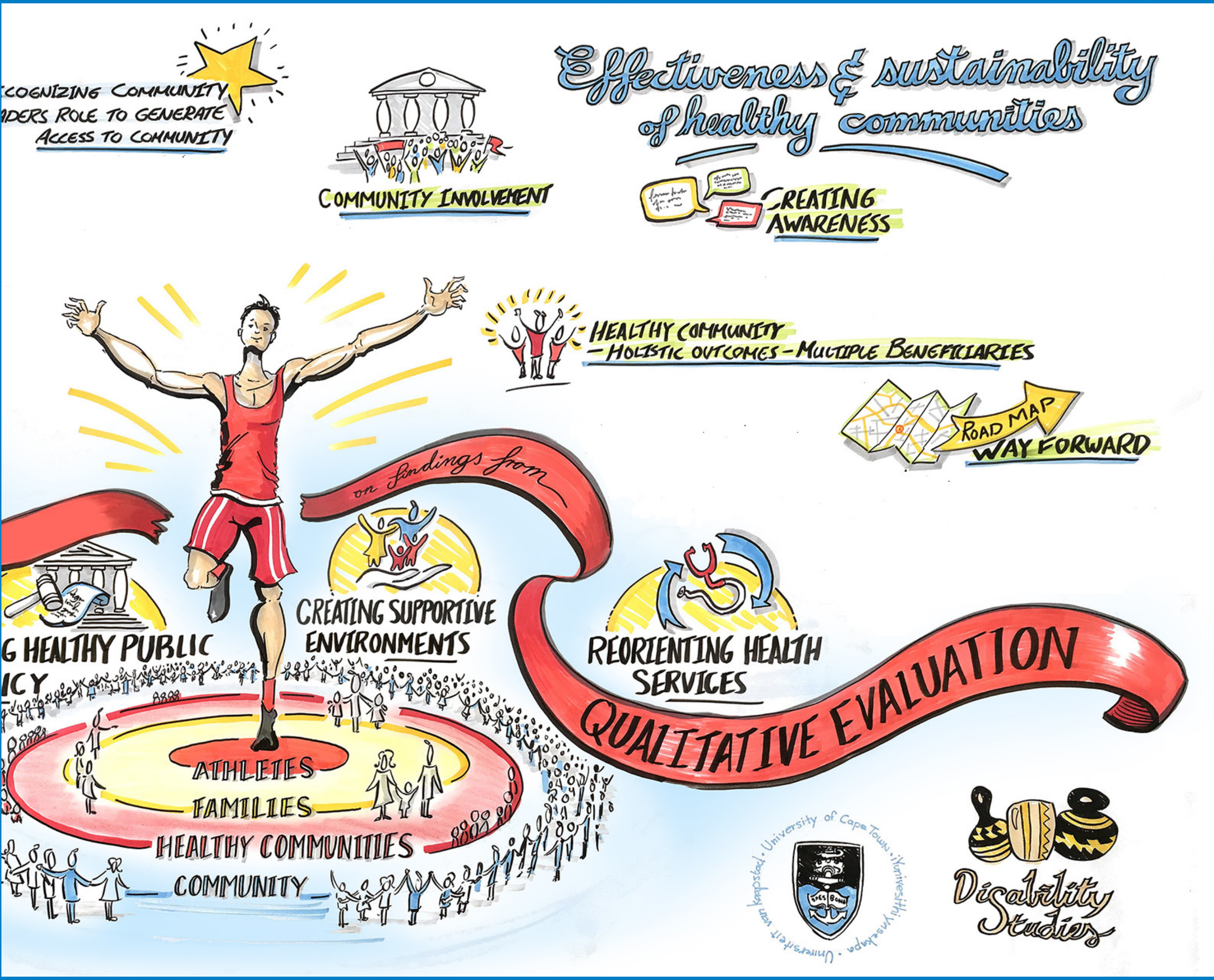
DISABILITY CATALYST AFRICA



IMPLEMENTING INCLUSIVE POPULATION HEALTH FOR YOUTH

SERIES NO. 6

DISABILITY CATALYST AFRICA

IMPLEMENTING INCLUSIVE POPULATION HEALTH FOR YOUTH:

EXPERIENCES FROM LOW- AND MIDDLE-INCOME COUNTRIES

Edited by Roy McConkey

Series Editor: Prof Theresa Lorenzo

DISABILITY CATALYST AFRICA SERIES NO. 6

AFFIRM ADVOCATE ACCOUNT

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AIMS AND INTENTIONS OF DISABILITY CATALYST AFRICA

The situation of persons with disabilities calls for a catalyst to prompt the changes and shifts to the status quo that will ensure their participation in society as active citizens. *Disability Catalyst Africa* intends to create spaces for dialogue, debate and action among different stakeholders in higher education institutions, civil society organisations and government, particularly local government. It also intends to generate awareness on disability-inclusive development, and facilitate the self-representation of persons with disabilities in academic and public forums.

The pillars are **affirmation**, **advocacy** and **accountability**. The series of *Disability Catalyst Africa* should appeal to those at every level who are able to influence disability inclusion in their institutions, and make a difference in the lives of disabled people, their families and communities.

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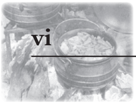
Dedication

The authors dedicate this publication to the memory of Dr Paul Chappell, activist for disability-inclusive development and improved quality of life for disabled people in Africa, who died in 2018. Dr Chappell was an Honorary Lecturer in UCT's Division of Disability Studies in the Department of Health and Rehabilitation Sciences, Faculty of Health Sciences. He worked for many years in disability and community-based development programmes both in South Africa and the Democratic Republic of the Congo.

ABBREVIATIONS

ABCD	Asset-Based Community Development
ALP	Athlete Leadership Programme
BFM	Brand Fischer Mogensen and Associates
CBR	Community-Based Rehabilitation
CRW	Community Rehabilitation Worker
DIA	Disability Innovations Africa
DPO	Disabled People's Organisations
IASSIDD	International Association for the Scientific Study of Intellectual and Developmental Disabilities
ICF	International Classification of Functioning, Disability and Health
LMIC	Low- and Middle-Income Countries
M&E	Monitoring and Evaluation
NGO	Non-Governmental Organisation
SDG	Sustainable Development Goals
SOI	Special Olympics International
ToC	Theory of Change
UCT	University of Cape Town
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNICEF	United Nations International Children's Emergency Fund
WHO	World Health Organization



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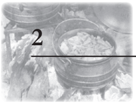
FOREWORD

In recent years there have been significant shifts in the way health and health promotion are viewed, illustrating the movement from an illness to a wellness focus, and from a narrow medical to a broader approach that embraces comprehensive, multi-dimensional and multi-partnership initiatives. Addressing the issues of health and health promotion of persons with intellectual and developmental disabilities has involved no small challenge in overcoming the significant barriers of marginalisation and inequality of access to health services and programmes. Consideration of health and health promotion of persons with intellectual and developmental disabilities in low- and middle-income countries (LMICs) has been a low priority, with progress consistently lagging behind other global initiatives. Parity will only be achieved by inclusion in the mainstream thinking and practice of policies, programmes and services.

This timely collection of expert contributions is underpinned not only by current evidence and best practice principles, but also, appropriately, by a human rights and advocacy ethos. The United Nations Convention on the Rights of Persons with Disabilities, other international declarations of human rights, and the 2030 Agenda for Sustainable Development, are used as the foundation for motivating for equality and right of access to health care and health promotion. The range of comprehensively covered topics in this book addresses the call to action and provides extensive information on low- and middle-income settings, where there is generally a paucity of health care and health promotion. The evidence presented spans four continents, enabling cultural considerations and comparisons, alongside some generalisation across contexts.

The *Disability Catalyst Africa* series has application for service and educational practitioners, scholars, families and communities, and decision makers in health services. Considerable focus is placed on the need for strategic partnerships among governments, non-governmental and non-profit organisations, communities and other stakeholders in order to effect shared goals for change and the possible positive outcomes that are outlined. Evidence and arguments are clearly presented, offering accessible and logical direction to strategic changes in the ways that health and health programmes for persons with intellectual and developmental disabilities can be developed and delivered in LMICs. Importantly, the data includes the voices of those with expertise through experience, which is an encouraging international direction in research methodology that is vital to the integrity and validation of stakeholder information that includes vulnerable populations. This is core to self-determination, choices about health and health activities, inclusion



and belonging. However, given that individuals fall within the influence of communities and larger societal structural systems, the data and framework focus includes both person-centred and population-centred approaches to health and well-being.

The key aspects of promotion of fulfilment of the right to health inclusion and well-being, and of excellence through healthy activities involving persons with intellectual and developmental disabilities, are amply demonstrated though Special Olympics and Healthy Communities case studies in several LMICs. Factors necessary to sustain the promotion of health of persons with intellectual and developmental disabilities, and the prevailing barriers, are also examined, with the relevant components set out in a logical, holistic framework that underpins the vision of healthy communities at various global levels. Ultimately, success depends on enacting participation and inclusion as leverage for change in local, national and international agendas driving laws, policies and programmes. From an operational perspective, implementation strategies including advocacy and community collaborations and partnerships within health and other services, such task-shifting and the role of community-based rehabilitation, are addressed.

The authors are to be congratulated on the production of this timely and comprehensive publication, and it is likely to become a widely used reference in Africa and continents beyond.

Colleen M. Adnams
President-elect and Vice President: Africa and Middle Eastern Regions
International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD)

PREFACE

The United Nations Sustainable Development Goals (UNSDG) came into effect in 2015, with 'Good Health and Well-Being' set as a core target for every member country; yet persons with disabilities are among those who experience the poorest health worldwide. This book elaborates on several UNSDG-relevant approaches and actions to promote the health and well-being of persons with intellectual disabilities in particular, and details four important foci requiring the attention of role-players.

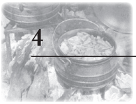
First is the need to include persons with intellectual disabilities in population-based approaches to health and well-being. Poor access to universal health care remains a key issue for people living in low- and middle-income countries (LMIC), where health budgets are low and available resources are minimal or located mainly in specialised care. Centres are often far from the homes and communities of persons with intellectual disabilities, who are often vulnerable to a range of health risks. This book reminds us that priorities for policy and practice must still focus on access to good health care for all, and the transformation of services to better serve excluded citizens. Persuasive arguments are offered for population-based approaches to health promotion at a community level, taking into account the unique needs and strengths of persons with intellectual disabilities and their support networks within the context of local social, cultural and environmental factors that impact on health disparities experienced by persons with intellectual disabilities.

Secondly, emphasis is placed on accurate data collection. There is sparse good quality, disaggregated data on the health needs of persons with intellectual disabilities to inform decision makers about the key issues that should be addressed in planning for their inclusion. Also needed is evidence to support the adaptation of proven strategies and the identification of low-cost existing local strategies to provide contextually relevant, inclusive public health programmes informed by indigenous knowledge and practice.

Thirdly, given that people are often the main resource of LMIC, this book emphasises the need for extensive trans-disciplinary and trans-sector partnership building. Disability stakeholders will benefit from using the content of this book to inform their work and enabling them to:

- *Engage governments to revise policies and practices* at country level to explicitly include persons with intellectual disabilities in health, economic, social and environmental development policies and implementation plans.

