Peru, Romania and Thailand).

Table 1 The main difference between the USA and LMIC.

	High income countries (HIC) USA sites	L-MIC sites
Access to Health	• Organize events by using existing mainstream healthcare facilities.	• Had to plan for the creation of opportunities to bring athletes/families together as mainstream facilities were not easily accessible for the project, especially in rural areas where such facilities are scare.
Policy and Legislation	• relatively good and stable health infrastructure • Majority of persons with ID are covered medical insurance. • High prevalence rates of lifestyle illnesses. • Data on persons with intellectual disabilities are available	• The sites are situated in contexts with a legislation outlining a universal public health cover. • Due to inadequate resources and poor infrastructure, the implementation of the legislation is a challenge and the public healthcare systems are generally not able to provide sufficient healthcare to a large part of the population, especially to persons with intellectual disabilities. • Information and data on persons with intellectual disabilities are not frequently available
• **Activities**	• Focused on healthcare facilities/providers to provide appropriate services to persons with intellectual disabilities. • Improve access to existing services within the mainstream facilities • Increase knowledge and skills of healthcare professionals • Partnering with higher learning institutions to integrate disability into curriculum for healthcare	• Focused to influencing the healthcare system at a national level through engagements and partnerships with the government. • Lobby government for financial resources of healthcare for persons with intellectual disabilities and the continuation of HC activities. • Developed partnerships with schools and group homes in order to deliver services through their network.
Access to information and services	• Access to information and services- through the SO network and events • As well as using mainstream healthcare providers, Sites engaged the athletes directly to a higher extent than the LMIC sites.	• Focus on athletes/families to ensure easy access to information and services- through the SO network (events & using mainstream healthcare providers) Partner with NGOs and Schools to access athletes
Partnerships & Higher Education	• Developed partnerships with higher education institutions and influencing the	• Sites had a lesser focus on engaging and partnering with higher education institutions

Institutes	curriculum within the healthcare profession.	
Information Technology	• Tested the paperless tablet system at health screenings	• Survey on the access and use of cell phones and SMS amongst the athletes/ families
Project Management	• Limited information about the context and analysis of the challenges and potential risks in their project plans. It is unclear to what degree organizations have conducted any situational analysis	• Project plans developed had a higher degree of details in the context and situational analysis, which they then sought to respond to through the planned activities.

All sites included the four HC strategic approaches (mentioned above) and focused on the same long-term outcomes and impact as identified in the original Logic Model[6] (Addendum 14) namely 1) the improvement of athlete health and well-being, and 2) improved access to healthcare, health promotion and wellness resources for all with ID.

The main differences between the sites were in how they implemented the strategies and where they focused most of their resources within the different contexts in order to bring about the changes and have the planned impact as outlined in the original Logic Model. Poor infrastructure and inadequate resources for healthcare to persons with intellectual disabilities, characteristic of the L-MIC, meant a higher degree of focus on improving the healthcare system through lobbying and partnerships with the government and influential partners such as international NGOs. The USA sites (high-income), had a comparatively stronger focus on delivering services directly to the athletes and their families, as the healthcare infrastructure is considerably better in the USA. All sites were able to contribute to the overall Goal of the HC project.

In summary, these analyses provide a common framework against which the similarities and contrasts of the different HC Initiatives can be identified and variations noted from the original logic model for the Healthy Communities Initiative devised in 2012[7]. These

[6] A logic model can be seen as a map that you develop to clarify and communicate the implementation of your project, focusing on the activities and intended outcomes and its presumed impact. In relation the ToC shows the big, messy "real world" picture, with all the possible pathways leading to change, and why you think they lead to change. A Logical Model is like zooming in on the specific pathway that your program deals with and creating a neat, orderly structure for it. The USA and LMIC theories of change grouped sites with similar planning and project management strategies. The LMIC definition is constructed on the Work Bank analytical classification of the world's economies based on estimates of gross national income (GNI) per capita for the previous year (Peru, Romania, Malawi and Thailand fall within the LMIC classification)..

[7] A logic model can be seen as a map that help to clarify and communicate the implementation of your project, focusing on the activities and intended outcomes and its presumed impact. By contrast the ToC shows the big, messy "real world" picture, with all the possible pathways leading to change, and why they might lead to change.

analyses, coupled with the activity data reported in Appendix 2, serve to validate the four pillars of activity intended to underpin the Healthy Communities Initiatives. The Theories of Change are included in Appendix 2 with a more detailed description of the strategies employed and the outcomes, as well as a similarities and differences between the sites.

The next section describes the methodology used in gathering and analyzing the qualitative data followed by the findings of the process evaluation and perceptions of the main stakeholders in the HC Initiatives.

Methodology for Gathering and Analyzing Qualitative Information

Figure 3 Number of Informant Groups for Evaluation

The evaluation design used a multiple case-study approach, which involved looking at multiple cases (the HC Initiatives) to facilitate holistic and meaningful, context-related knowledge and understandings about the Healthy Communities initiatives (Yin, 2009). This design allowed the evaluation to seek commonalities and contrasts among the experiences and perceptions of the key stakeholders involved in each of the Healthy Communities sites. Full details of the methodology are given in Appendix 3

Local evaluation partners (LEPs) were recruited in each of the seven chosen sites (Florida, Wisconsin, New York, Peru, Thailand, Romania, Malawi), mainly university-based researchers with experience of undertaking studies with people who had intellectual disabilities and/or a prior involvement with Special Olympics. A member of the UCT team[8] visited each partner in the period March to May 2015, to ensure consistency in our approaches to sampling and data gathering. An attempt was also made to recruit co-researchers with intellectual disabilities, although this was only successful in Thailand and Wisconsin. Further detail regarding co-evaluators is provided in Appendix 3.

[8] Prof. Theresa Lorenzo, Dr. Judith McKenzie, Dominique Brand, Anthea Hansen, Siphokazi Sompeta

Information was gathered from a range of informants through one-to-one interviews, group interviews or self-completed questionnaires (used mainly with health professionals). Figure 3 illustrates the informant groups and totals within each across the seven sites.

All the information was translated as needed, and then entered into a software package – Dedoose – to assist with data management. An inductive analysis was first undertaken (thematic content analysis) to identify all the specific themes and the emerging higher-level themes. These themes were then examined against a theoretical framework (deductive/interpretative analysis) to answer the key questions of the evaluation.

Member checking was used to improve accuracy and internal validity of data. This was initially undertaken within the UCT team but was later extended to LEPs, Healthy Communities personnel and Special Olympics national directors through an online conference, the sharing of a preliminary report containing the main findings and phone interviews.

Approval was obtained from Human Ethics Committee of UCT to conduct the Pilot in South Africa. The Institutional Review Board of Special Olympics provided approval to conduct the evaluation across all sites. In addition, approval from Human Research ethics committees in Malawi, Rochester NY, and Wisconsin was also obtained as advised by our local evaluation partners).

Theoretical Frameworks

Initially, an inductive thematic analysis was undertaken (thematic content analysis) to identify all the specific categories, patterns and the emerging higher-level themes. Although the findings have been influenced by the evaluation questions posed during information gathering, the findings arose directly from the analysis of the raw data, not from a priori expectations, models or theories.

Once the Inductive analysis process was completed and we had a condensed coding tree that included high-level superordinate themes, we switched to a deductive approach to match the superordinates and subthemes to theoretical models. From the diversity of the data coded, the theme revealed led us to more general, higher-level abstract constructs. We then reviewed these superordinate themes and subthemes and by acknowledging how they were systemically interrelated leading towards the application of a relevant theory. The deductive approach guided evaluators to search for theories that matched the tenets of social phenomenology highlighted in the superordinates and subthemes. The UCT evaluation team identified and started to work with pre-established theories as reviewed in Appendix 1 (bio-ecological, empowerment and organizational capacity theory) to explain the phenomenon presented by the superordinate coding tree.

For each of the three questions in the evaluation, we chose a theoretical framework against which the HC Initiatives can be judged. The following criteria were used in selecting the frameworks:

- They are universal and common to all persons and all societies. Hence, they position persons with intellectual disabilities as *part of* society and not *apart* from society.
- They are well established and accepted frameworks, rooted in evidence and experience, and around which a further body of knowledge has developed.
- They are intended to guide practitioners and the further development of services and supports to improve population health and wellbeing.

The use of theoretical frameworks brings additional benefits:

- They situate and judge Healthy Communities Initiatives within mainstream public health promotion rather than as a disability-specific initiative.
- The frameworks provide a common language and understanding for improving the health and wellbeing of persons with intellectual disabilities across initiatives in different countries and regions.
- They locate the activities and strategies used by Healthy Communities within a more holistic context.
- They enable local initiatives to profile their focus and draw their attention to domains within the framework that may have been ignored or overlooked.

Hence, in this report we map the evidence gathered from our informants on to the chosen frameworks in order to bench mark the impact of the HC Initiatives.

The Findings of the Process Evaluation

In order to evaluate the process of instigating and managing the Healthy Communities Initiatives, information was drawn from the face-to-face interviews undertaken by UCT evaluation staff with the Healthy Community Coordinators and associated staff. They had a strategic overview of how the HC project plan has been implemented across the three-year project period. The aim was to assess how activities were implemented and supporting processes and structures developed in order to reach the intended outcomes. This would identify practical problems encountered, and the ways such problems were resolved. Understanding how interventions and participant interaction trigger change is key in grasping the casual mechanisms that will lead to enhanced future impact or replication of the Program.

Quantified Qualitative Analysis data

Dedoose - a Qualitative analysis tool - provided access to limited descriptive analysis. The analysis related to the frequency of prevalence of codes overall, or within site or informant group. Where possible, this prevalence rate of codes was used by evaluators to ensure codes that had a high prevalence rate were well represented within the write up of the findings. In Addendum 10, graphs illustrate the prevalence of the superordinate and subthemes within each site.