- *Involve and build the capacity of persons with intellectual disabilities, their families*



and local community structures to sustainably address their health and well-being needs within their local contexts, and to advocate for the support they need from government and other social structures.

- *Transform training programmes* for the health, social services and other sectors to include disabilities in their curricula.

- *Reorientate and reskill* public health workers and personnel in non-governmental organisations (NGOs) to adapt and include persons with intellectual disabilities, and their supporters, in available services for health promotion, assessment and treatment, and provide for community inclusion.

- *Reconfigure the use of health and related personnel*, focusing on better utilisation of specialist services, where available, and expanding, training and supporting community-based service providers, community-based organisations, NGOs and disabled people's organisations to work with persons with intellectual disabilities at a local level.

Finally, this book is also timely as the fortieth anniversary of the Declaration of Alma-Ata on primary health care is celebrated in 2018, with a call for health equity, universal health coverage and a recommitment to the goal of Health for All. The Declaration of Alma-Ata (WHO, 1978) focuses on health promotion and the provision of effective and affordable primary health care for individuals and families within their local communities, while creating an enabling environment for the social and economic development of these communities. This is to be achieved through community participation in all decisions and activities, in the service of promoting self-reliance and self-determination for all community members. Similarly, the UNSDG focus on integrated, inter-agency and trans-disciplinary approaches to health and well-being, linked to economic opportunities, social development and environmental support. Opportunities must be integrated into mainstream initiatives, with additional support as required.

This book encourages readers to broaden the current focus on clinics and hospitals as sites for intervention. The health and development agenda espoused by Special Olympics through its Healthy Communities initiatives, allied to the insights from community-based rehabilitation, should inspire the identification of under-explored social spaces for potential collaborators and new platforms for the promotion of health, access to healthcare and the inclusion of persons with intellectual disabilities in community life.

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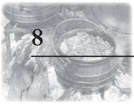


Introduction

Roy McConkey

Most of the world's population who are labelled as having an intellectual disability live in low- or middle-income countries (LMIC). They are among the most marginalised in every society – at greater risk of poverty, social exclusion and poor health – and invariably rely on their families to survive as support services are poorly developed or non-existent. This means that the lives of family carers, mothers especially, are also adversely affected. Often the prejudices associated with intellectual disabilities has meant that communities and governments have ignored the needs of these citizens. This cannot continue and here's why …

Over the past 50 years, a wealth of information has been gathered which demonstrates that persons with intellectual disabilities can be supported to lead productive lives. Although these insights have emerged mostly from high-income countries, they have been confirmed through practice and research in many other countries in Asia and Africa. Moreover, 'low-tech' approaches have proven to be effective and are especially suited those in countries with scarce professional resources. It would be deeply unjust to deny people living in LMIC access to this knowledge and, through it, the opportunity to lead happier and healthier lives. This book describes how people and families can be helped.

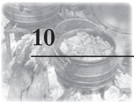
Although specialist assistance to overcome intellectual impairments has its place, it is equally important that persons with disabilities and their families have access to services and support that everyone in the community can benefit from. Of particular significance are poverty-alleviation strategies, disease prevention, the provision of safe water and sanitation, and education. Ironically, persons with disabilities have often been excluded from community development programmes when they stand to benefit from them the most. A major reason has been the stigma that accompanies disability around the world and the social exclusion that results; hence the emphasis on making community development inclusive of all citizens, with additional adaptations provided to meet particular needs. This book will outline strategies for making inclusive health a reality.

International experience of working with marginalised groups has led to a rethink about how we view illness, impairment and health, and the jettisoning of simplistic and outmoded models about medical services. Modern conceptions place greater emphasis on the wider social factors underpinning human health and well-being, rather than the narrow focus of illness diagnosis and treatments that has dominated health services worldwide. Adopting these new approaches means rethinking the personnel who work in health services, their roles, the training they receive and where they work. This book will give you a flavour of the changes that are likely to occur worldwide in the coming years.

The book was stimulated by the evaluation of the Special Olympics' Healthy Communities initiative conducted by the University of Cape Town. The idea was simple: to improve the health of athletes with intellectual disabilities through local community initiatives that were resourced through the provision of seed funding from a charitable foundation. Four LMIC participated in the evaluation: Malawi, Peru, Thailand and Romania. By interviewing athletes, family members and community personnel, we learnt first-hand what had worked and what more needed to be done. In addition, staff from the Disability Studies Unit at the University of Cape Town have undertaken various research projects across southern Africa into the health and well-being of persons with disabilities. This book brings together the insights they have gained over the past decade.

Finally, there is a small but growing literature that confirms and extends our own learning, which we have incorporated into the chapters that follow. We have also shared our thoughts on how practitioners can contribute more to the worldwide understanding of promoting Health for All.

When writing this book, we had in mind staff working in primary health-care, community development projects and community-based rehabilitation, alongside disability advocates such as disabled persons' organisations, and parent and friends associations. We hope that includes you. We believe that you hold in your hands the future betterment of persons with intellectual disabilities across the globe and trust you will take up the challenges that past generations have shirked. With this book we aim to eliminate the age-old excuse: We don't know what to do to help.



Chapter 1

The need for action

Roy McConkey

Persons with intellectual disabilities are among the most marginalised worldwide. Their exclusion from society has compounded the impact of this disability on their health and well-being and is particularly marked in low-income countries, which are home to an estimated 90% of the world's population of persons with intellectual disabilities. Here, many are found among the poorest in society; hidden away by families or placed in institutions. Most cannot access healthcare services so they succumb to illness and injury. Yet the health of persons with intellectual disabilities internationally can be enhanced through relatively simple and low-cost actions. The result is a better quality of life for them and their families, and their prospects of becoming productive members of society is considerably improved.

In this chapter we summarise the two main reasons why the health of persons with intellectual disabilities deserves particular attention. First, like all citizens, they have the right to good health and equity of access to health services and social support. However, the barriers they experience are well known and action to tackle stigma and prejudice are necessary. Second, their increased risk of illness and poor health is well documented, and to take no action negates the professional responsibility of responding to those in greatest need.

The right to health

Over 70 years ago, the World Health Organization (WHO) defined health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (WHO, 1948). Thus, health means more than the curing of illness or the prevention of disease; yet in affluent countries, most of their resources were devoted to medically-led services rather than promoting the overall well-being of the population. Moreover, less affluent countries were seduced into believing that world-class health services were dependent on emulating their northern neighbours, from whom development aid flowed.

The emphasis on illness rather than health has resulted in marked inequalities in the health and well-being of citizens both within and across countries, which has been well documented over many years. For example, Section II of the Declaration of Alma-Ata (WHO, 1978) proclaimed that:

> *The existing gross inequality in the health status of the people particularly between developed and developing countries as well as within countries is politically, socially and economically unacceptable and is, therefore, of common concern to all countries.*

In subsequent years, the extent of the inequalities within nations has become more apparent. Globally, those most at risk are the poor and persons with disabilities; those with intellectual disabilities and their families faring worst of all. More recently there is widespread recognition that persistent inequalities threaten the social and economic cohesion of nations. All citizens enjoy better health and a more fulfilled quality of life in nations or states that are more equal (Wilkinson & Pickett, 2010).

Human rights

The starting point for creating more equal societies is based on shared values and principles, chief of which is our conception of what it means to be human and the rights and freedoms that flow from being human. Although these values have been recognised for centuries in diverse cultures, they have been enshrined in the United Nations Universal Declaration of Human Rights. In particular world governments have ratified two important conventions of rights. For example, Article 25 of the Convention on the Rights of Persons with Disabilities (United Nations, 2006) details rights to health:

> *States Parties recognise that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.*

Similarly, Article 23.3 of the Convention on the Rights of the Child (United Nations, 2001) states:

> *Recognising the special needs of a disabled child, assistance … shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.*

In 2015 the international community committed governments to seventeen Sustainable Development Goals (SDGs). Goal 3 is to 'ensure healthy lives and promote well-being for all at all ages' (United Nations, 2015). Specific targets are detailed, including:

- *Achieve universal health coverage, including financial risk protection, access to quality essential healthcare services and access to safe, effective, quality and affordable essential medicines and vaccines for all.*
- *Substantially increase health financing and the recruitment, development, training and retention of the health workforce in developing countries, especially in least developed countries and small-island developing States.*

These laudable goals can only be achieved if persons with intellectual disabilities are among those targeted for special attention; yet in many countries, the policies and practices of health services makes sparse mention of persons with disabilities, let alone those with intellectual disabilities. This must change. The fact that nearly all countries are signatories to one or other of the United Nations' conventions and to the SDG, should be a game changer later if not sooner.

Barriers to attaining rights

Signing conventions is easy, but implementing them is much harder. The World Report on Disability (WHO/World Bank, 2011: 81) concluded that:

> *People with disabilities experience health disparities and greater unmet needs in comparison to the general population. All countries need to work towards removing barriers and making existing health care systems more inclusive and accessible to people with disabilities.*

In a study by Eide, et al. (2015) conducted in four African countries – Malawi, Namibia, Zambia and Zimbabwe – the perceived barriers for accessing health services among persons with disabilities were:

- cost of visits to health facilities;
- inadequate equipment and medicines;
- negative experiences with health personnel;
- insufficient skills of health personnel;
- distance from health facilities; and
- lack of suitable transport.

Moreover, these barriers were more pronounced for poorer people living in urban rather than rural settings and those with more marked impairments. It is unsurprising, then, that the main research priority identified by Tomlinson, et al. (2009) was:

> *[The] identification of barriers that people with disabilities have in accessing health services at different levels, and finding the best possible strategies to integrate their needs into primary healthcare systems and ensure local delivery. Results showed that addressing specific impairments is secondary to ensuring that health systems provide adequately for all people with disabilities … especially in low-income and middle-income countries.*

The impact of stigma

Barriers to health access are likely the symptoms of a deeper malaise within many societies, chief of which is the stigma and shame associated with disabilities that persists, either implicitly or explicitly. Intellectual disability is often interpreted as misfortune befalling a family because of their misdeeds, the breaking of a taboo, or a curse that has been placed on them. Possession by evil spirits is a common explanation, especially when the person shows unusual behaviours such as epileptic seizures. Traditional healers often reinforce such beliefs through their rituals and medicines. Social exclusion, either by choice or enforced, is the most common consequence, largely predicated on preventing 'normal' people becoming 'contaminated', for example when disability is seen to threaten the marriage prospects of other family members. This further reinforces the sense of worthlessness and hopelessness that surrounds disability. Unfortunately, health professionals are not immune from such beliefs, especially when they have to decide among competing priorities for their scarce resources; and community leaders and politicians often respond similarly.

Removing stigma and prejudicial attitudes is not easy, but increasingly it is seen as essential if persons with disabilities are to attain their human rights. This means it has to become a conscious and integral part of all initiatives designed to promote the well-being of persons with intellectual disabilities. Internationally, three interrelated strategies have proven to be effective (Werner & Scior, 2016):

- People need to meet and get to know persons with disabilities, and to realise they have more in common with them than differences. Personal contact provides the 'heart knowledge' that motivates changes in attitudes and behaviours.

- Communities need to be educated about the causes of disabilities. They need to be told and to understand the reasons why a person is disabled and, more importantly, what can help them.

- Societies need to experience advocacy by or on behalf of persons with intellectual disabilities. Speaking up for oneself or for another person is a well-attested way of ensuring you are not ignored or forgotten.

A case can be made for campaigns whose main aim is to change community attitudes; indeed they have featured in various countries, albeit with varying degrees of success. However, this approach seems inadequate to the task at hand. National campaigns cannot reach everyone whose attitudes need to change and success is more likely when they are targeted to specific people in particular settings. A campaign also tends to be a one-off event, whereas sustained action is needed in response to changing circumstances. Stigma reduction is the responsibility of everyone rather than a select few, which absolves others of doing their bit to change attitudes. Stigma reduction is an integral part of all health initiatives and, fundamental to this, is promoting a new perception of how disabilities are viewed.

Changing perceptions of disability

International understanding of disabilities has evolved markedly in recent years. Disability is no longer seen as a medical issue or a deficit within individuals; instead, the International Classification of Functioning, Disability and Health (WHO, 2001) conceives of disability as an interaction between bodily impairments, activity limitations and participation restrictions. Thus, social, cultural and environmental influences are factors that play a role alongside bodily impairments in disabling people. Moreover, these factors influence the health and well-being of everyone, making them crucial in the promotion of better health for all citizens, including persons with disabilities.

The critical influences are summarised in the Rainbow Model of social determinants of health (Dahlgren and Whitehead, 1992) (see Figure 1.1). The health of a person is shaped by biology, lifestyle factors, social and community networks, and the general socio-economic, cultural and environmental conditions. An evidence base for the latter is detailed in the publication *Social Determinants of Health: The solid facts* (Wilkinson and Marmot, 2003).

This thinking has had a major influence on how the needs of persons with disabilities are met within community settings. For example, the WHO (2010) guidelines on Community-Based Rehabilitation (CBR) provide a comprehensive and multi-sectoral approach to disability embracing health, education, livelihoods, social and cultural, advocacy and empowerment. For more on this, see Chapter 2: Promoting better health for persons with intellectual disabilities through community-based inclusive development.

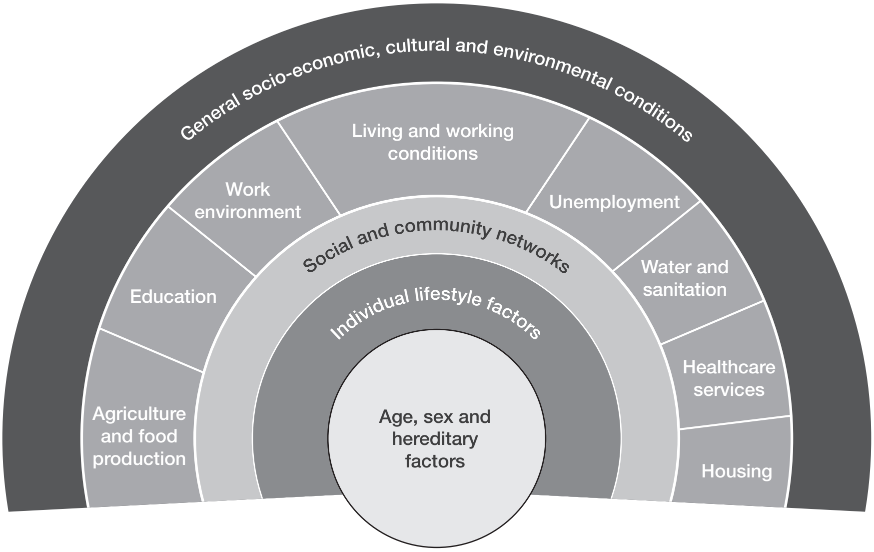


FIGURE 1.1: RAINBOW MODEL OF SOCIAL DETERMINANTS OF HEALTH

In summary:

- There is international consensus on the rights of persons with disabilities to better health.
- The social and environmental factors that influence poorer health are well established and must be addressed in order to produce healthier lives and lifestyles for persons with disabilities.
- Tackling the stigma associated with intellectual disabilities has to be an integral part of health-improvement initiatives.
- Health gains are more likely to come through accessing mainstream health provision and community-based development programmes, rather than specialist disability services.

The poorer health of persons with intellectual disabilities

In this section we review the evidence base for the poorer health of persons with intellectual disabilities compared to that of their non-disabled peers. This is termed a health disparity, defined as '… differences in health outcomes at the population level, that these differences are linked to a history of social, economic, or environmental disadvantages, and that these differences are regarded as avoidable' (Krahn, et al., 2015).

In the main, evidence for health disparities comes mostly from high-income countries, but similar patterns are likely to be found for people living in the developing world, as well as additional ones arising from increased risks of disease and malnutrition. Figure 1.2 summarises the cascade of disparities that result in the well-attested health disparities experienced by persons with intellectual disabilities (Krahn and Fox, 2014).

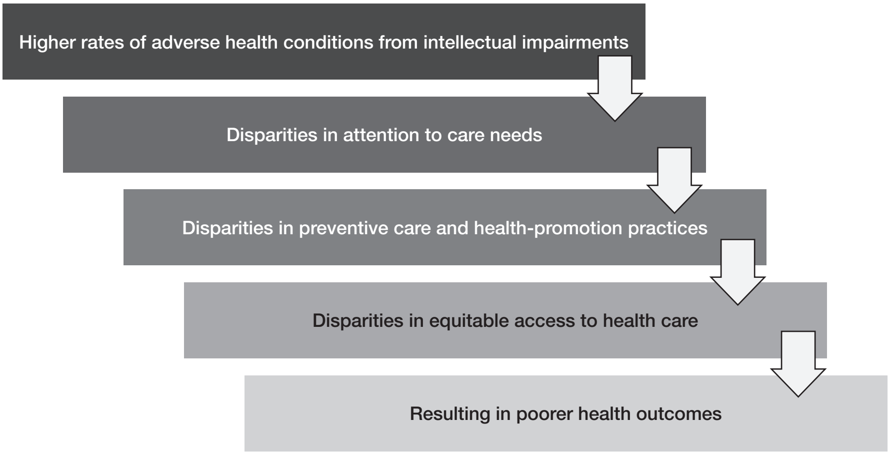


FIGURE 1.2: HEALTH DISPARITIES EXPERIENCED BY PERSONS WITH INTELLECTUAL DISABILITIES

Persons with intellectual disabilities have higher rates of adverse health linked to their impairments, such as epilepsy. However, these primary factors are compounded if health needs are not identified and attended to by carers; if they cannot effectively access preventive care and health promotion, and are denied access to healthcare interventions attuned to their needs. The major outcome is reduced life expectancy and more years of living with poorer health compared to their non-disabled peers. There is now a great deal of evidence documenting the increased risk of various illnesses and diseases for persons with intellectual disabilities (Emerson, et al., 2012; Krahn, et al. 2006). These are summarised in Figure 1.3.

As the life expectancies of persons with intellectual disabilities improve it is likely that more will present with the diseases of old age. Also, medical advances have improved the survival rates of those with more complex physical healthcare needs.

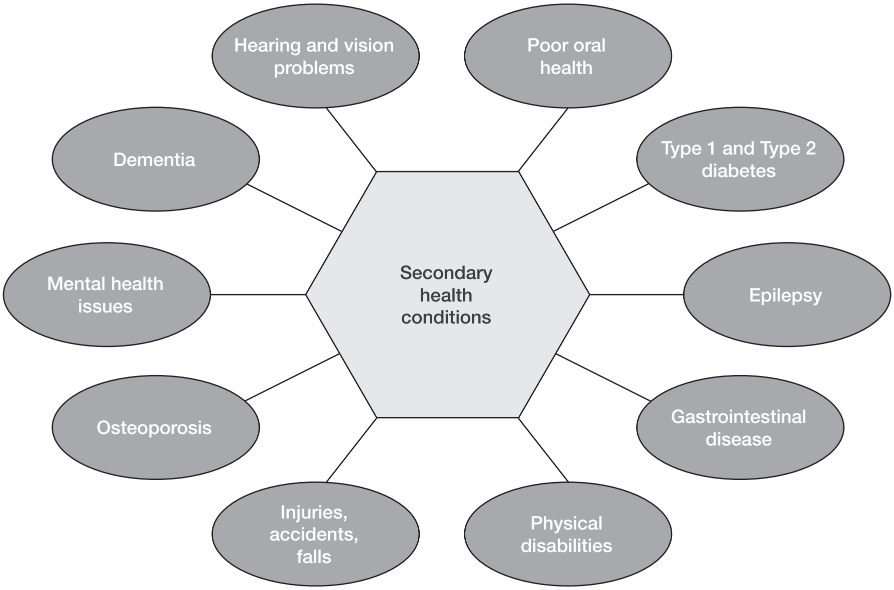


FIGURE 1.3: HEALTH INEQUALITIES: SECONDARY HEALTH CONDITIONS

Low- and middle-income countries

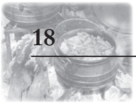
Although there is less reliable data available from low- and middle-income countries (LMIC), the Special Olympics' Healthy Athletes Database enables comparisons to be made across the world regions participating in Special Olympics. Based on national population data (Lopez, et al., 2006; UNICEF, 2014), persons with intellectual disabilities in LMIC are at additional risk of:

- malnutrition and underweight;
- recurrent and chronic infectious diseases, with poorer access to immunisation;
- illnesses due to poor water and sanitation;
- HIV/AIDS infection;
- undiagnosed and untreated vision and hearing problems; and
- lack of cognitive stimulation and social exclusion.

This list implies that health-screening and health-promotion activities need to be attuned to the particular needs of LMIC. Moreover, persons with intellectual disabilities may have multiple impairments and illnesses that present atypically, making diagnosis and treatment more complex.

Social determinants of health

All of the disparities noted earlier contribute to poorer health outcomes in rich and poor countries alike. Looking beyond healthcare, Emerson and



Baines (2011) identified four additional social determinants of the poorer health of persons with intellectual disabilities, to which a fifth could be added. Although this listing emerged from high-income countries, the elements are also applicable to less affluent nations.

- *Greater risk of exposure to the social drivers of poorer health, such as poverty and poor housing*. The link between poverty and disability is well established internationally, limiting access to healthcare as well as increasing the risk of malnutrition and diseases.

- *Communication difficulties and literacy problems experienced by persons with intellectual disabilities*. They have difficulty informing others about their symptoms and have less access to health-promotion information either orally or in written form.

- *Personal health risks and behaviours, such as poor diet and lack of exercise.* The sedentary lifestyle imposed on persons with disabilities increases their health risks, especially in more affluent countries.

- *Lack of access to health care provision and to health promotion.* This is a major issue for less-developed countries, but internationally the stigma associated with intellectual disabilities means people are often discriminated against in accessing health services, even by their families.

- *Social exclusion and isolation.* Persons with intellectual disabilities and their families are often socially isolated and lack informal support networks due to the stigma associated with disabilities. This reduces their opportunities for accessing advice and help.

In summary, we can conclude that globally:

- Persons with intellectual disabilities invariably experience poorer health than their non-disabled peers and even persons with physical or sensorial impairments. They 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 LMIC.

- Social influences play a major part in perpetuating poorer health and reduced quality of life.

Whereas the twin drivers of rights and needs can fuel action, success is more likely if there is evidence of improved health. How to make this happen is the focus of Chapter 2.