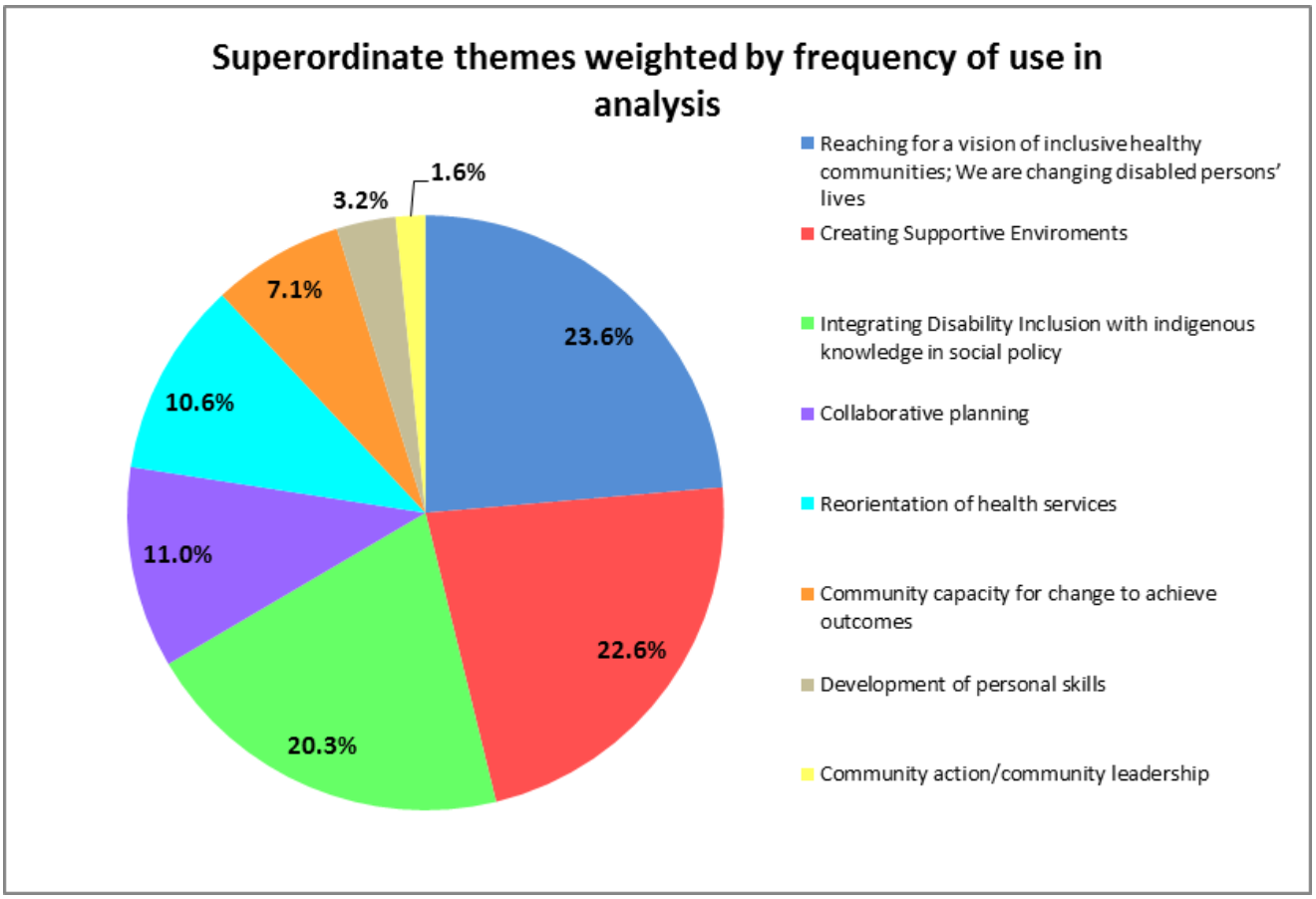

Figure 4 Prevalence rate of Superordinate themes across all data collected

The Pie chart in Figure 4 illustrates the overall prevalence of themes after the coding of all data was completed. The table 2 represents the evaluation questions and the themes covered within the evaluation question.

Table 2 Evaluation question and contributing themes

Question 1	1. Creating Supportive Environments; 2. Reorientation of health services; 3. Development of personal skills
Question 2	4. Collaborative planning; 5. Community action/community leadership; 6. Community capacity for change to achieve outcomes
Question 3	7. Integrating Disability Inclusion with indigenous knowledge in social policy; 8. Reaching for a vision of inclusive healthy communities; We are changing disabled persons' lives

Table 3 and 4 provides an overview of the dispersion of both SO sites and informant groups and their specific data contribution to each of the evaluation questions. Pie charts will illustrate the data in table 3 and 4 for each question below.

Table 3 Dispersion of data contributed by HC site

HC Site:	Question 1 Access to Healthcare	Question 2 Partnerships	Question 3 Sustainability
Florida (HIC)	17,1%	8,9%	12,2%
New York (HIC)	10,4%	13,8%	15,9%
Wisconsin (HIC)	11,3%	13,1%	16,5%
Malawi (L-MIC)	9,7%	11,8%	8,7%
Peru (L-MIC)	28,3%	25,0%	23,8%
Romania (L-MIC)	14,1%	16,7%	12,6%
Thailand (L-MIC)	8,9%	10,8%	10,4%
	100%	100%	100%

Table 4 Dispersion of data contributed by Informant Groups

Informant Group:	Question 1 Access to Healthcare	Question 2 Partnerships	Question 3 Sustainability
Athlete	25,8%	4,3%	12,1%
Parent	24,4%	12,1%	10,7%
Coach	8,7%	4,7%	13,5%
Healthy Community Coordinator	4,6%	14,8%	12,2%
SO Director	0,8%	6,9%	5,6%
Healthy Community Staff	7,8%	24,2%	13,6%
Volunteer	4,0%	2,8%	2,2%
Community Member	17,1%	18,9%	20,1%
Health Professional	6,8%	11,1%	10,0%
	100%	100%	100%

The following figures summarize the main themes in the interviews with HC coordinator staff across the seven evaluation sites. The success factors, challenges, proposed

solutions, stakeholder's reactions representative of a summary of findings from the initial interviews with HC coordinators during the site visitation phase. These initial interviews also helped to give the evaluators an initial current overview of the HC sites.

The appendices will elaborate further.

Success Factors

Figure 5 summarizes the factors that HC coordinators felt had contributed to the success of the HC Initiative. The larger circles describe the five main success factors of the HC Initiative, especially the financial and material resources provided to Programs these themes will be elaborated on further in Appendix 6 & 7.

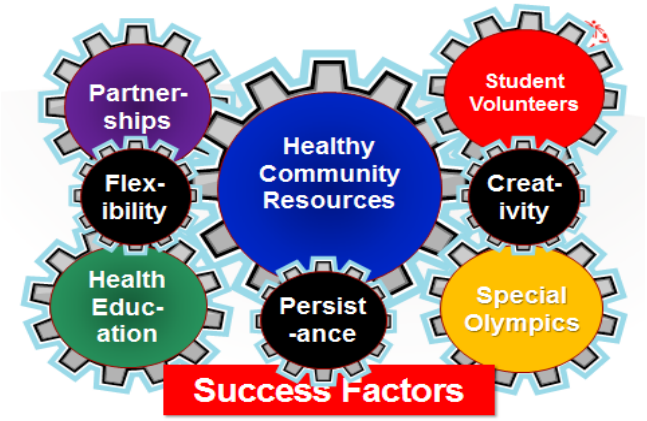

Figure 5 HC Co-ordinators success factors

The three smaller (Black) circles are the personal attributes that the HC staff felt was necessary for success – the need for flexibility in decision-making, creativity in planning and leadership development and persistence will be elaborated on further in Appendix 7.

Challenges

As with any new initiatives, many different challenges were noted by the staff across all the seven Programs. The most commonly mentioned challenges across the seven sites are shown in Figure 6. These included the receptiveness of coaches and parents, and the present lifestyle of athletes. Three arose from the HC aims, such as problems with IT, issues around funding for health services nationally and a narrow focus on specific health issues arising from the health screenings.

Figure 6 HC- Coordinator identified challenges

However, four deeper issues were also recounted: namely family poverty, the social stigma associated with intellectual disabilities, the competing priorities within SO Programs and funding for health activities. HC coordinators have shown that they have a unique capacity to generate an in-depth understanding of the challenges faced by both persons with

intellectual disability and their families. Although multiple challenges have been identified, most importantly, HC coordinators have shown that they can be reflective, non-defensive, self-critical and resilient when dealing with challenges that can affect the project implementation.

Proposed Solutions

Various solutions were proposed to the challenges they face; some of which they had endeavored to implement whereas others were dependent on increased resources and opportunities (see Figure 7). Within Special Olympics Healthy Community sites, the idea was proposed of having health coaches working alongside sports coaches, and/or the one person being trained and supported to fulfil both roles. However most of solutions were focused on the wider community context, such as improvements to the training of health professionals; better information sharing and coordination across services; and, the need for culturally - appropriate health education these themes will be elaborated on further in Appendix 6 & 7.

Three essentials strategies were also noted when implementing these solutions: effective communication; the dispelling of myths around the health and wellbeing of persons with intellectual disabilities; and, maintaining of motivation to making change happen. The HC initiative has made great strides in fostering an inclusive health system that is responsive to the needs of disabled persons and their families. It will be sustained through reciprocal capacity building that embeds the skills, knowledge and values of inclusive policy of government services as well as university programs.

Figure 7 HC-coordinator proposed solutions

Stakeholder reactions

The bulk of the evaluation focused on obtaining the reactions to the other stakeholders (athletes, family members, community members and health professionals) who were involved with the Healthy Communities Initiative in the seven chosen locations. In all, over 500 participants took part making this one of the largest, cross-national evaluations of health Programs for persons with intellectual disabilities. The bulk of this report is devoted to these findings. The findings are summarized in the following three sections. Together they address the central aim of the evaluation: How do Healthy Communities initiatives bring about improved health and healthier lifestyles for persons with intellectual disabilities?

A final section summarizes the conclusions and recommendations that arise from this evaluation.

1. How has improved access to health promotion, healthcare and treatments been achieved?

Healthy Communities had a vision of "A world where every person with ID & their family understands what they need to do in order to optimize their health and where accessible information, resources, systems & policies exist at the individual, community, national & global levels that support them in realizing healthy & productive lives". HC set out to promote the health and well-being primarily of athletes involved with Special Olympics. In order to assess the process and outcomes of the HC strategies in relation to health promotion, healthcare and treatments, we adopted the long-established and agreed framework of the World Health Organization's Ottawa Charter for Health Promotion (WHO, 1986). The Ottawa Charter argues that health needs to be viewed as a positive concept encompassing social, personal, physical resources and capacities.

The Charter outlines five strategies that contribute to health promotion (see Figure 8):

For the findings of question 1, we have focused on the first three strategies: the latter two strategies are dealt with under Question 3.

In addition, we draw on an eco-systemic approach by recognizing that the individual is part of multiple systems and change at any level of the system has a ripple effect on the other levels (Donald, Lazarus and Lolwana, 2002).

Figure 8: Eco-systemic approach to view the Ottawa Charter for Health Promotion

The interaction between the health promotion strategies and the levels within the ecosystem are illustrated in Figure 8.

The athletes are central. Their primary and initial access to healthcare is through the family or a paid or unpaid caregiver. Although families would ordinarily be the link to community health provision, this link may not happen. Special Olympics, in general, and HC Initiatives, in particular, may be a mediating link in facilitating families and athletes to gain access to health professionals in the public or private sector within their communities. For this report

the community level is inclusive of the national socio-cultural networks that include legal and health policies.

This question had the greatest number of specific themes identified across all three evaluation questions within the total analysis. A total of 36.4.5% (Refer to figure 4) of excerpts speak to this question, which would indicate that this was a particularly salient question for our informants. The figures 9 & 10 below give a more detailed breakdown of the informant sites and informant groups for question 1.