Chapter 2

Promoting better health for persons with intellectual disabilities through community-based inclusive development

Roy McConkey, Dominique Brand and Theresa Lorenzo

In this chapter we review the two main strategies used to promote better health of persons with disabilities. One focuses on the individual, assessing their health and prescribing treatments. The second concerns improving the health of populations, addressing social determinants of health and overcoming barriers to accessing healthcare. In reality, both approaches are required, with the levels varying according to national circumstances and resources.

FIGURE 2.1: STRATEGIES FOR PROMOTING BETTER HEALTH

Person-centred approaches

Person-centred approaches have tended to focus mostly on the identification of specific health problems and ensuring the person receives the necessary treatment or interventions to reduce or cure their health issues (US Public Health Service, 2001). This involves:

- Undertaking regular health checks (assessments) to identify any existing or potential health problems. These need to be done by competent health professionals, such as doctors, trained nurses or therapists, ideally with experience of assessing persons with intellectual disabilities.
- Formulating an action plan of the health interventions that are needed and sharing this plan with all interested parties.
- Making referrals to appropriate and competent health professionals to provide the necessary treatments or interventions.
- Having a competent monitoring system that allows referrals to be traced and enables follow-through and accountability of health service providers for continuity of care.
- Ensuring the person and his or her carers are informed and competent to manage prescribed treatments and interventions, and are compliant with them.
- Ensuring access to chronic treatment needs and health-promotion programmes.
- Reviewing the impact of any treatments and interventions, and making any necessary adjustments.

This cycle of assessment and intervention is a long-established medical response to personal illnesses, and one that is advocated for the early detection of illness and disease. This approach is dependent on the availability and accessibility of health services, but even in countries with well-resourced health services, persons with intellectual disabilities are often overlooked. Some of the more common reasons for this are:

- Youth with intellectual disabilities do not recognise or communicate the symptoms that would trigger a health check.
- Initial physical access to accessible healthcare facilities might be out of range as youth with disabilities who often live in rural areas.
- The co-morbidity of intellectual disability and mental health problems

can mask physical health issues and make treatment compliance more difficult.

- Carers, including paid service staff, may not recognise the significance of certain symptoms and assume they are a feature of the impairment and therefore not treatable.
- Health professionals will give priority to other people.
- People and families cannot afford the costs involved to attend clinics and hospitals.

Special arrangements have been devised to address these barriers, focusing on the provision of regular health checks tailored specifically to the needs of persons with intellectual disabilities, such as those provided by community health workers, the development of referral pathways, education of the person and carers, and regular review procedures. However, person-centred approaches have their limitations:

- They are resource-intensive and their impact is often restricted to selected persons rather than to the population.
- They are dependent on the availability of personnel and treatments.
- They do not address the broader social factors that influence people's health and lifestyle.
- They risk segregating persons with intellectual disabilities from mainstream health-improvement strategies that are of benefit to the wider population.

Thus, there is growing recognition that person-centred approaches need to be complemented by population-based health-improvement initiatives such as Special Olympics' Healthy Communities.

Promoting population health

Population-based approaches to health focus on promoting health in the wider sense of the term, rather than detecting illnesses or illness prevention. These approaches take cognisance of the social and cultural influences on health, and focus on the empowerment of individuals and communities to address the health deficits that they experience. Hence, a different set of strategies is needed in promoting better health through a population-based approach. According to Taggart and Cousins (2014), there are six challenges in applying a population-based approach to persons with intellectual disabilities:

1. *Empowering persons with intellectual disabilities to make informed lifestyle choices.* This entails making health information accessible and usable to persons with limited cognitive and communication skills. There have been limited attempts to do this internationally and fewer still that have convincingly demonstrated sustained health improvements.

2. *Increasing the knowledge of family and carers.* By definition, persons with intellectual disabilities are reliant on the support of others to achieve necessary life skills such as reading and money management. However, family and carers are often less knowledgeable about the roles they can and should fulfil in relation to promoting better health.

3. *Addressing unrecognised physical and mental health needs.* Health problems may be seen as a consequence of intellectual disabilities rather than a distinct condition that can and should be addressed as it would with a non-disabled peer.

4. *Creating health-promoting cultures in intellectual disabilities settings.* When people are receiving specialist intellectual disabilities services, such as residential facilities or Special Olympic programmes, specific attention needs to be paid to their health and well-being. In particular, support staff and volunteers need to be alert to the promotion of healthy lifestyles and provide suitable role models for their service-users.

5. *Ensuring persons with intellectual disabilities can access public health community services.* Although this echoes points noted under person-centred approaches, the focus in this context is on more strategic actions to widen access for all persons with intellectual disabilities rather than specific individuals; for example, by making health information more accessible by using visuals rather than text.

6. *Developing greater partnerships among specialist intellectual disabilities services, health promotion and healthcare services.* Following on from point 5, the goal is greater partnership working with mainstream services. For this it is likely that specialist organisations will have common cause with organisations supporting other marginalised groups.

There has been little concerted effort to implement population-based approaches with intellectually disabled populations and especially their inclusion within mainstream public-health programmes. The necessary conditions for so doing have been identified by Krahn and Fox (2014) as:

- The use of data to educate decision-makers, particularly around health disparities and inequalities;

- Attention to social determinants of poorer health among families and organisations supporting persons with intellectual disabilities;
- Applying a life-course model so that appropriate health actions are taken from early childhood through to old age; and
- Emphasis on leveraging inclusion in mainstream services, especially in low- and middle-income countries (LMIC) where specialist provision is likely to remain scarce.

Thus, there is growing consensus not only on the need for action, but also on the strategies that are most likely to result in the improved health and well-being of the sub-population of persons with intellectual disabilities.

An ecological model combining both approaches

Person-centred and population-centred approaches are not alternatives, but rather can be combined, taking the best attributes of both. Health-promotion initiatives designed specifically for persons with intellectual disabilities are an example of such a strategy that changes the context to make an individual's default decisions healthy, and encourages long-lasting protective interventions to enhance well-being.

A growing number of health-promotion programmes have been devised for persons with intellectual disabilities, mostly in high-income countries, although their effectiveness and sustainability remain to be assessed (Marks, et al., 2010; Marks and Sisirak, 2014). These intervention programmes have tackled a range of topics, but most commonly focus on physical fitness, weight reduction and healthy eating. They share several common features:

- Information is presented visually, using simplified language.
- Existing health-promotion programmes can be adapted and shared; there is no need to reinvent the wheel.
- Group-based programmes enable the development of peer support.
- Advances in information technology provide new opportunities for sharing knowledge and shaping behaviours.
- The programmes allow for a slower pace of learning among participants.

The programmes also face common challenges around implementation:

- Implementing structured recruitment strategies that target those in need and not just the willing.

- Obtaining buy-in from persons with intellectual disabilities, coaches, family members and carers, to ensure that participants receive ongoing support to maintain the changed behaviours.

- Plans to cover any costs of participation, such as entrance fees and transportation.

- Identifying suitable assessment measures and keeping records of progress.

- Having strong working relationships with community partners so that there is programme continuity within mainstream facilities.

An ecological model has been proposed for sustainable health-promotion strategies with sub-populations of persons with intellectual disabilities (see Figure 2.2). At the heart is the person with intellectual disabilities, allied with their support network who are most likely family members or carers, but can also include paid staff in mainstream or specialist services, or volunteers recruited and supported by non-governmental organisations (NGOs). Changes in the organisational culture of support services may be required in order for them to provide more effective services that address individual health needs and social influences on health, such as poverty alleviations and stigma reduction.

FIGURE 2.2: SUSTAINABLE HEALTH PROMOTION FOR PERSONS WITH INTELLECTUAL DISABILITIES

Other major influences are the environmental and community resources available both locally and nationally. Changes here are likely to produce gains for families and communities and, in so doing, benefit persons with intellectual disabilities. Efforts may be focused on removing the barriers preventing access to health services for everyone in the community, including persons with intellectual disabilities. Invariably, adopting this model will mean working in partnership with existing community systems.

The following examples – the Special Olympics' Healthy Athletes programme and Healthy Communities initiative – illustrate how this ecological model has been put into practice in LMIC.

Special Olympics

Special Olympics is the world's largest sports organisation for persons with intellectual and developmental disabilities. Some five-million athletes from 172 countries take part in year-round sports training and athletic competitions in a variety of Olympic-type sports. The organisation's mission is to give athletes 'continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendship with their families, other Special Olympics athletes and the community'.

Healthy Athletes

In 1997, Special Olympics International (SOI) launched the Healthy Athletes programme to address the health disparities faced by persons with intellectual disabilities. During regional, national and international competitions, athletes are offered free health checks provided by specially recruited and trained health professionals. These include assessments of vision, hearing, oral health, podiatry, physical therapy and healthy behaviours. The competitions take place in a fun, welcoming environment that removes the barriers persons with intellectual disabilities often face visiting a doctor or a clinic.

Since its establishment, Healthy Athletes has conducted 1.7 million health assessments in more than 130 countries. The data gathered from these assessments have been aggregated into the world's largest database on the health of persons with intellectual disabilities. In 2014-2015, over 14 000 athletes were screened in sub-Saharan Africa (Special Olympics International, 2016).

Healthy Communities

While the Healthy Athletes programme has been successful at identifying health issues and training healthcare professionals internationally, there was the realisation that additional measures needed to be taken at the local community level to ensure athletes received proper treatment and follow-up care. With the support of the Golisano Foundation, Special Olympics started Healthy Communities in 2012. The aim of this initiative is to bring about improved health and healthier lifestyles for persons with intellectual disabilities. Grants are made available from SOI to fund the employment of personnel to coordinate health projects. Each country is free to set its own targets and work programmes within the broad aims set for Healthy Communities so that they can respond to local needs and opportunities. Regional coordinators are appointed to support and guide national personnel, and regular site visits are undertaken by SOI staff.

Activities to promote better health

The activities undertaken in the initial eight LMIC (Mexico, Peru, South Africa, Malawi, Kazakhstan, Romania, Malaysia and Thailand) as part of the Healthy Communities initiative to promote the health and well-being of athletes is summarised in Figure 2.3. Two main strands of work were undertaken: firstly, educational activities targeted at athletes and/or families and/or coaches; and secondly, recruiting and mobilising healthcare students and professionals to ensure better access to follow-up healthcare. The lessons learned from this programme became applicable to the national population of persons with intellectual disabilities and their families. Not all of the activities were undertaken by each group, but together they demonstrate the range of initiatives deployed internationally.

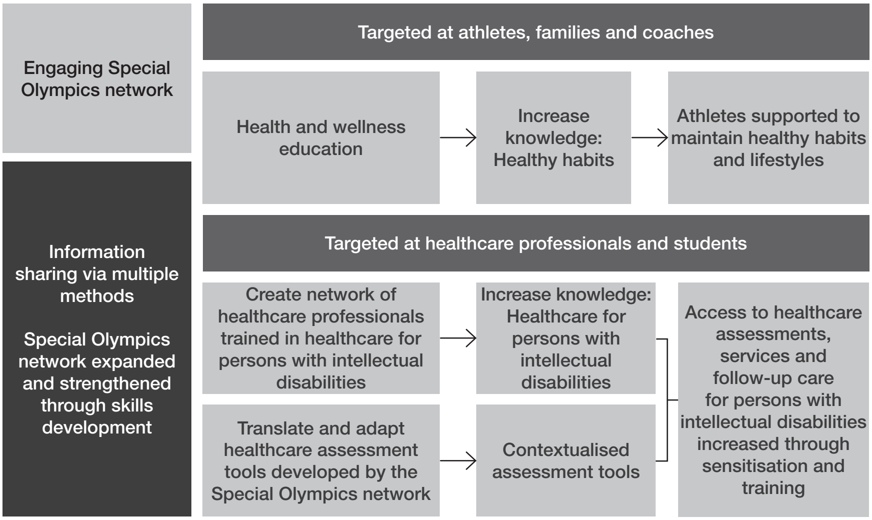


FIGURE 2.3: ACTIVITIES AIMED AT PROMOTING HEALTH WITHIN THE SPECIAL OLYMPICS NETWORK

Activities to promote partnerships

The activities undertaken by Healthy Communities to enhance partnerships essential to effect changes in healthcare arrangements in local communities and, ultimately, nationally, are summarised in Figure 2.4. These reach beyond the work that Special Olympics undertook with athletes.

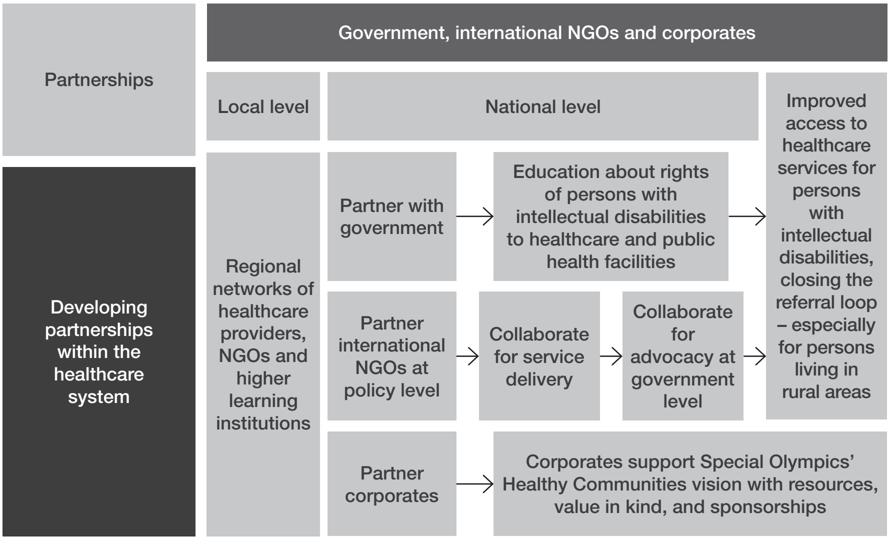


FIGURE 2.4: ACTIVITIES AIMED AT PROMOTING PARTNERSHIPS

Achievements

The reports from the eight LMIC illustrate the achievements of Healthy Communities over three years:

- Over 40 000 people had a health assessment.
- 7 000 healthcare professionals were trained to undertake health assessments.
- 5 000 healthcare professionals and community health workers were educated on the health of persons with intellectual disabilities.
- 4 500 family carers attended health forums.
- 2 500 athletes attended health-promotion events.
- Over 1 000 healthcare professionals were willing to be listed as providers of follow-up care.
- Over 4 000 people received follow-up care.

- 128 partnerships were formed either locally or nationally.
- 27 higher education institutions included intellectual disabilities in their training curricula for healthcare professionals.

The Special Olympics' Healthy Communities initiative is the most ambitious transnational attempt to reduce health disparities experienced by persons with intellectual disabilities. The main lessons that have emerged are:

- A multi-faceted approach is needed; there is no single action that makes the biggest difference.
- Actions need to be attuned to national circumstances although there are common approaches.
- Identifying health problems is of limited use unless strategies are in place to address them.
- A particular focus needs to be placed on the education and training of healthcare professionals to respond to the needs of persons with intellectual disabilities.

Community rehabilitation and disability practitioners as facilitators of community-based inclusive development

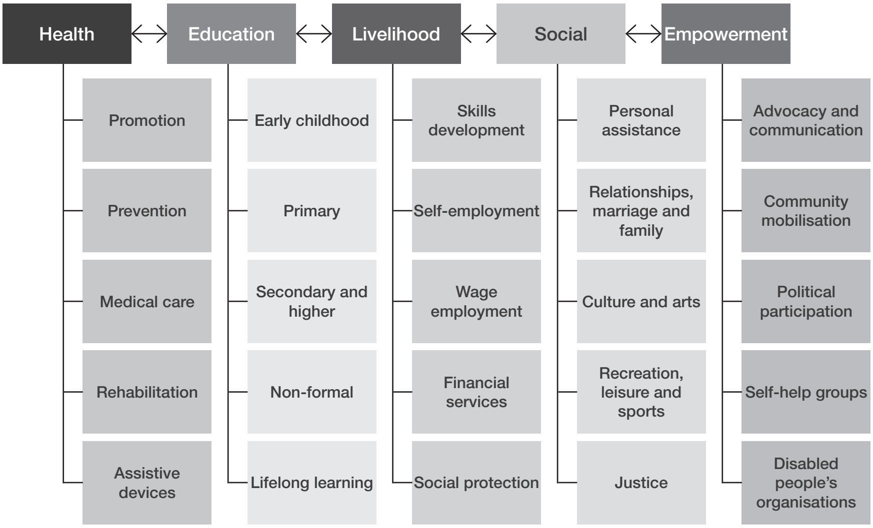
In recent times a greater understanding has emerged of effective strategies to assist persons with disabilities in poorly resourced community settings. The World Health Organisation's *Community-Based Rehabilitation: CBR Guidelines* (WHO, 2010) encapsulates much of this learning and provides a framework against which national policy and practices can be developed for disability inclusion in local communities. It emphasises the multi-sectoral approach needed to underpin national policy making. It advocates for community-based inclusive development to shift the focus from rehabilitation to poverty reduction and social inclusion. This shift is able to drive greater access to activities, services, communication and information, in order to facilitate equal participation of persons with disabilities in development opportunities relevant to their life stage.

In a study of inclusive youth development in South Africa, youth with disabilities identified poor health and limited skills development as major barriers to accessing employment compared to youth without disabilities (Cramm, et al., 2012). Community rehabilitation workers were found to facilitate greater access to health services for youth with disabilities through home visits, and able to provide information and support to youth with disabilities and their families to facilitate participation in mainstream opportunities in education and employment (Lorenzo, et al., 2015; Cramm, et al., 2014). Their competencies include screening and early identification of physical, mental and sensory impairments across the life span.

On the topic of marrying community development and rehabilitation, McConkey comments that the absence of human resources and willpower limits the removal of barriers to the full inclusion of persons with disabilities in everyday living (McConkey, 2012). He suggests the need for a new way of thinking to meet the aspirations of disabled children, youth and adults. The roles, responsibilities and relationships of community rehabilitation workers and disability practitioners with staff in mainstream and specialist services needs attention in order to create authentic, inclusive primary healthcare and education systems that will contribute to long-term inclusive social and economic development.

Training community-based workers

The CBR matrix shown in Figure 2.5 illustrates the interlinking of five domains that affect the well-being and quality of life of persons with disabilities, which includes health promotion and prevention so that health services become more inclusive.



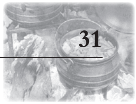
Health	Education	Livelihood	Social	Empowerment
Promotion	Early childhood	Skills development	Personal assistance	Advocacy and communication
Prevention	Primary	Self-employment	Relationships, marriage and family	Community mobilisation
Medical care	Secondary and higher	Wage employment	Culture and arts	Political participation
Rehabilitation	Non-formal	Financial services	Recreation, leisure and sports	Self-help groups
Assistive devices	Lifelong learning	Social protection	Justice	Disabled people’s organisations

FIGURE 2.5: THE CBR MATRIX

Although families and communities will always be the primary source of care for persons with disabilities, CBR envisages a new type of community rehabilitation worker (CRW) (Chappell and Lorenzo, 2012). They are often drawn from the communities where they work, so they have context-specific knowledge about the cultural, economic and politic factors influencing participation and service delivery (Van Pletzen, Lorenzo, and Booyens, 2014). Their practice focuses on disability empowerment, which is underpinned by the principles of participation, inclusion, sustainability and self-advocacy (Binken, et al., 2009; WHO, 2010). They advocate for active forums to network and share experiences to achieve equal opportunities for persons with disabilities.

Chappell and Lorenzo (2012) identified the competencies needed for community-based service delivery using the *CBR Guidelines* (WHO, 2010) and Rule's (2013) framework for curriculum development, which illustrates the complexity of factors needed to inform the training and implementation of inclusive services. Community rehabilitation workers and disability practitioners act as catalysts for disability-inclusive development as they are able to integrate rehabilitation outcomes into community development processes that facilitate coordinated access to resources that address inequities in the system. They are able to monitor barriers to participation and the renewal of programmes to address the needs of persons with disabilities and the family or carers (Chappell, Motau and Lorenzo, 2012). They also coordinate and network with different organisations, including local leadership structures, disabled people's organisations and other non-governmental service organisations, the business sector and government departments. They are able to mobilise persons with disabilities and the parents of children with disabilities to form self-help groups to strengthen advocacy (Lorenzo, Booyens and Van Pletzen, 2015).

NGOs have largely been responsible, with some government support, for training community-based personnel. The focus and length of training differs across countries and according to the different contexts and service-delivery systems that exist. The length of training has varied from six months, with adhoc in-service training, to accredited two-year diploma programmes. Employment opportunities and conditions of service also differ, with NGOs being the main employers. For community-based inclusive development to be sustainable, government departments could consider employing this cadre of worker to support persons with disabilities and their families. They are able to facilitate participation in and access to services, change stigma and prejudice by providing information about the different impairments and health conditions, and contribute to strategies for development.



Key lessons

Although strategies for improving the health of persons with intellectual disabilities have been proposed, implemented and evaluated to varying degrees in recent years, this essentially remains a new field of enquiry.

- In more affluent countries, person-centred approaches have been based around regular health-screening and referrals for preventative treatments and interventions as needed.

- Population-based approaches hold greater promise for bringing about sustained health improvements for a large number of persons with disabilities, especially in countries where health resources are scarce.

- A combination of both approaches has been incorporated into an ecological model of health promotion that can be used to guide practitioners, especially in LMIC.

- The long-term sustainability and use of these approaches across populations remain to be tested.

Chapter 3

Improving access to health promotion, healthcare and treatments

Judith McKenzie and Anthea Hansen

In this chapter we reflect upon the findings of the Special Olympics' Healthy Communities study and other pertinent literature to understand better specific ways in which access to health promotion and care can be improved. We adopt an ecological model (*see* Chapter 2), and combine this with the model offered by the 1986 Ottawa Charter for Health Promotion (WHO, 1986). By examining the collective experiences of Healthy Communities, we make some claims about how health promotion and healthcare can be made more accessible to persons with intellectual disabilities, primarily through community-based approaches with a focus on inclusive health services.