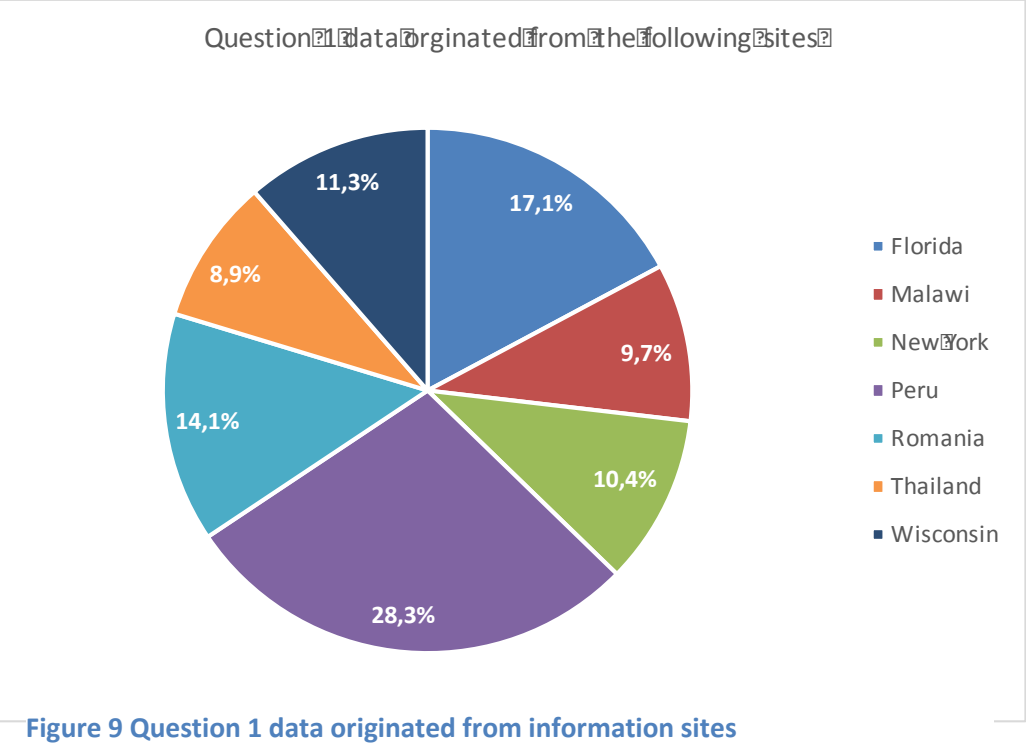

Figure 9 Question 1 data originated from information sites

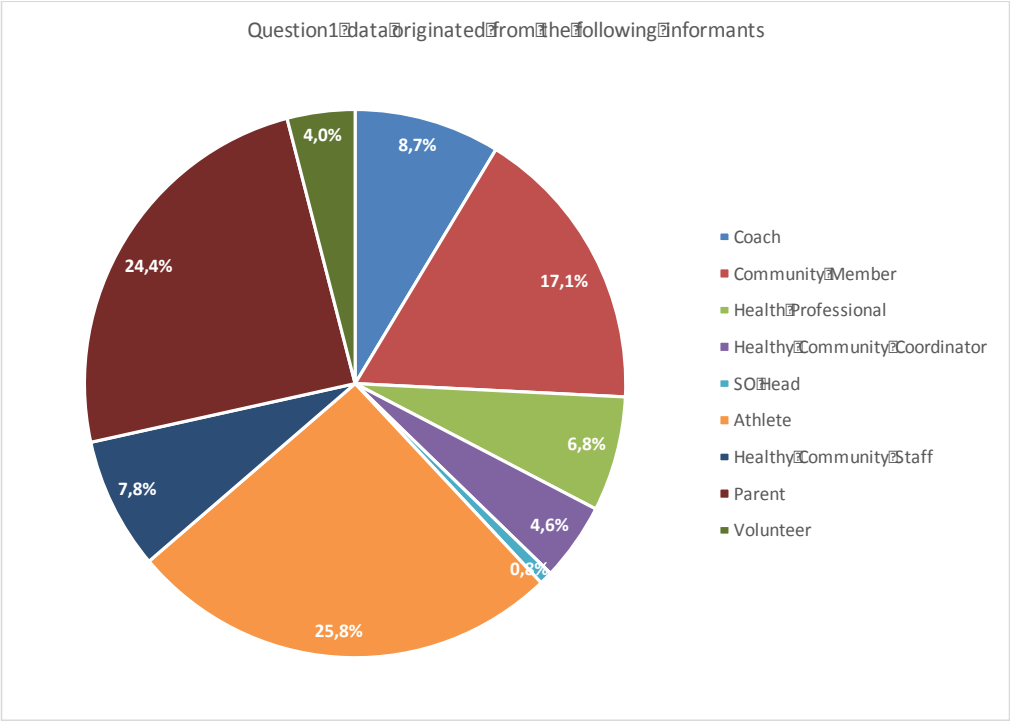

Figure 10 Question 1 data originated from the different categories

Creating Supportive Environments

HC made a significant contribution to supportive environments. The data reflected that creating a supportive environment was done through the following subthemes: creating health awareness among families and SO programs; building relationships and friendships for athletes, in health promotion and advocacy groups as well as using sport to promote health (see Appendix 5 for a detailed look and examples of these subthemes). Community members contributed 25.8% of the codes for this theme, which highlighted the significance they perceived of creating supportive environments for this informant group. Additionally, creating supportive environments was mentioned more often in low- and middle-income countries with 64.5% of their data highlighting the need for supportive environments compared to 35.5% for high-income countries.

HC focused actions on reducing the differences in current health status and ensuring equal opportunities and resources for athletes, thereby enabling them to reach their best health potential. As awareness of the health needs and choices of athletes developed, the environment became more supportive for them to make the right health choices. However, environmental barriers still exist for persons with intellectual disabilities and families, and for health professionals, in terms of cultural, linguistic and material resource barriers. For example in Malawi, there was a request that more material resources, for example soccer balls, be provided to allow for increased participation within the community.

Reorientation of health services

HC worked toward achieving a re-orientation of health services provided locally to persons with intellectual disabilities and the results reflected that this was done through the following subthemes; the promotion of access to healthcare after health screening, the availability of health diagnosis and follow-up care, and the prevention of ill health. The data contributed from parents (24.9%), community members (18.7%) and athletes (15.2%) revealed the significance of this theme to these informant groups. HC was good at realizing that achievement of health does not solely depend on the health sector, and that a coordinated response from all stakeholders was required. HC together with trained health professionals provided a mediating link between the different role-players in the pursuit of health. HC increased awareness about persons with intellectual disabilities and health concerns amongst health workers through courses and workshops. Since the beginning of the HC pilot project, 15,130 health professionals and students have been trained as part of SO HC initiatives. (HC, Pilot Final results report, September 2015). Health professionals were encouraged to know the rights of the athletes and to manage their health in a holistic manner. This facilitated the creation of a network of skilled healthcare providers to which persons with intellectual disabilities could be referred. Additionally, HC partnered with the

local communities to link HC goals to those of the local community. The evidence of these efforts was reflected in the findings as a change in the attitudes towards athletes and a change in the manner of engagement of health providers as well as community members with athletes. Healthcare providers who participated in the evaluation reported transitioning from being uncertain and avoiding treating persons with intellectual disabilities to being confident and eager to provide better healthcare to athletes. Community members reported an increased understanding and positive attitude towards persons with intellectual disabilities and included them in daily tasks. Reorientation of health services was also evident in curriculum changes at universities and the development of service learning programs, with 46 universities across the 14 HC sites committing to better prepare health professionals to treat persons with intellectual disabilities (HC, Pilot Final results report, September 2015). Although the use of technology to promote health, enhance record keeping and facilitate referrals shows significant potential, an area that still needs extensive work to strengthen it. It also appears that there further work remains to provide holistic services at a primary care level as opposed to the reliance on specialized services.

Development of personal skills

HC took a comprehensive approach to promoting health and wellbeing by stimulating the development of personal skills among athletes through strategies such as health education, building relationships and friendships, and engaging athletes in sport activities as well as social and communication skills. Athletes and their families were educated and taught context-specific skills and strategies to help them maintain health. HC has contributed to athletes becoming aware of their health thereby enabling them to make choices that are conducive to health, for example, choices related to healthy nutrition, increased physical activity/exercise and dental hygiene. A total of 20 213 athletes were reported to receive health education in the 14 HC pilot sites with a total of 669 athletes who were trained to be health educators for other persons with intellectual disabilities (HC, Pilot Final results report, September 2015). This allows athletes to take responsibility for their health and be active participants in their healthcare. The skills of caregivers for supporting the health needs of athletes were also developed through family forums and workshops. HC staff developed programs and resources, relating to nutrition, hand washing and dental hygiene. Even so, more needs to be done to provide for healthy choices; for example, athletes struggled with finding healthy food choices – especially in the USA – and even within the SO sport activities. A neglected area across many sites is in sexuality and relationships education, which was a particular concern of families as well as athletes.

In conclusion, HC are working broadly within strategies of the Ottawa Health Charter, albeit with greater emphasis on the three strategies directly affecting persons with intellectual

disabilities and their families. Successes were achieved in many areas such as creating a supportive environment for persons with intellectual disability especially in L-MIC countries. The findings from parents as well as HC community members confirmed that the use of athletes in creating awareness was powerful in challenging perceptions and positively changing attitudes towards ID. Parents were motivated and inspired by these athletes, allowing parents to believe in the possibilities for their own children with intellectual disabilities. This fostered the inclusion of persons with intellectual disabilities in many areas such as going to school and community-related activities. HC was successful in creating support for families and caregivers of persons with intellectual disability, a point for which the parents were particularly grateful. The use of sport to promote health continued to grow positively. With regard to health services, HC made a significant contribution by creating a network of health professionals trained in working with persons with ID, this in turn enhanced the referral pathway and follow-up care process. Further attention needs to be paid to strengthening and extending the referral and follow-up processes, the use of technology in health education as well as strengthening community action, which is the focus of our next question.

Key lessons learned: How has improved access to health promotion, healthcare and treatments been achieved?