An ecological model of health promotion

The Ottawa Charter (WHO, 1986) was developed through the World Health Organization (WHO) in response to the need to see health not only as the absence of disease, but also as a positive state of well-being. The charter defines health promotion as:

> *[T]he process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realise aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasising social and personal resources, as well as physical capacities. Therefore, health*

> *promotion is not just the responsibility of the health sector, but goes beyond healthy lifestyles to well-being.*

When considering persons with intellectual disabilities, health promotion can be seen as a fairly novel concept. Families and communities have not always recognised the aspirations and goals of persons with intellectual disabilities and, therefore, have not taken seriously the contribution that healthy living makes toward these goals. Mostly, persons with intellectual disabilities are seen as people who should be cared for and they have not been given a significant role in taking responsibility for their own health. Healthy Communities has challenged this way of thinking by asking how health can be promoted through the engagement of whole communities in supporting healthy lifestyles.

The Ottawa Charter outlines five strategies that contribute to health promotion for everyone (see Figure 3.1). In this chapter, we focus on the first three: creating supportive environments, reorienting health services, and developing personal skills. Strengthening community action and building appropriate public policy are covered in chapters 4 and 5. Themes are identified in each of these areas, and their relevance for low- and middle-income countries (LMIC) in general is discussed. In doing this we also draw on an ecosystemic approach by recognising that the individual is part of multiple systems, and that change in one system has a ripple effect on the others (Donald, et al., 2006).To promote health, it is necessary to act across multiple levels simultaneously. Thus, we will examine the barriers to and facilitators of health promotion at different levels of the system (Singal, 2006).

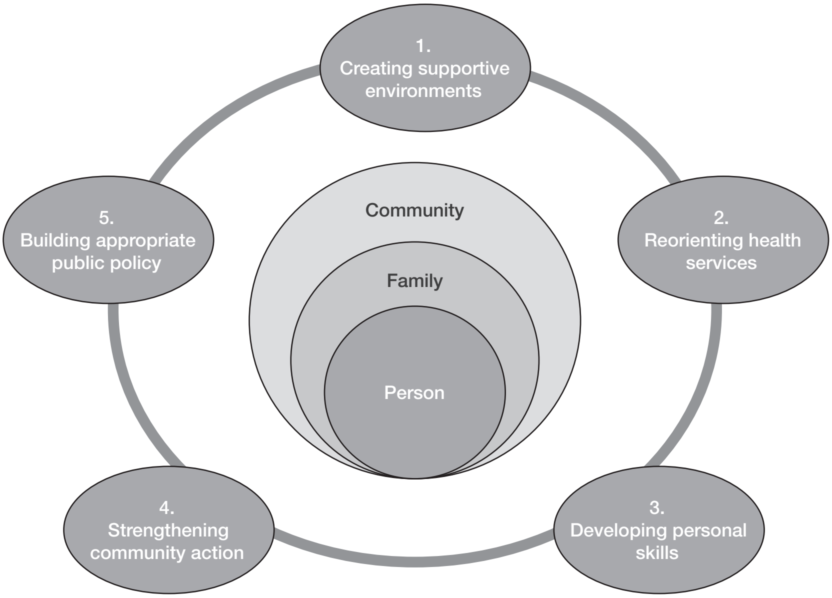


FIGURE 3.1: ECOSYSTEMIC APPROACH OF THE OTTAWA CHARTER FOR HEALTH PROMOTION

The person with intellectual disability is central, and his/her primary access to healthcare is usually through the family or a carer, which forms part of the ecosystem. Although families would ordinarily be the link to community health provision, this link may not happen. Special Olympics and other similar community networks may play a mediating role in facilitating family and individual access to health professionals in the public or private sector. The community is nested within national socio-cultural networks that include legal and health policies, and, for the purposes of this analysis, we include wider society at the community level.

Creating supportive environments

The concept of supportive environments in the Ottawa Charter recognises that health-promotion strategies need to be adapted to the local context and should take into account the different social, cultural and economic circumstances in which people live. A supportive environment is one in which the need for health promotion is recognised and translated into action. The results of the Healthy Communities study provided an opportunity to examine what proved effective across the different countries, and specific conditions that impacted upon health promotion. Figure 3.2 indicates the four sub-themes identified by the various stakeholders.

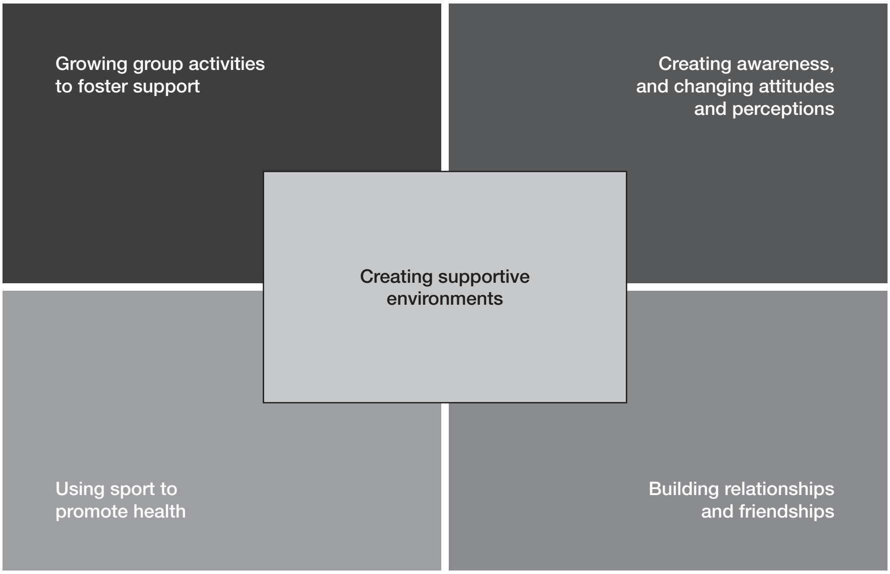
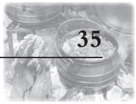


FIGURE 3.2: CREATING SUPPORTIVE ENVIRONMENTS FOR HEALTH PROMOTION



Creating awareness, and changing attitudes and perceptions

In many countries there is still significant shame and stigma associated with intellectual disabilities. Families may hide their children, denying them the opportunities for healthcare and education that they would ordinarily try to provide for their non-disabled siblings. This points to a need not only to challenge and create awareness about intellectual disabilities within families and the wider community, but also to remove the self-stigma that persons with intellectual disabilities may feel.

An effective way of changing attitudes and perceptions is through self-advocacy by persons with intellectual disabilities. When they are trained in health-promotion strategies, they become effective ambassadors for change. Through Healthy Communities, the athletes played an important role in successfully challenging perceptions and creating awareness of their abilities, and promoting inclusion.

> *Our athlete leadership programme [ALP] uses assistant coaches to help young athletes. When we introduce young athletes we also have the athlete leaders there to help, and the parents of young athletes will look at the athlete leaders and say 'my goodness, I want my child to grow up like that – oh, you know, this is a great example'.*
>
> – Healthy Communities staff, Thailand

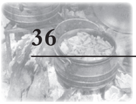
Another way of changing perceptions and creating awareness is to work with parents. Healthy Communities staff took on an educational role in communicating with parents, informing them about the nature of their child's condition and the implications. This helped to build the capacity of parents to improve their children's health.

> *I've been able to convince most of the parents that I've interacted with to say these are normal children, just like anyone else, and they have to be treated like anybody else. The response of the guardians has been positive.* – Healthy Communities staff, Malawi

Healthy Communities staff also recognised the importance of ensuring that health professionals had the capacity to communicate appropriately with persons with intellectual disabilities.

> *All professionals should receive information and training about people with intellectual disabilities to know how to communicate with them.*
>
> – Volunteer, Romania

The training provided in Malawi contributed to changing the perception that persons with intellectual disabilities are useless and not part of social activities. They are now recognised like anybody else, especially in their families.



> *We know about Special Olympics' Healthy Communities because, as leaders, we were trained on how to take care of children and people with disabilities in our communities. We were told to treat people with disabilities with love, not shouting at them, not to use abusive or derogatory words for them, and to ensure that parents send children with disabilities to school.* – Community member, Malawi

Building relationships and friendships

Healthy Communities has created an opportunity to build a robust social network for athletes, their families and their communities. Sport activities were reported to promote the overall health of athletes on physiological and psychological levels, to provide opportunities for friendships to develop, and to enhance socialisation skills. Families have indicated their gratitude for the impact Special Olympics has had on athletes' well-being.

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

Some parents recognised the limited opportunities their children had for social interaction due to behaviour problems not being understood and feeling the need to protect them. These constraints led to children dropping out of school, isolation and anxiety for the parents. Carers and parents valued the support they themselves received, which ultimately contributed to maintaining their own health and mental well-being.

> *We also had a meeting with friends and we shared our problems because that's what we are here for; always together, right? As a family, because our children bring us together, they are the union. We are like family over here. If something happens to us, we talk about it right away. I tell her so many things, we advise each other.* – Parent, Peru

Using sport to promote health

The inclusion of sport in Healthy Communities provided an innovative solution to holistic healthcare for athletes and their communities. The coaches were instrumental in conveying positive health messages to athletes and their families through sporting activities. The coaches were seen as a consistent, reliable and respected presence in the athletes' lives. The health messages offered by the coaches were valued and taken seriously. Coaches were also able to use the training they received to adapt their coaching strategies.

> *I have participated in a Swedish-Romanian project. The importance of the diet was explained … The physical exercises that I learned at the training really helped my practice with my kids. I learned how to adapt my practice so I could have their attention.* – Coach, Romania

Coaches promoted the health of athletes by encouraging them to exercise and to maintain healthy eating habits. Athletes acknowledged that the encouragement they received from their coaches helped to motivate them to reach health and fitness goals that they initially thought were impossible. Special Olympics also provided opportunities for unified sport in which persons with and without intellectual disabilities played together. This integration contributed towards creating an inclusive environment and challenged perceptions about disability, examples of which were reported in Malawi and Peru. Other countries also adopted inclusivity through volunteerism.

Growing group activities to foster support

Healthy Communities worked towards empowering and enabling parents and health professionals to be advocates for athletes. Organising group activities and regular meetings proved to be a successful way of fostering support for change. Family forums were held in various locations and addressed topics relevant to the needs of local participants. In Malawi, for example, the focus was on helping families to understand intellectual disability and the rights of persons with intellectual disabilities. In some cases, this radically changed the lives of individuals.

> *I'm sure you've heard of the story about a boy who they used to tie on a chair on a tree … Special Olympics was able to help the parents understand and, after this, he even went to school.*
>
> – Healthy Communities staff, Malawi

Through the family forums, parents became aware of the crucial and challenging role they have, and wanted further input and guidance from Healthy Communities' staff.

> *We have a big task as parents; our role is to make sure our child learns all that we were taught. We have a big task teaching our children with intellectual disabilities. We ask you to help us learn how to support our children better.*
>
> – Parent, Malawi

Parents expressed gratitude to Healthy Communities staff for creating awareness, and had an increased desire for unity among parents of children with disabilities and those without.

> *[We need] unity and communication from all; between those who have problems and those who could be our support.* – Parent, Romania

Community members also expressed a desire for a united response to the promotion of rights of persons with intellectual disabilities. They recognised that athletes are often excluded from many spheres of everyday life, especially priority areas such as education and health, which needed to be challenged. Sites such as Peru used different advocacy methods, including research, to influence policy and foster a supportive environment.