- There is a need for an increased involvement of the family, as they are key to sustaining the health of the athlete.
- Communication with parents is crucial. It needs to be continuous and consistent. It is important to build the capacity of professionals/ coaches to communicate effectively with parents so that partnerships are forged between school, and healthcare.
- Parents and caregivers have expressed a desire for more support for themselves. Therefore there is a need for support through professional-family networks as well as family-to-family networks to improve the quality of life of individuals and families.
- Athletes and coaches requested more activities, skills development and more frequent events. Coaches requested that sports/ exercise activities happen more regularly throughout the week so that it becomes part of the athletes' lifestyle. Athletes requested personal development skills such as being taught how to cook healthily as well as sew. Athletes also requested more frequent SO sports events.
- Adopting the principles of health promotion and disease prevention as part of HC strategies towards better health for persons with intellectual disabilities has proven to be successful and should be continued.
- The involvement of HC into SO sports has been beneficial. Additionally a comprehensive approach to health promotion, together with efforts to connect with the community is needed (this point is expanded in question 2); this approach needs to overtly recognize the impact of social and environmental factors in healthy lifestyle choices.
- Health education of athletes such as teaching them a range of skills and empowering them to make healthy choices has been successful. The use of ALPS in promoting health of other athletes has been a great success and this should be continued.
- The investments made by HC in training health professionals to be better equipped to provide quality healthcare to persons with intellectual disabilities has generated significant rewards. Health professionals have transitioned from being uncertain and reluctant to provide care to athletes to being eager and capacitated to provide quality healthcare.
- The commitment of universities to changing their curriculum to better capacitate health professionals to work with persons with intellectual disabilities is an aspect that HC can continue to contribute towards. Research on health disparities to influence policy and foster a supportive environment was used in Peru and could be recommended for other sites as well.
- Referrals and follow-up care is essential and many creative ways have been used to enhance this, however this remains to be strengthened.

2. How were community partnerships mobilized and created?

Empowerment theory has been central to collaborative partnerships for community health and development The model proposed by Fawcett and colleagues (1995) [9]draws on models of health promotion and of community development with which to examine the effectiveness of community action and leadership. It is an interactive model that speaks to reciprocal influences between the personal or group factors and environmental factors that echo the social model of disability. In drawing on empowerment theory, we recognize that community efforts can act as a catalyst for further change by modifying the conditions under which the health concern occurs.

However, the main focus is in the process of empowerment and community partnerships. The community empowerment process begins with collaborative planning where an agenda is set for community action. This action then leads to community change, which should result in enhanced community capacity that can be used for further change as illustrated in figure 11 below.

The findings from the evaluation identified the following elements, as they appeared the most frequent and are related to empowerment theory:

1. Collaborative planning,
2. Community action leading to change, and
3. Capacity-building for community change.

Figure 11 The cycle of community empowerment (Based on Fawcett et al., 1995)

Within each of these themes, we identify significant sub-themes to help us understand better how HC programs were able to contribute to community empowerment for the promotion of access to health for people with intellectual disabilities. (Note: We have not included the category of adaptation, renewal and consolidation as the aspects have been covered in collaborative planning. It features also in the superordinate themes relating to effectiveness and sustainability of HC Initiatives in the 3rd question and Appendix 7).

[9] Fawcett, Paine-Andrews, Francisco, Schultz, Richter, Lewis, Williams, Harris, Berkley, Fischer and Lopez, 1995.

A total of 19.7% (Refer to figure 4) of excerpts speak to this question. The figures 12 & 13 below gives a more detailed breakdown of the contribution of the informant sites and informant groups for question 2.

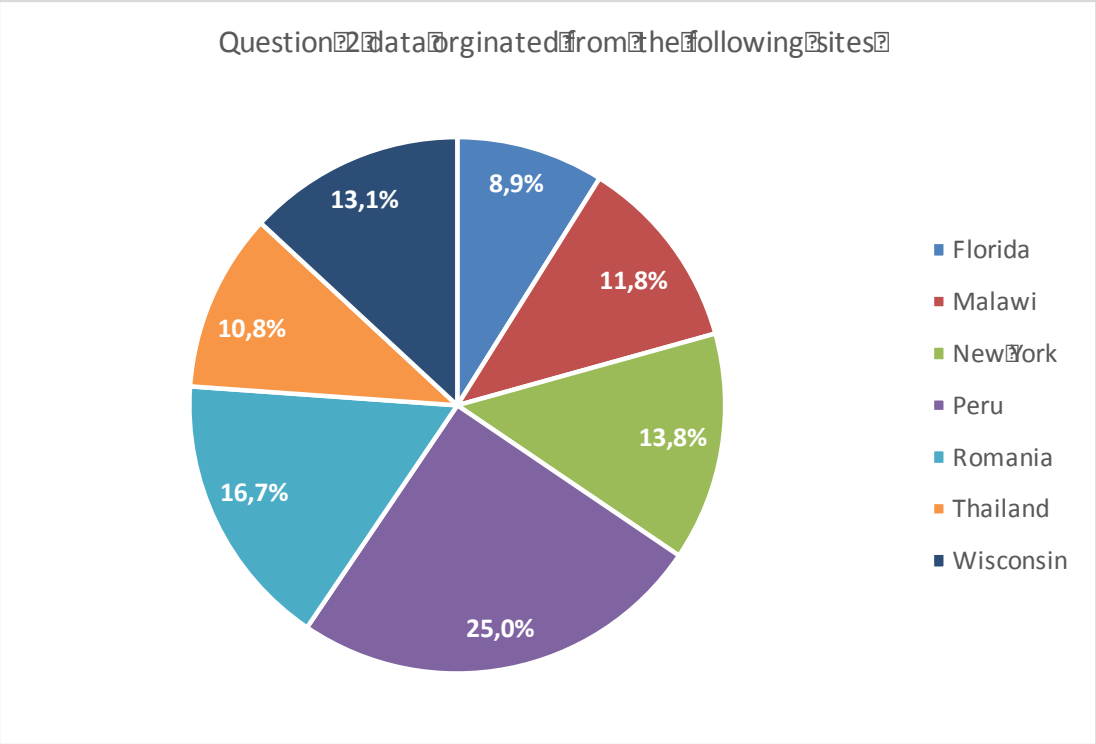

Figure 12 Question 2 data originated from the following sites

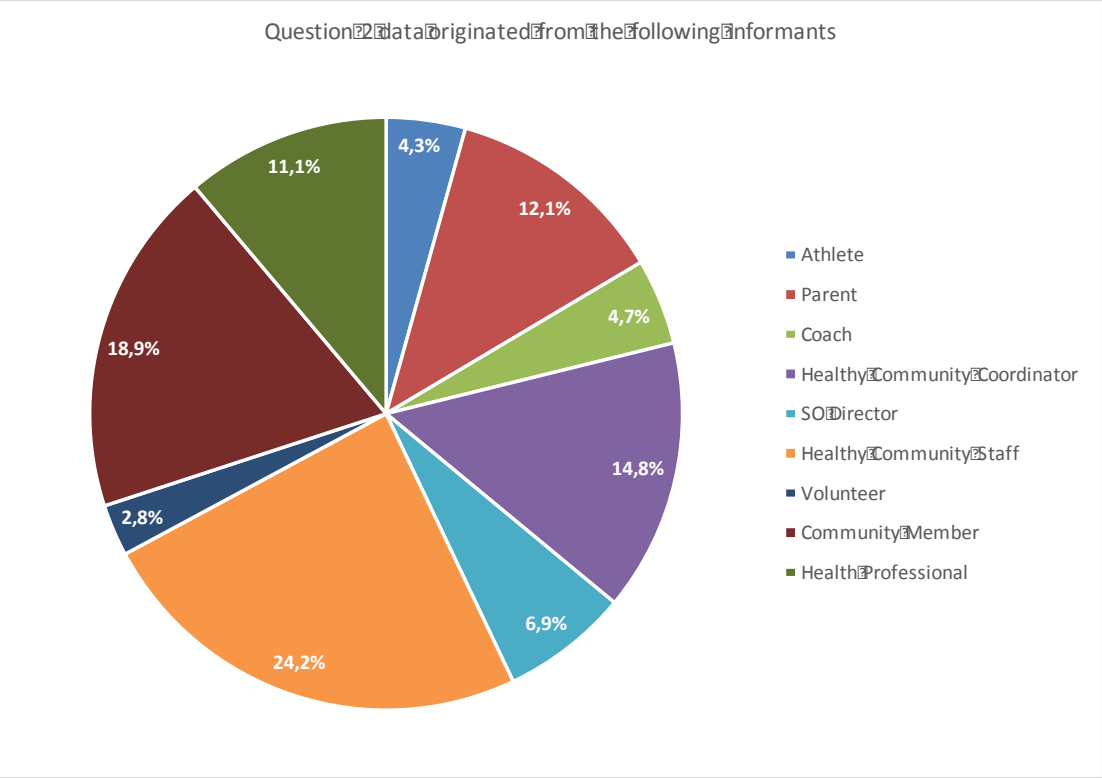

Figure 13 Question 2 data originated from the following informants

Collaborative planning

This element is a crucial for effective community engagement and requires a continuous process of planning and consultation with partners. The theme Collaborative Planning yielded 41.4 % responses from USA sites and 58.6 % responses emerged from L-MIC. Through undertaking collaborative planning, projects are able to enhance group structure and functioning to build capacity for achieving identified goals.

The sub-themes that emerged in the data from the various stakeholders in the seven participating sites could also inform steps that projects or programs take. For detailed examples and differences across sites, see Appendix 6:

- Identifying partners
- The fruits of advocacy and lobbying
- Forming associations
- Fostering cross sector involvement
- Action learning, evaluations and needs assessment

Identifying partners

In order to establish collaborative planning, potential partners had to be identified from the start of the collaboration. It entailed training and support throughout the planning process discussing issues, reflecting, re-planning, and resolving an issue. The needs and strengths of potential partners needed to be assessed and recognized. The informants felt that this meant becoming immersed and engaged with partners.

Examples of successful partnerships were evident in Peru where partners worked together until they developed an MOU with UNICEF as well as strengthened their partnerships with other partners. In Malawi, it was found that it was important for partner to be involved at the start of the project as well the planning of the project. In New York, it also helped to build partnerships when there was a clear vision of what needed to be done.

The fruits of advocacy and lobbying

Advocacy and lobbying took place at the level of the individual and the group or organization in order to prepare and recruit people for the collaborations that are needed for effective planning. In Wisconsin at the individual level, athletes indicated that they are aware of and feel supported when they can see that their advocates are active in pursuing their interests. Moreover, self-advocacy could lead to persons with intellectual disabilities finding their own voice to speak about their concerns and influence change. In Wisconsin, athletes were encouraged to contribute to planning and gain a voice in what affects them directly.

Advocacy by organizations raises awareness amongst potential partners so that collaborative planning can then take place. In Peru, a report on the healthcare needs of persons with intellectual disabilities alerted the Ministry of Health to the nature of their difficulties and HC was then invited to advise and plan with the committee concerned with disability issues in the ministry

Forming associations

Bringing people together into formal or informal associations was important in the various sites. There was also a drive to establish new associations, especially for parents in L-MIC. In Thailand, there was a strong desire expressed for the development of parent associations that would be able to sustain the project. In Romania, families had come together to form associations through which they could develop their knowledge and awareness of health promotion.

There is a marked contrast between the USA, with only 15% of the excerpts within this sub-theme, and the L-MIC with 85% of the excerpts. This difference seems to suggest that the need for associations (often described as parent associations) is perceived as very high in L-MIC.