> *I always put a lot of emphasis on this issue at the advocacy office; this is a right. But in practice there are many schools who don't integrate kids with disabilities; they tend to send them to other schools, and only with kids with disabilities. I think this is a problem.*
>
> – Community member, Peru

Healthy Communities made a concerted effort towards fostering a supportive environment for athletes through group activities. But as they did, it became even more apparent that other environmental barriers existed for persons with intellectual disabilities, their families, and for health professionals.

> *I also think they have realised we cannot fix everything only through health services or Healthy Communities. We need to introduce other components related to the protection of children with disabilities, their education, and things that governments need to do at a policy level. It's something that we can better achieve as a team.*
>
> – Community Member, Peru

Overall, creating supportive environments depends on building connections in such a way that stigma is reduced and participation enhanced. In LMIC it is usually families that have led the way in building these connections, often with the support of health professionals (McConkey, et al., 2016).

Reorientation of health services

The Ottawa Charter highlights the need for health services internationally to reorientate away from an illness focus, towards an emphasis on health promotion, which is especially pertinent to persons with intellectual disabilities. However, it requires major changes to the culture, structures and activities undertaken by health services, and has particular implications for the education and training of healthcare professionals.

In terms of changing service systems from an individual perspective, Healthy Communities and community-based rehabilitation (CBR) programmes focus on three main strategies: health promotion and prevention; health diagnosis and follow-up care; and record keeping, data management and information technology. Chapter 6 addresses the issue of changing service systems from a population perspective.

Health promotion and prevention

Healthy Communities partnered with local communities to link its health goals to those of the local community, in many cases using and training community health staff as advocates for health promotion for the athletes. Healthy Communities increased awareness about persons with intellectual disabilities and health concerns amongst health workers through courses, workshops and creating opportunities to engage with persons with intellectual disabilities. Screening athletes for health problems was an important starting point.

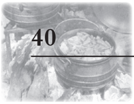
> *After the health-screening, some problems were identified, like hearing and seeing, and this helped teachers with seating plans. For example, there is a learner who was epileptic some time back, but the way she responds to issues made teachers think she was rude and she was being punished regularly. But the screening showed that she had a hearing problem in one ear and the teachers realised that they were wrongly punishing her.* – Community member, Malawi

Health professionals were encouraged to know the rights of athletes and to manage their health in a holistic way. This aspect is evident in the findings from Peru:

> *We can teach them how to be more patient, how to engage more with their patients' illnesses. We are going to provide better service if we understand the people's conditions … Maybe the family is stressed because of domestic problems and here we will provide them tranquillity by giving them small tips. For example, I keep 'red noses' in my office and this has good results because, when they arrive, we give them the noses and they are happy. So there are little things that we can get and give to the patients so that they are calmer during the treatment.*
> – Healthy Communities member, Peru

Healthy Communities facilitated the creation of a network of skilled healthcare providers who were trained in specific skills to manage persons with intellectual disabilities and to whom they could be referred. Health professionals felt that they were giving back to the community, promoting access to affordable health care, and encouraging better referral systems and follow-up health care through partnerships with other health projects.

> *FMR* [Motivation Romania Foundation] *contributed to this partnership by integrating the Healthy Communities programme in*



> *our joint project of the year. So now the young people with intellectual disabilities from poor and isolated areas can receive health evaluations and recommendations to improve their health conditions.*
>
> – Community member, Romania

Another emphasis of Healthy Communities was the prevention of ill health in athletes, with the hope that preventative strategies would also facilitate health within families and communities. This is a key principle in comprehensive primary health care.

> *I really believe that what we do is a kind of prevention of the incidence of certain diseases. To them, the disease incidence is higher than the average population for diabetes, obesity and other things. What we succeeded to do, without emphasising it, is to help them, stimulate them, so that we can effectively postpone diabetes and other problems.*
>
> – Coach, Romania

Prevention strategies were also crucial in equipping parents and carers with skills needed to prevent diseases and maintain athletes' good health.

> *The carer needs to have at least some understanding of cleaning, maintenance, how to cut toenails and avoid ingrowing nails, the right way to dry feet and avoid fungus; especially because these people have a poor immune system and are more likely to get fungus or some other bacteria.*
>
> – Healthy Communities staff, Peru

Health diagnosis and follow-up care

Coupled with health-promotion strategies is the need to make a health diagnosis and ensure follow up care. Healthy Communities health-screening facilitated early diagnosis of health conditions, but referrals were needed for further investigation and follow-up care. Limited family resources led to concerns that families might not be able to give the kind of follow-up care that was needed, therefore it became important to check if referrals had been followed through on. It became apparent that they did not always happen.

> *You call the clinicians for that facility and find out from them: Did they come for the referral? Did they get the management? Did they get assisted? So they say, 'Yes, they came and we assisted them and this happened', but this one didn't come.*
>
> – Healthy Communities staff, Malawi

In many cases, Healthy Communities staff are puzzled about why parents or carers do not follow up on referrals. There is sometimes an assumption that they do not care enough about their children, but it might also reflect parents' lack of understanding of the condition and what can be done about it. Clear communication with families and carers is important, and a parent in Malawi felt it was important for the relationship to be maintained. It was suggested that the mental health and well-being of primary carers should also be followed up and monitored.

> *Members of the Special Olympics committee make follow-ups with families of children with disabilities. They are supposed to monitor improvements in the attitudes of parents and the community at large towards children with disabilities. This helps to maintain relationships between Special Olympics, parents and the athletes.*
>
> – Healthy Communities staff, Malawi

Partnering with community rehabilitation workers is one way of providing ongoing support to families and ensuring that follow-up actions are taken when referrals have been made.

Record keeping, data management and information technology

One of the pillars of Healthy Communities internationally is the use of information technology to collect and record health data, and to assist communication with athletes and their families. For example, information technology was used to facilitate record keeping, the referral process, and remind athletes about their referral appointments. Social media was used for health promotion.

In Romania, participants recognised the value of text messaging and phone calls to remind athletes about their follow-up appointments:

> *I also have to take care of someone who is schizophrenic, and a reminder signal is very welcomed.*
>
> – Parent, Romania

However, it appears that the use of information technology might be better suited to more affluent countries; in Peru and Malawi, the availability of technology was neither sufficient nor affordable. Healthy Communities staff and parents shared that few people have mobile phones and that Internet access is limited due to the financial cost.

> *It doesn't work … that's something that, at the beginning, we never felt would work; it is not easy to do text messages as it's not something that is common. We have many rural areas here and people don't have access to it.* – Healthy Communities staff, Peru

It was also evident that the infrastructure of some rural areas does not allow for even the simplest of databases:

> *'Okay, so I thought that was like one way of going forward, but it's a thing that the whole nation has to embrace at some point because, if they started with the health passport book, there must be records, there are records, everybody has a file, but they are not inputted on a computer.* – Healthy Communities staff, Malawi

It appears that the use of technology in health promotion is a work-in-progress that has great potential for record keeping and communication, but requires further development in order to add value to programmes.

The Healthy Communities experience highlights the importance of systemic changes to promote access to health care of persons with intellectual disabilities. A 'twin track' approach, such as that advocated for in the UNCRPD (2006), would mean ensuring that all services are made accessible to persons with disabilities by becoming welcoming of and responsive to their needs. At the same time, specific skills are needed and should be developed within the healthcare sector, such as communication with persons with intellectual disabilities and their families. Locally-based community staff are well placed to make both types of responses, provided they have training and support to do so.

Development of personal skills

Another strategy of the Ottawa Charter is the development of personal skills, encouraging greater understanding and ownership of the purpose of leading a healthy lifestyle. Even within CBR programmes, this aspect has often been overlooked with persons with intellectual disabilities as they were thought incapable of learning to take care of and protecting themselves from common dangers. Healthy Communities challenged this assumption by devising health education programmes for athletes and their families; athletes learned about nutrition and exercise and how to make healthy choices. Information was provided in various formats using relevant, accessible materials and resources, with the aim of fostering independence in health care for athletes.

> *We made a booklet showing them how to brush their teeth. My son has this booklet in our bathroom and he follows each step to brush his teeth.*
> – Healthy Communities staff, Peru

The skills of carers for supporting health needs were also developed, and some sites have promoted the health of athletes as well as the wider family through family forums. The approach has empowered and enabled families to take better care of themselves and athletes.

> *In our communities, we believe the family or home is the beginning of everything. Now if we make the parents aware, and if we empower the*

> *parents to combat all this stigma, all this ridicule, they are the ones that can bring up the athletes and easily provide proper health and proper lifestyles for the athletes in the community.*
>
> – Community member, Malawi

Preventative care was also key in empowering parents and carers with the skills needed to prevent disease and maintain good health of the athletes.

> *Creating this awareness on health, on health care, through the parents in small groups specifically, and sharing with them the health issues that have been popping up, concerns that they, that we have … I think it's also a good way of making sure the parents are aware and know the preventive measures.*
>
> – Healthy Communities staff, Thailand

Some of the health-education packages were targeted at sports coaches so that they, in turn, could pass on the information and resources to athletes and carers.

> *I have attended training about sexual education and training about nutrition. After the training I tried to promote this information to the parents.* – Coach, Romania

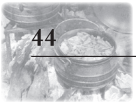
Sexuality and relationships education was a particular concern of families and athletes, and more education was needed on it.

> *I have been in this kind of meeting before. It was very interesting. I am sorry I couldn't attend all the presentations. Sadly, at this forum, a presentation on sexual behaviour was cancelled. I am very sorry.*
>
> – Parent, Romania

Developing personal autonomy is a central tenet of the disability rights movement. Autonomy is enhanced when access to health care and promotion is linked to personal development and increasing the individual's responsibility for their own well-being. People's disabilities are often compounded by being denied opportunities to become more self-reliant; hence the focus on empowerment as a strand within the CBR framework.

Key lessons

Healthy Communities has shown how it is possible to apply the principles of the Ottawa Charter to persons with intellectual disabilities and their families, particularly when it comes to creating supportive environments, reorienting health services, and developing personal skills for healthier lifestyles, which could be readily incorporated into community-based health services.



These are some of the key lessons learnt:

- There is a need for increased family/carer involvement, as they are key to sustaining athletes’ health.
- Communication with parents and carers is crucial, and needs to be continuous and consistent. It is important to build the capacity of health professionals and community workers to communicate effectively with parents so that partnerships are forged among them.
- Parents and carers have expressed a desire for more support for themselves, raising the need for support through professional-family and family-to-family networks to improve the quality of life of individuals and families.
- The identification of health problems through screening programmes requires follow-up care that is not always available. However, strategies have emerged for connecting with healthcare professionals, especially through community-based workers.
- The health education of persons with intellectual disabilities has been successful, and has included teaching them a range of skills and empowering them to make healthy choices. The use of peer educators in promoting the health of other athletes has proved viable and should be continued.
- A comprehensive approach to health promotion is needed that addresses the impact of social and environmental factors in healthy lifestyle choices, such as improved housing, poverty reduction and greater social inclusion.