Fostering cross sector involvement

Given the nature of the goals of HC, which emphasizes partnership and collaboration, cross-sector involvement was essential to consider in collaborative planning. It was fairly common across all sites in both L-MIC and the USA to consider the need for planning across health and social services, especially where the families were struggling financially.

The issue of transport needs to be flagged as a real barrier to implementation of healthcare initiatives and indicates the need for cross sector planning. There were some indications of solutions that came up to deal with the transport issues:

- In Wisconsin, a car-pool to bring families from rural areas to a central point.
- In Peru, parents clubbed money together and used one taxi to take them for health services
- Bring the services to the locality where people are in the community.
- Utilizing connections and available local facilities rather than referrals to specialist facilities in major cities.

Action learning, evaluation, needs assessment

Effective projects begin by looking at the community needs within action research and community empowerment models, although it appears that this was not systematically

carried out across the different sites. The extent to which this proactive approach was applied varied from site to site and depended on both the knowledge of staff and availability of local resources

One HC coordinator from Wisconsin offers specific advice with regard to the needs assessment, to include athletes/consumers from the start or from the beginning.

Projects are constantly seeking to improve or to spread their coverage based on their experiences and successes. The importance of continuous evaluation and reflection was highlighted. Projects did not only learn from their successes but they also developed strategies to address mistakes or failures.

Community action

Community action refers to the actions that are taken by the leaders and members in existing communities toward achieving the desired outcomes. This action can result in changes to policies, practices and programs that are consistent with the mission of the project. Community action was the least prevalent subordinate at 1.6% and this seemed to suggest there is a need to improve in this area. The premise of HC is that community-instigated actions will result from the leveraging of partnerships in order to gain access to resources and health skills, to the extent that they are available in local communities

Thus, in Malawi, engagement and consultation with community leaders was crucial in accessing families and athletes. It is important to involve community leaders because they can influence other community members to take ownership and responsibility towards executing the idea of Healthy Communities programme. Malawi was the best example that illustrated community action, because they were aware of their context and circumstances, and they used a bottom up approach; see Appendix 2 for Theories of Change.

However, there were few examples of communities spontaneously taking actions; rather the onus was on HC to undertake the work.

The data gathered in the evaluation suggested the following sub-themes underpinned community action:

- Generating engagement and consultation
- Complexity of multiple roles and responsibilities

Generating Engagement and consultation

Engagement and consultation with community leaders was crucial in accessing families and athletes. Changes were evident in the attitudes and behaviour of community members in

Malawi who were engaged through training processes. This approach had a knock-on, catalytic effect within the community.

Likewise, the links with universities entailed access to students for screening and access to training courses. This provided further examples of how community action can be mobilized once the leaders are persuaded of the need, and offered support and encouragement to change their usual ways of working. This was evident in University of Rochester were SO has long standing partnership and the university was able to draw volunteers for volunteers.

Complexity of multiple roles and responsibilities

The capacity to bring about community change within the HC and SOI models is related to mobilizing community resources. The main way that HC has tried to effect this mobilization is through the recruitment of volunteers; an approach that requires the delineation of roles and responsibilities of these volunteers and their relationships to HC staff.

HC coordinators were often required to take on multiple roles and responsibilities in the absence of paid staff. To address this, in Peru the staff supported each other by developing work schedules that clarify their roles and responsibilities.

These volunteers and workers, range from skilled professionals to students who are studying to be health professionals. The universities are instrumental in providing these volunteers and there is an expectation that, through their engagement as students, they buy in to the vision of SO and would take this throughout their career. In Peru, a volunteer student talked about her wish to come and work for SO because of the bond developed while still a volunteer.

In the L-MIC, the volunteerism is not always a well-established culture. In Malawi, volunteerism was not always a realistic resource to rely on as people had to think about basic needs for survival first and could not justify working for no compensation.

Capacity-building for community change

Community capacity-building refers to increasing the knowledge, resources and partnerships in the community so that its members become better able to reach their chosen goals. The idea of “healthy communities” is based on an understanding of communities as places that promote health; therefore, it is critical that capacity-building of the entire community for this purpose is achieved in order to bring about community change. Findings related to the subordinate capacity building for community change accounted for 26.6% of overall findings.

In this section, capacity-building and community change were merged due to overlaps that culminated in the above-mentioned heading, capacity-building for community change. Within this theme we identified the sub-theme was communication with partners

Communication with partners

The communication strategies mentioned by informants were those that maintained relationships and joint capacity to achieve the goals of HC. The fact that disability is multi-sectorial and a crosscutting issue helps in the establishment mobilization of partnerships with various sectors. In Thailand, there was a cross sector representation for example; they actively invited representatives from the different ministries of health, public health, education, social service or human resources. In Thailand, HC brokered a relationship between ministries that led to a partnership that built the capacity for combined action.

SO staff recognize that communication is critical to maintaining the gains that have been made. In New York, they recognized that staff stewardship and responsive participation are essential for communication.

The task of bringing about change at a systemic level as opposed to helping individuals is not an easy one.

Conclusions

In summary, community partnerships were evident in all HC sites to varying degrees and more often with a specific focus rather than addressing the more holistic needs of persons with intellectual disabilities and their families. Nonetheless, the main impression from our participants is that HC largely “owned the problem” rather than the communities in which the initiatives took place, see Appendix 8. This perception is not unexpected given the newness of HC in the various sites and the limited resources at their disposal.

The key lessons learnt: How were community partnerships mobilized and created?

- There is greater need to identify possible partners locally and nationally for the development of the project at its initial stages.
- HC should build critical mass through partnership with NGO's and international agencies by involving them in the lobbying processes for improved access to health for persons with intellectual disabilities so they can gain access to government.
- HC needs to expand their partnerships with Community Based Rehabilitation projects in some L-MIC sites for collaborative planning and/or strategies for improved access to health for persons with intellectual disabilities where volunteerism might be a challenge because of contextual related issues.
- There is a need for the formation of formal or informal associations at in the various sites. These associations whether professional bodies or parent associations bring about resources and support for persons with disabilities and the families.
- Cross sector planning should be used by HC to expand their partnerships with the following sectors: Health, Social Development, Education, Transport and Employment.
- Continuous evaluation and reflection needs to be a high priority in planning as this will help the projects to come up with improved strategies.
- HC must consult with Community leaders as they give a directive to other community members to take ownership and responsibility towards executing or implementing the idea of Healthy Communities program.
- There is a need for a designated coordinator to keep communications flowing among the partners as it could determine the kind of services that people with intellectual disabilities and their families could access at any given time.

3. To what extent are Healthy Community Initiatives effective and sustainable?

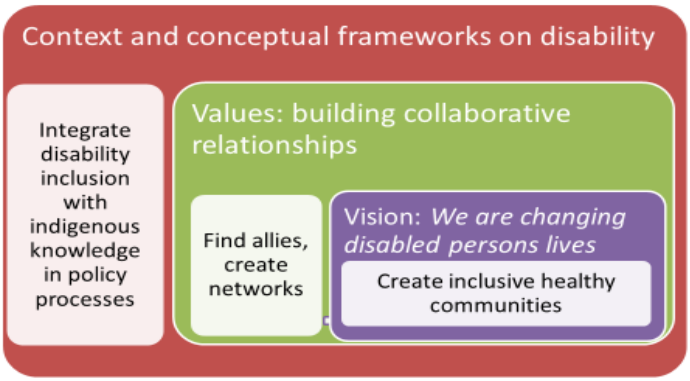

Figure 14 Kaplan's (1999) Elements of organisational capacity

We chose to use Kaplan's (1999) theory of organizational capacity to identify the factors influencing the sustainability of programs (See Figure14). At its most basic, sustainability of HC Initiatives could be considered as local funding replacing the monies provided by SOI in establishing the HC Initiatives within the pilot sites. However, this aspect did not feature in our interviews but is covered by the monitoring reports provided by the pilot sites to SOI. Another objective is for HC initiatives to become embedded and sustained by the community partnerships as outlined in the previous section, albeit with SO continuing to have an influential role in advocacy and advice – although not necessarily through funding. It is the latter option on which we have chosen to concentrate, primarily because the best use of short-term donor funding is to work towards community sustainability. The participants in the study seemed to focus on the financial aspects related to sustainability, without appreciating the depth of human resources and experiences that could be drawn on to develop networks of reciprocal support and relationships that would strengthen their efforts. Kaplan argues that the tangible elements of funding, infrastructure and individual skills and abilities are usually focused on as they are more measurable than the intangible elements of values and aspirations, and the vision that drives a new initiative. These aspects are expanded on under three themes that follow.

A total of 43.9% (Refer to figure 4) of excerpts speak to this question. The figures 15 & 16 below gives a more detailed breakdown of the contribution of the informant sites and informant groups for question 2.

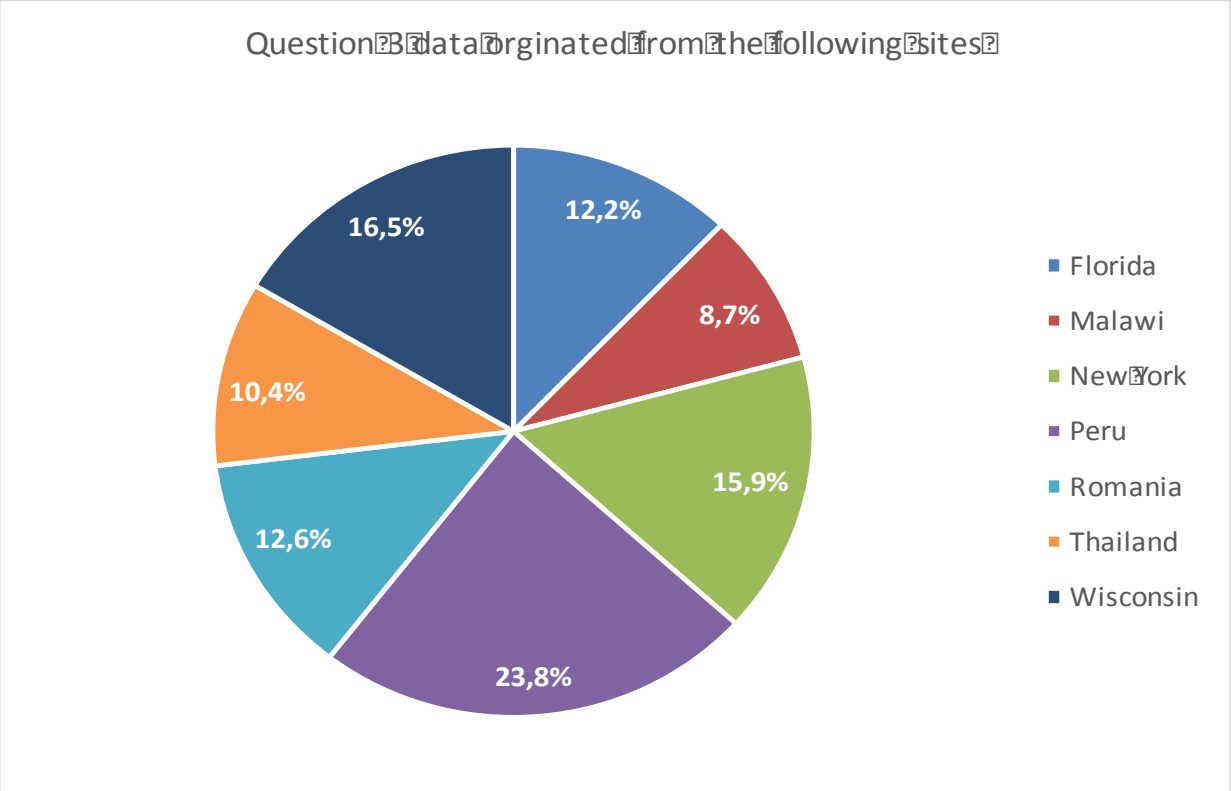

Figure 15 Question 3 data originated from the following sites

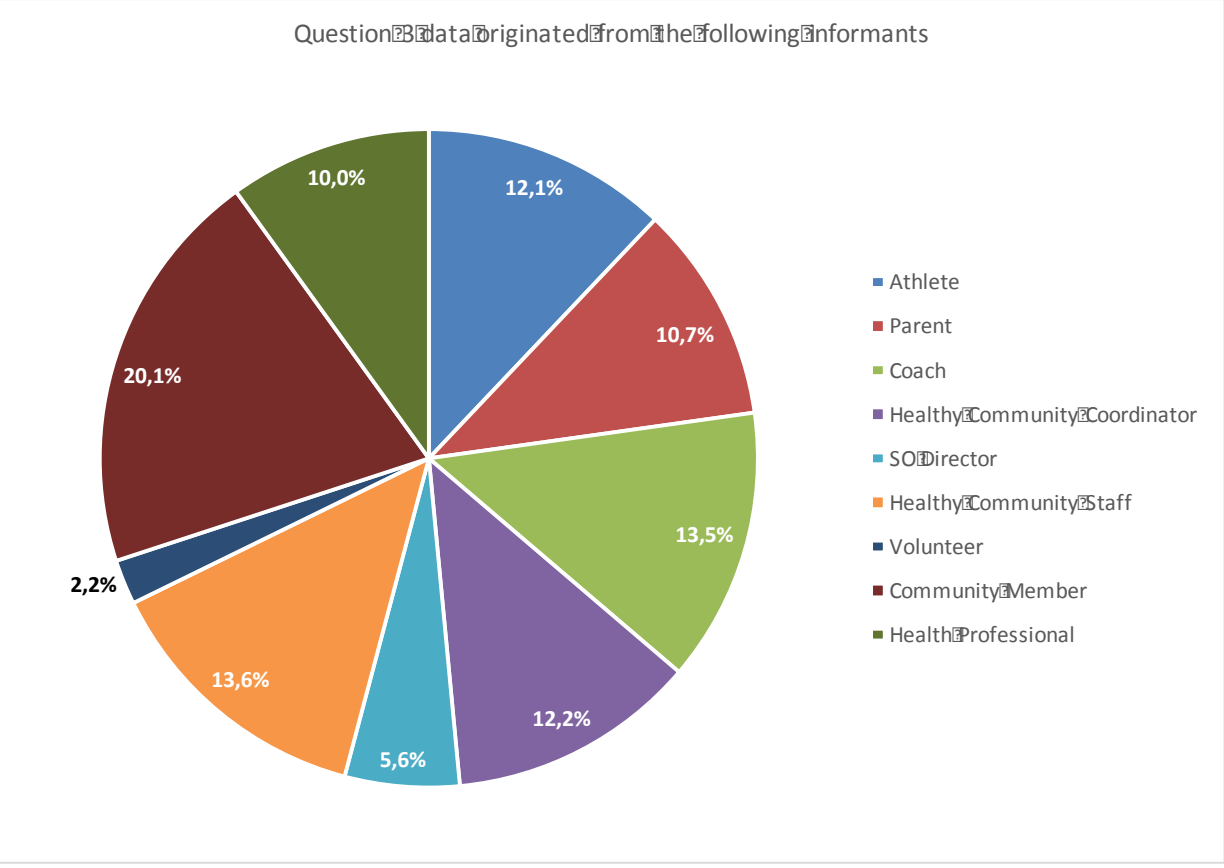

Figure 16 Question 3 data originated from the following informants

Theme 1 - Integrating Disability Inclusion with indigenous knowledge in social policy: Conceptual understanding of disability in context

This theme explores how the extent to which different sites was able to tap into local wisdom and practices to integrate disability in social policy. Secondly, identifying global policies for action at a local level emerged as a sub-theme.

Tapping into local wisdom by actively-aligning the work with indigenous people and the policy processes of the country contributes significantly to sustainability as it fosters community ownership, as seen in Peru, Malawi and Thailand. Grounding the programme in the *recognition and respect of indigenous people* integrates the influences of culture during stages of planning and implementation that leads to sustained change in attitudes to remove barriers to inclusion. The HC programme is more likely to influence relevant and inclusive policy processes, for example, through engagement with international NGOs like UNICEF and SCF on children's rights to health and education and safe living conditions. The surveys integrated disability into focus on implementation of programs and policies with local and regional governments.

Identifying global policies for action through engaging regional and local government was also valued as a means to sustain programs. For example, aligning HC with the UN Convention on the Rights of People with Disabilities along with the UN Convention of the Rights of the Child serves to contrast existing rights and then assess their level of fulfilment by examining barriers in health, education, and protection against violence. HC initiatives could also be closely aligned with WHO's Community Based Rehabilitation Guidelines, which operationalize the values and principles of the CRPD. There were no HC sites where this was evident, but it is an aspect that should focus on in the future rollout. WHO would gain from the experience of SOI's HC regarding implementation of inclusive sports to promote health and well-being of persons with disabilities.

Theme 2- Finding allies, creating networks: Building collaborative relationships

This theme reflects the values and beliefs related to building collaborative networks at two levels: finding allies at different levels of public and private health services, as well as the NGOs and DPOs. Secondly, the creation of professional and family networks was achieved.

Flexibility in decision-making enabled each site to be responsive to identified priorities, which are informed by contextual factors and beliefs about disability. An attitude of curiosity and being open to learning more about persons with intellectual disability promoted *reciprocal learning* among professionals and families who contributed positively to

sustainable implementation. A mother in Florida mentioned the support she received from other parents in managing difficult domestic situations.

There was wide recognition that persons with intellectual disabilities are less visible and usually more marginalized in accessing services and opportunities. The results of surveys on the living conditions of children with intellectual disabilities identified priorities related to exclusion, which informed how barriers are addressed and what partnerships were developed.

The attitudes of staff and volunteers seemed to be deeply rooted in the *fight for social inclusion* of intellectually disabled children and youth through participation in sport and social media such as Facebook, as seen in Florida and Wisconsin. The parents in other sites also recognized the limited opportunities their children had for social interactions.

Monitoring change in people was appreciated as a means to sustain a programme more than just having numbers. The mental and emotional well-being of children and family members was promoted through professional and peer support.

Theme 3 - We are changing disabled persons' lives: Reaching for a vision of creating inclusive healthy communities

Fundamentally, sustainability requires identifying and committing to a shared vision. Informants identified six strategies to define and reach the vision set out by Healthy Communities. These illustrate how Kaplan's tangible elements of organizational capacity in achieving a shared vision.

1. Training of trainers and leadership development

Building capacity through training different categories of stakeholders is the crux of the SOI strategy for sustainability as they invest in the human resource development to ensure effective organizational capacity. The Athlete Leadership Programme, for example, can be a potent catalyst for change both locally and globally as well as training people with ID to be health educators this notion came from Wisconsin and Thailand. There was also a strong family focus on developing individual skills, abilities and competences. In Florida, the staff met with parents or the healthcare provider of the family or the caregiver once a week for six weeks. In Malawi, family health forum offered parents the first opportunity to share their experiences and concerns about health. However, motivating parents to participate in training events and meeting, and to even follow-up on appointments HC staff made for children to obtain treatment, remained an ongoing challenge across sites. The mental health and wellbeing of the family members who are the primary caregivers needed to be monitored.

Further attention needs to be paid to the composition of the HC teams and the differentiation of functions. SO's tradition and experience is to build the capacity of volunteers. It remains an open question the extent to which volunteers could contribute to the human resource capacity of HC initiatives in the future, as personnel in resource-poor countries where unemployment is high need to be remunerated for their time.

2. Creating effective information and communication systems using technology

Sustainability is dependent on effective information and communication networks for the co-ordination of activities across the different stakeholder groups of athletes, parents, coaches, volunteers and health professionals. HC personnel must be competent in accessing and using technology for efficient communication and in leading programs. The use of technology to develop databases and an information system to capture data was evident in more than three sites. There were limitations in the use of IT related to infrastructure and financial costs in L-MIC sites.

The monthly Webinar that the evaluation team participated in during the pilot were led by SOI to review best practices and to share research from different countries to identify how programs can be improved. These opportunities were valued although the implementation of initiatives across sites is still emerging.

Information Technology has been leveraged in all HC sites for information dissemination and communication as well as marketing and fundraising. Most sites needed financial support in order to use technology effectively.

Thailand noted that parents were from poor families and unable to use text messages and cellphones; some caretakers of children were elderly people. Also in Thailand, they talked about the time-consuming usage of Excel and their need for an application. In Wisconsin, they noted that in order to develop an Information Technology, a fundraising strategy was also important. Additionally, in Wisconsin, they were happy about the funds they used to buy tablets to take down the results of healthy athletes' screenings electronically. This was new territory for HC. Lastly, in Thailand, their partnerships with UNICEF connected them to DTAC who supported them with sim card for text message reminders and awareness. In other words, DTAC carried the costs of sending the text messages.

3. Influencing curricula changes in training of health professionals

When training and capacity building of health professionals is absent or insufficient in sites, exchange programs might be considered across countries. For example, the need for dental-care skills could be shared between Rochester and Peru, which also indicates curriculum changes. There was a request for guidance in community committee

development raised in Malawi and for IT in Thailand. The international networks potentially available through Healthy Communities could contribute significantly to its sustainability.

4. Networking with local and international organizations

Creating networks across agencies to build capacity of individuals allowed for sharing success stories, locally and internationally. Athletes experienced the benefits of health screenings when community resources were mobilized. In New York, it also helped to first clarify their vision to undertake health screening and afterwards HC was able to attract partners, see Appendix 6 on sub-theme: identifying partners. In addition, for capacity building of staff and parents see Appendix 5 for the following sub-themes group activities; new training; individual skills; and family health promotion. In some collaborations, there was a specific focus on rural areas, which are usually poorly serviced and under-resourced. How these relationships were maintained is addressed in Appendix 6.

5. Research collaboration through partnerships

The strategy of developing collaborative partnerships with Universities or other international NGOs such as Save the Children or UNICEF helped local HC Programs to develop capacity to do case studies of contextual matters affecting the access to services for disabled children. These collaborations could be extended by looking at other issues affecting persons with intellectual disabilities. There was some innovative thinking about promoting inclusive research and development by having disabled children and youth as co-researchers.

6. Prolonged engagement with partners

The need was widely recognized for funding, infrastructure, equipment and other facilities needed for the effective and sustainable running of the Healthy Communities programs in the countries where they were piloted. Innovative fundraising strategies are needed to contribute to indigenous sustainability. Value-in-Kind seems to dominate but fund-raising can deflect HC staff from the many other roles they need to fulfil and which are outlined above.

In summary, these strategies were used in specific sites rather than commonly across all sites, in large part due to the opportunities and resources available to the HC in each site.

Perhaps it would be wiser to think about sustainability for the outset when establishing new HC Initiatives and to make this a priority throughout all planning and monitoring of project work.

Possible strategies for sustainability:

- Create professional and family networks to sustain programmes
- Develop consensus among community partners on approaches to disability inclusion based around social justice,
- Actively align the work of the HC program with local policy processes of the country as it fosters community ownership
- Build collaborative relationships with public-private service providers, corporates, universities and international non-governmental organisations as well as disabled people's organizations to research and monitor policy implementation.
- Local sites should develop partnerships with local businesses through corporate social responsibility (Examples *Wisconsin and Peru*).
- Lobby universities and professional bodies to institute curricular changes to integrate disability into the training of health professional training
- Flexibility in decision-making enables each site to be responsive to identified priorities, which are informed by contextual factors and beliefs about disability.
- The Athlete Leadership Programme was recognised as a potent catalyst for change both locally and globally.
- When training and capacity building is limited in sites, exchange programmes of resources and personnel might be considered across countries.

Healthy Communities: The Future?

Finally, we would like to share with you some of our thoughts on the implications of the foregoing analyses that have emerged from this evaluation of Healthy Communities Programs across seven sites. We realize that these thoughts may not present a complete picture of the many facets of the program as it has evolved in all 14 sites. Our aim at this stage is to stimulate reflection and reaction.

The achievement of Healthy Communities in the short period of its existence is nothing short of remarkable. It reflects the enormous value of investing in human resources of staff, athletes, parents, coaches and the volunteers who contribute to use their time and energy effectively to drive the implementation with scarce financial and material resources. All sites showed an ability to be reflective, non-defensive, self-critical and resilient. These organizational characteristics revealed a healthy capacity to make a significant contribution to improving the health outcomes and quality of life of persons with intellectual disabilities and that of their families. In this concluding section, we bring together the successes and challenges faced by SO in the implementation of HC pilot initiatives and begin to use this learning to look to the future of HC internationally.

Realizing the vision

The vision for Healthy Communities is very ambitious (Figure 17). The initial programs are but a first step in a journey towards laudable goals that encompass:

- ALL persons with an intellectual disabilities and their families;
- Inclusive individual, community, national and global initiatives;
- Optimal health and productive lives for all.

Figure 17 Healthy Communities Vision

Balancing Approaches

Thus far, the main focus of Healthy Communities has been centered on Special Olympics Programs within the chosen sites and on the persons with intellectual disabilities who participate in them. The dominant focus has been enhancing their health assets; the first column in Figure 18 shows the main activities, which flowed from this focus.

Presumably, however, the intention is to use these experiences to extend programs into local communities. This intention brings into focus the environmental influences listed in the central column of figure 18 that affects everyone's health and which the evaluation has confirmed.

A third strand would focus on national and global policies. The main priority is to ensure that persons with intellectual disabilities are included in the range of policies that currently exist and that have achieved global support.

Figure 18 Holistic views of main Evaluation themes

As the global Healthy Communities Initiative moves into a further phase of its development, it should reflect on the balance of time and energy that is invested in activities across the three domains shown in Figure 18

In order to assist with this process we pose three questions that may be helpful in working toward the ambitious vision. Each of these questions is summarized below and details reflecting on past experiences in order to inform the future are given in Appendix 8.

How could HC initiatives be extended to other SO sites within a country/state?

The evaluation provides evidence of the impact that HC has had on the beneficiaries. Models of good practice have been devised, implemented and tested. Yet the impact of this approach is largely limited to SO participants. Two aspects are discussed, namely integrating sport and health, and project planning with critical stakeholders.

Integrating sport and health

In many of the sites, we observed that confusing relations existed between the sport and health functions of SO. The question is – how can health screens be extended beyond competitions? Some suggestions include training coaches to perform simple screening – especially within Health Promotion and Physical Fitness domains of Healthy Athletes – so that they can identify the risk factors to health among their athletes. Parents seem to be an under-utilized resource and may be keen to be trained to do health screenings as they are often present at the events and have shown commitment to improving the health outcomes of their children. The success of health forums for parents could usefully be extended to

look at mental and emotional well-being of individuals and parents. The possibilities of merging health and sports to contribute to the skills-development of persons with intellectual disabilities for employment and income generation should be explored more consciously and explicitly in the next stages of HC developments, especially in LMIC countries.

Project planning with local and national stakeholders

SOI should be vigilant in the next rollout of HC initiatives to ensure that planning for high- and low-middle income countries should not necessarily follow the same pathway but be adapted according to differences in cultural understanding and responses to disability. More attention needs to be given to the rollout of HC projects in rural areas, which are often under-serviced, and under-resourced (Booyens, Van Pletzen and Lorenzo, 2015).

The most important stakeholders are persons with intellectual disabilities and their families who need to be consulted from the start as any intervention must be informed by the users.

Other stakeholders include government, service providers, agencies, disabled persons' and parent organizations, NGOs, universities, international organizations and the community. There is evidence of successful partnerships with universities and/or global NGOs, which have influenced changes to curricula so that health services become more inclusive as providers are better equipped to treat persons with intellectual disabilities.

How can HC be extended to people with intellectual disabilities beyond SO?

This question relates to the heart of the HC mission – how do communities become health-promoting places? It is not just about a few athletes getting increased access to health services but about creating an environment, which promotes the health of all persons with intellectual disabilities. Successful strategies need to be contextualized to different cultures.

Contextualize strategies

There was a tendency to under-utilize knowledge and experience from countries outside the USA to inform the programs in the initial stages of planning and fund-raising. For example, voluntarism – as it occurs in the USA – draws upon the fact that there are institutional mechanisms for supporting and rewarding voluntarism; i.e. it is part of university students' courses to work as volunteers in organizations like SO and is often an essential part of the undergraduate and postgraduate curricula. In LMIC countries such as Malawi, where subsistence needs are high, a community-based strategy works better with the community leaders buying into the strategy of SO and being responsible for disability issues within their own locality. Community rehabilitation workers, community health workers

and/or community development workers, who are present in many L-MIC, partnerships with them could be better utilized. They too would benefit from further training around the needs of people with intellectual disabilities.

In order to achieve their health outcomes, there needs to be some sort of community health-mapping capacity within HC. This mapping could follow an asset-based community development approach where a survey of community assets that contribute to health could be determined. These considerations are relevant for developing national policies and services that are inclusive.

Innovative funding strategies in local contexts should be supported as the HC staff are able to build partnerships with businesses and companies that will provide relevant services, products and technology to contribute effectively to the four pillars of HC Initiative.

Streamlining advocacy

In the empowerment model, the agenda to be followed by health projects arises from the community and is owned by the community in its purpose and process. The reach of the HC initiative could also be expanded through local advocacy groups, especially parent associations, to advocate for improvements of access to health services in their locality. Where parent organizations are established then a family-centred approach should be emphasized. At a national level, there is a need to engage further with national advocacy organizations such as DPOs and parent associations who can lobby politicians to take up, or integrate, disability into local and national policy. The health data which SO gathers could be shared with NGOs and DPOs to provide information for writing a shadow or alternate report on implementation of the UN Convention on the Rights of Persons with Disabilities within their country which are required to be submitted every five years to the UN Special Rapporteur on Disability..

Creating networks to maximize resources

The nature and benefits of professional and family networks that maximize the use of available resources have provided valuable lessons to share as HC expands. While funding is often seen as the means to sustainable development through effective programs, it is actually the nurturing and valuing of human relationships that contributes most to improved physical, emotional, mental and spiritual health and well-being within communities. The efforts of the HC “extended family” provide hope for sustained social change and inclusive systems for health, education, social and livelihoods development. This goodwill can be further developed in, for example, building local partnerships at a sub-national level targeting doctors, dentists, nurses, therapists and teachers.

Sponsorship and fund-raising could occur at the local community level. The success of these partnerships would largely depend on the success of the empowerment process that nurtures community ownership.

Leveraging technology

The use of technology is another issue that needs to be adapted to the local context. It is clear that the power of technology has not been sufficiently harnessed within the current HC projects. For example, health promotion programs can be offered over a wide range of sites through video conferencing, webinars or Skype, to a group of participants who can have this experience mediated for them by a local health coach. However, issues around user capacity and engagement with technology need to be coupled with considerations of cost and bandwidth, especially in low-income countries. The use of technology for record keeping is already being addressed by HC to ensure that record systems are compatible with those used by the national healthcare system as far as possible.

How can the healthcare of persons with intellectual disabilities be integrated into national policies and health services?

The amount of data on health screenings and outcomes is impressive, and it needs to be translated to inform the integration of the healthcare of persons with intellectual disabilities into national policies related to health and social services. Currently, here is a tendency toward parallel systems for persons with intellectual disabilities and a closer consultation with governments is needed around an awareness of national policies and ensuring they are inclusive of persons with disabilities. Influencing curriculum changes in health professional training also offers the hope for more integrated and inclusive policies and services going forward.

Changing and implementing policies

Where there are gaps in national policy that ignore disability issues, these need to be targeted. Consultative processes between government departments and SO at country level become crucial. As a strategy, SO could learn from some of the successes observed in Thailand and Peru, with university partnerships strengthening the advocacy and lobbying by SO programs and their engagement with government departments.

Many international policies can form the basis on which advocacy and lobbying can take place. For marginalized groups, such mobilization is best done through alliances. The goal is to ensure that these policies are implemented and monitored to identify progress made and further changes needed. The evaluation suggests that this collaboration has been limited thus far. SOI and HC could use the UNCRPD (2006) and the CBR Guidelines

(WHO, 2010) as frameworks to generate a common understanding of disability across all programme initiatives. These frameworks promote holistic health. Addressing socio-economic determinants of health at a population level (Frieden, 2010) requires that persons with disabilities and their families become economically active in accord with the Sustainable Development Goals.

The following activities could be undertaken: For example:

- Sensitizing SO programs and partners on the global policies affecting the health, wellbeing and inclusion of persons with disabilities.
- Mobilizing community coalitions to take ownership of improved health access and health promotion activities for persons with intellectual disabilities and their families.

Lobbying national governments to implement and fund specific service improvements in line with global policies and based on the insights and information gained within the countries in which Healthy Communities is required. Also needed is engagement with policy-makers across different sectors regarding implementation of international accords and adapting mainstream services to meet the needs of persons with intellectual disabilities.

Influencing health professionals

The potential to influence change in the curricula of health professionals at undergraduate and postgraduate level is evident. Exchange programs within and across countries have been fruitful, and use of information technology would assist in extending these exchanges. Professional associations, that determine the core practice of various professionals, also need to be engaged in how they meet the needs of persons with intellectual disabilities and their families, as well as strengthening community involvement in training initiatives. Disability service providers also need to be addressed, as they can become allies in pressing for change. There is a need to reflect upon the difference between associations ***of*** persons with disabilities and associations ***for*** persons with disabilities. Which one would SO and HC consider themselves to be?

Evaluation lessons

As we draw this report to a close, we would like to highlight some of the lessons learnt from identifying the limitations of this evaluation that can be taken into account in assessing the outcomes of the evaluation as well as in planning future evaluations. For future research, co-evaluators (who were athletes) should form part of the evaluation team as they could assist with the formulation of questions that are expressed in a way that can be easily

followed by peers. There is a need for further advocacy with IRBs as the gatekeepers of researchers for inclusion of persons with intellectual disabilities as co-evaluators.

We have recognized that there was a difference in services and resources between high-income and low-middle income countries, which needs contextualizing in the planning of projects and their implementation across varied contexts. A Theory of Change (ToC) model could be used to design a monitoring and evaluation framework from the beginning that accounts for such complex initiatives.

The HC evaluation was commissioned as a summative assessment. There would be value in planning a more longitudinal study to monitor change processes. A panel study design could be considered to follow athlete development at two-year intervals in the different sites.

Summary of Recommendations

This evaluation has shown how the HC initiative is able to make a significant contribution to ensuring that persons with intellectual disabilities are included in the SDG targets. We suggest the following recommendations in this regard:

- Professional and family networks should be developed and supported as peer support and reciprocal learning has improved emotional and mental well-being of individual family members and caregivers. It has also capacitated health professionals to address needs of persons with intellectual disabilities.
- Disabled Peoples and Parent Organizations need recognition as critical partners that will contribute to leadership development and policy implementation and monitoring, which could be used to report on the implementation of the CRPD in their countries, if the government has signed and ratified the CRPD.
- In countries where there are community-based health and rehabilitation workers, they should be utilized to help bridge the gaps in service delivery so there is a better continuum of care and supportive environments are created. A critical mass of health coaches to work with sports coaches should be developed. They will reinforce collaborative efforts between health, education, social and livelihoods sectors so that it is strengthened and sustained. These efforts will address social and economic wellbeing at a population level.
- Strengthening partnerships between SO programs, health services and universities in countries to engage undergraduate and postgraduate students as volunteers for health screenings, as their involvement influences curriculum changes so health services become more inclusive.

- Research partnerships with universities and global organizations have helped to build capacity for evidence-based advocacy campaigns. Use of information technology and social media can extended to the dissemination of successful strategies for improving health outcomes and quality of life of persons with intellectual disabilities and their families.
- Livelihood initiatives linking sports, skills development and income generation is needed, as children with intellectual disabilities become adults who need to find opportunities to become economically active. The link between work and improved health outcomes is well known.

Conclusions

This evaluation, across five continents, seven HC Initiatives and involving over 500 informants, has provided a unique opportunity to step back from the busy-ness of activity to reflect on why and how the Initiatives are working, the impact they have had and the implications for future action. It has shown what is possible when there is coherent vision and committed staff who collaborate with athletes, their families, coaches and health service providers as well as business, universities and international organizations. The successful strategies and lessons learnt should be shared widely to promote the inclusion of all disabled persons and improved health outcomes and quality of life for all.

References

Blanche MT, Durrheim K, Painter D (2006) *Research in practice: Applied methods for the social sciences,* Juta and Company Ltd.

Booyens, M., Van Pletzen, E., & Lorenzo, T. (2015) The complexity of rural contexts experienced by community disability workers in three southern African countries *African Journal of Disability* 4(1), 1-9 Art. #167,9 pages. http://dx.doi.org/10.4102/ ajod.v4i1.167

Cassell, C., & Symon G., eds. 1994. *Qualitative methods in organizational research: A practical guide.* London: Sage.

Cole, J & Gardner, K (1979) Topic work with first-year secondary pupils. In: Lunzer, E & Gardner, K (eds) *The Effective Use of Reading*. London: Heinemann: 167-192.

Connolly, P. (2003). *Ethical principles for researching vulnerable groups*. University of Ulster, Coleraine.

Dahlgren G, Whitehead M (1992*). Policies and strategies to promote social equity in health*. Copenhagen, WHO Regional Office for Europe (document number: EUR/ICP/RPD 414(2); http://whqlibdoc.who.int/euro/-1993/EUR_ICP_ RPD414(2).pdf, accessed 16 June 2006).

Denzin, N. K. (1978). *The research act: A theoretical introduction to sociological methods* (2nd ed.). New York: McGraw-Hill.

Donald, D., Lazarus. S. & Lolwana, P. *Educational Psychology in Social Context (3rd Ed).* (2010) Cape Town. Oxford University Press.

Emerson, E., Baines, S., Allerton, L. and Welch, V. (2012) Health Inequalities and People with Learning Disabilities in the UK: 2012. *Improving Health and Lives: Learning Disability Observatory*. London: Public Health England.

Fawcett, S.B, Paine-Andrews, A, Francisco, V.T., et al (1995) Using empowerment theory in collaborative partnerships for community health and development. American *Journal of Community Psychology*, 23 (5), 677 – 697.

Frieden, T. (2010) A framework for public health action: The health impact pyramid. *American Journal of Public Health*, 100, 590–595.

Healthy Communities Pilot Final Result, 2015, Special Olympics International, viewed January 2016

International Network on Strategic Philanthropy (2005) *Theory of Change Tool Manual*. Available at: http://www.dochas.ie/Shared/Files/4/Theory_of_Change_Tool_Manual.pdf.

Kaplan, A. (1999). The developing of capacity. *Community Development Resource Association*, 1-32.

Kaplan, A. (2000) Capacity Building: Shifting the Paradigms of Practice. *Development in Practice,* 10 (3/4), 517-526.

Krahn, G. L. and Fox, M. H. (2014), Health Disparities of Adults with Intellectual Disabilities: What Do We Know? What Do We Do?. *Journal of Applied Research in Intellectual Disabilities*, 27: 431–446. doi: 10.1111/jar.12067

Krahn, G., Hammond, L. and Turner, A. (2006) A cascade of disparities: health and healthcare access for people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 12(1): 70–82.

Krefting, L. (1991) Rigor in qualitative research: the assessment of trustworthiness. *Am J Occup Ther.* 1991 Mar; 45(3):214-22.

Lincoln, YS. & Guba, EG. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publication

Lopez, et al (2006) Global and regional burden of disease and risk factors, 2001: systematic analysis of population health data. *Lancet*, 367: 1747–57

Lorenzo, T., Motau J.; Van der Merwe T.; van Rensburg E Janse; Cramm J. M. (2015) Community rehabilitation workers as catalysts for disability: inclusive youth development through service learning. *Development in Practice* Vol 25, 19-28

Lorenzo, T., van Pletzen, E., & Booyens, M. (2015) Determining the competences of community based workers for disability-inclusive development in rural areas of South Africa, Botswana and Malawi. *International Journal for Rural and Remote Health,* 15: 2919, p1-14. (Online) Available: http://www.rrh.org.au

MacLachlan M., Amin M., Mannan H., El Tayeb S., Bedri N., Swartz L., Munthali A., Van Rooy G. & McVeigh J.. (2012). “Inclusion and human rights in health policies: Comparative and benchmarking analysis of 51 policies from Malawi, Sudan, South Africa and Namibia”, *PLoS One*, 7(5).

Mannan H, Amin M, MacLachlan M, the EquitAble Consortium.(2011) *The EquiFrame manual: a tool for evaluating and promoting the inclusion of vulnerable groups and core concepts of human rights in health policy documents*. Dublin: Global Health Press, 2011.

Marks, et al (2010) Evaluation of Community-Based Health Promotion Programs for Special Olympics Athletes. jp *Journal of Policy and Practice in Intellectual Disabilities*, 7 (2), 119–129.pi_258 119..129.

Marks, B. & Sisirak, J. (2014) Health promotion and people with intellectual disabilities. In L Taggart & W. Cousins (eds). *Health Promotion for People with Intellectual and Developmental Disabilities*. Open University Press, Maidenhead.

Marks, B., Sisirak, J., Heller, T., & Wagner, M. (2010). *Evaluation of Community-Based Health Promotion Programs for Special Olympics Athletes*, 7(2), 119–129.

Ottawa Charter: http://www.who.int/healthpromotion/conferences/previous/ottawa/en/

Silverman, D. (2001) *Interpreting Qualitative Data: Methods for Analysing Talk, Text and Interaction*, Sage publications.

Singal, N. (2006). Inclusive education in India: International concept, national interpretation. *International Journal of Disability*, Development and Education, 53 (3), 351-369.

Special Olympics (2015) Healthy Communities Pilot - Final Results Unpublished report. Washington DC.

Special Olympics (2015) Healthy Communities Pilot - Final Results. Washington DC

Stake R.E. (1998) Case studies. In: Denzin N. K, Lincoln Y. S, editors. *Strategies of qualitative inquiry.(2nd ed)* Thousand Oaks, CA: Sage; 1998. pp. 86–109

Stake, R.E. (2008). Qualitative Case Studies. In NK Denzin and TS Lincoln (Eds)., *Strategies of Qualitative Inquiry, (3rd Edition, pp119-150),* Thousand Oaks, CA, Sage.

Taggart, L. & Cousins, W. (2014) *Health Promotion for People with Intellectual and Developmental Disabilities*. Open University Press, Maidenhead.

U.S. Public Health Service. 2001. Closing the gap: A National Blueprint for Improving the Health of Individuals with Mental Retardation. *Report of the Surgeon General's conference on health disparities and mental retardation*. Washington, DC: U.S. Public Health Service.

UNICEF (2014) The State of the World's Children: Children with Disabilities.

Van Pletzen, E., Booyens, M. & Lorenzo, T. 2014 Community Disability Workers' potential to alleviate poverty and promote social inclusion of people with disabilities in three Southern African countries. *Disability and Society* DOI: 10.1080/09687599.2014.958131

Wilkinson, R., & Marmot, M. (Eds.). (2003). *Social determinants of health: The solid facts* (2nd ed.). Denmark: World Health Organization.

World Health Organization (WHO). (2010). Community-based Rehabilitation: CBR Guidelines (Geneva: WHO), www.who.int/disabilities/cbr/guidelines/en/index.html

World report on disability 2011

Yin, R. K. (2009). *Case study research: Design and methods* (4th Ed.). Thousand Oaks, CA: Sage.