Chapter 4

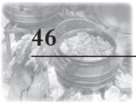
Creating community partnerships to enable health equity

Chantal Krüll, Siphokazi Sompeta and
Theresa Lorenzo

The dire situation of persons with intellectual disabilities living in low- and middle-income countries (LMIC) remains largely neglected. O'Shea, et.al. (2012) have argued that, due to the lack of available resources to address cognitive disorders, it becomes imperative to examine the role of socio-cultural and socio-economic factors within the lives of these individuals. All too often, health promotion concentrates on individual behaviours and how to address these, such as improving exercise and nutrition. However, these individual activities often do not lead to health improvements that can be sustained, and attention needs to be given to the underlying drivers of poor health, such as inequality and poverty (Kuper, et al., 2018). Cross, et al. (1989) commented that, 'Only when a community recognises and owns a problem does it take responsibility for creating solutions that fit the context of the culture.'

The Declaration of Alma-Ata (WHO, 1978) promotes the right and responsibility of communities to participate in health service delivery, but this is still debated in many national health systems. However, communities are an important aspect of people-centred health systems and it is vital to engage with them to address the health targets of the United Nations' Sustainable Development Goals (George, et al., 2016).

Healthy Communities was essentially a community collaboration developed to address an identified problem: that of inequality in access to healthcare for persons with intellectual disabilities. Its aim was to create community alliances to mobilise available resources towards what would become a shared goal of health improvement, and their experiences can inform other



communities around the world who share this ambition. This chapter shows how their findings can be applied to other communities and community-based rehabilitation (CBR) programmes that are looking for ways to promote health and want to create their own initiatives to address the health needs and concerns of not only persons with intellectual disabilities, but also within the community at large.

Community health initiatives that adopt a public health approach are frequently dependent on the establishment of collaborative partnerships to bring about changes in health behaviours and health systems. In LMIC, greater reliance has to be placed on local community initiatives due to the weaknesses in national service systems. But can communities be empowered to help themselves? Fawcett, et al. (1995) developed a framework for examining the effectiveness of community action and leadership that has been used successfully for a wide range of public health issues, such as substance abuse, cardiovascular disease and adolescent pregnancy. It seems well-suited to examining community action and leadership in relation to persons with intellectual disabilities. The model offers four strategies for facilitating empowerment:

- Enhancing experience and competence;
- Enhancing group structure and capacity;
- Removing social and environmental barriers; and
- Enhancing environmental support and resources.

Empowerment models and action research share many similarities. In action research, the stakeholders begin with an analysis of the existing situation and then develop a plan to address challenges and build upon strengths in order to reach their goals. The impact of these actions is then evaluated and further action is planned. Similarly, the community empowerment process (see Figure 4.1) begins with collaborative planning, where an agenda is set for community action. This action leads to community change, which results in enhanced community capacity that can be used for further change.

Within each stage, significant sub-themes can be identified from the research undertaken by Healthy Communities and CBR. This has enabled a better understanding of how communities can be empowered to ensure access to health for persons with intellectual disabilities.

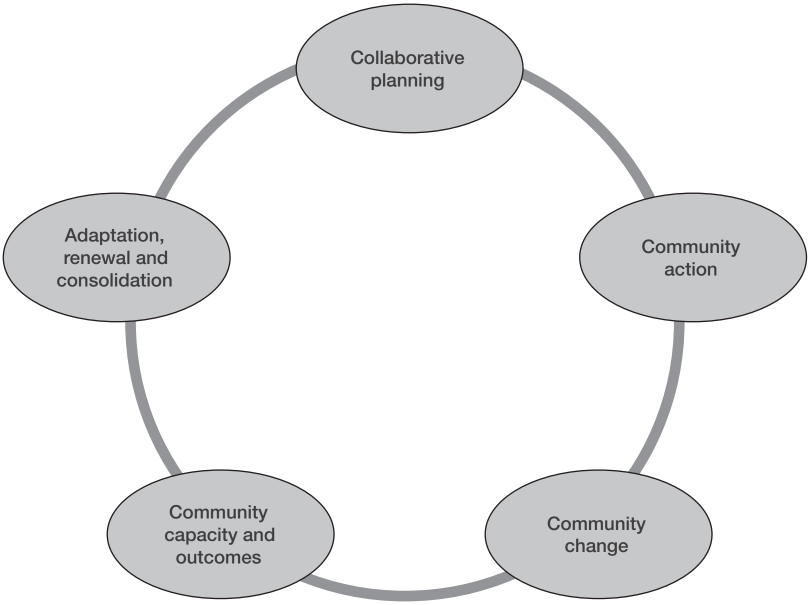


FIGURE 4.1: THE CYCLE OF COMMUNITY EMPOWERMENT (ADAPTED FROM FAWCETT, ET AL., 1995)

Collaborative planning

Collaborative planning is crucial for effective community engagement and requires a continuous process of planning and consultation among partners. By undertaking collaborative planning, projects can enhance group structures and functioning to build capacity for achieving identified goals. Several dimensions need to be considered when creating a collaborative partnership that focuses on health promotion (Addison, et al., 2015). Figure 4.2 illustrates the collaborative planning sub-themes that emerged out of the findings of the Healthy Communities initiative.

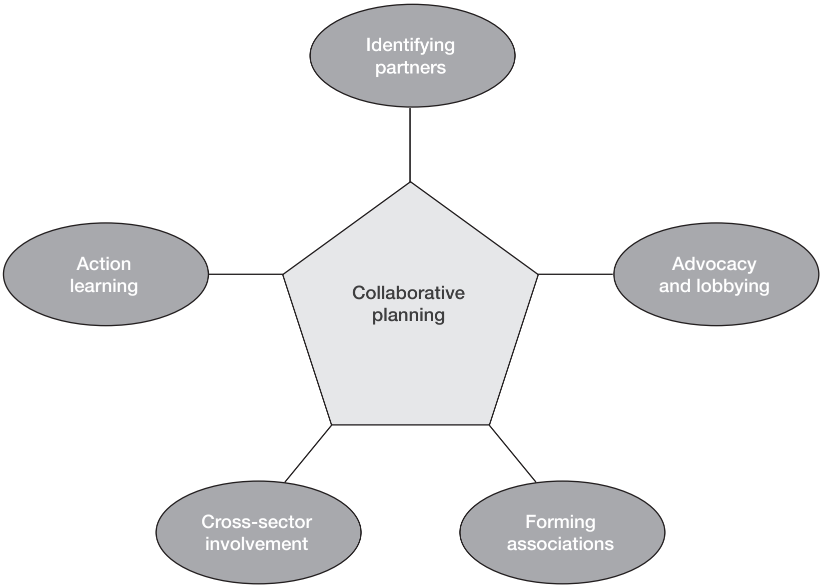
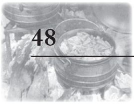


FIGURE 4.2: COLLABORATIVE PLANNING SUB-THEMES



Identifying partners

Potential partners for collaborative planning were identified who shared similar aims, although their focus was not necessarily on children with intellectual disabilities. Addison, et al. (2015) have also mentioned the importance of including diverse groups of community representatives who are able to assist in developing a vision for long-term change. This was reported to be a critical starting point for Healthy Communities projects.

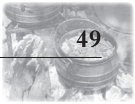
At the start of the project in Malawi, a partnership was developed with staff working in government agencies who volunteered their knowledge and expertise in screening their respective districts. At some sites, existing Special Olympics partnerships with UNICEF and Save the Children Fund were developed further through Healthy Communities, which shifted the vision. Formal partnerships agreements were signed with universities and a podiatry organisation that assisted with screening and follow-up dental services and foot-health problems. Partners planned together to achieve the specific goals identified by the programme.

Advocacy and lobbying

The Lancet series on global mental health (2007) called for effective public-health interventions that address the burden of mental disorders, especially in LMIC. It suggested that service users and their families are key advocates in prioritising mental health on governmental and political agendas. Burns (2009:19) agrees that it is ultimately persons with mental and intellectual disabilities themselves who have the right to 'exercise agency in their own lives and who consequently should be at the centre of advocacy and lobbying movements, as well as the setting of the advocacy agenda'. Healthcare professionals and community members also have a role to play in advocating for equality, justice and non-discrimination (Kleintjes, et al., 2013).

Advocacy and lobbying was needed to initiate Healthy Communities collaborations; in Peru, for example, a report on the healthcare needs of persons with intellectual disabilities alerted the Ministry of Health to the nature of their difficulties. Healthy Communities was then invited to advise and plan with the ministerial committee concerned with disability inclusion. In Thailand, Healthy Communities staff invited representatives from different ministries to plan health-promotion activities together.

Families also need to advocate for their relatives. Volunteers in Peru mentioned the importance of seeking professional advice when families start feeling that they are no longer able to help their relatives. The volunteers also found that parents often do not seek help and, over time, find it difficult to interact with their relatives with disabilities.



Forming associations

The formation of collaborative, strategic partnerships at national and local levels is an important process in creating sustainable inclusive change. The focus of these associations should be on developing public health initiatives that facilitate the needs of persons with intellectual disabilities (Vanderbom, et al., 2018). An important step was bringing together people from local communities in formal or informal associations. This included contact with existing professional associations, although more commonly there was a drive to establish new associations, especially for parents in LMIC. In Thailand there was strong desire for the development of parent associations that would sustain the project. In Romania, examples were given of how families had come together to form associations to develop their knowledge and awareness of health promotion, which operated from rented classrooms. In Malawi, community members mobilised the traditional leadership structure to assist in forming associations that could support persons with intellectual disabilities and their families:

> *The sensitisation will empower community leaders to initiate the formation of groups or clubs within their villages, as they will have information to deliver to their subjects or members.*
>
> – Community member, Malawi

There was also a call to develop groups to advocate for greater inclusion of persons with intellectual disabilities:

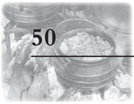
> *There should be created some organisations allowing socialisation between people with intellectual disabilities and ordinary people. This way people with intellectual disabilities would not be marginalised, and the society would have the chance to change its mentality regarding those with disabilities.* – Community member, Romania

Organisations are in a strong position and have capacity to engage different sectors to extend their reach.

Cross-sector involvement

Cross-sector involvement is essential in collaborative planning, given the impact that poverty, housing, safe water supplies and sanitation have on the health and well-being of everyone, including persons with intellectual disabilities. Common to all sites was the need to plan across health and social welfare services, especially where families were struggling financially or needed rehousing (O'Shea, et al., 2012; Kuper, et al., 2018).

Most sites indicated that insufficient transport was an issue that not only affected the ability of Healthy Communities programmes to function, but



also impacted the way in which families and their relatives with disabilities were able to attend events. These experiences suggest that collaboration with transport providers might be a critical area to explore.

> *One may have the desire to move around, carry out the activities of the programme, but we are weakened by the long distances. So the issue of transportation has to be looked into and that can really strengthen the cooperation of the concerned groups.*
> – Community member, Malawi

Insufficient transport also impacts on persons with disabilities and their families being able to attend clinics and training events.

> *We know plenty cases where people gather their five souls or three souls to come all together in one taxi. And the times that we've had contact with the parents, the appreciation is great, even if two or three of them have told us that they haven't been able to afford a taxi; all of them when they come they are grateful.* – Community member, Peru

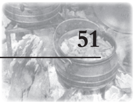
> *In rural villages the lack of transportation, information, medical personnel, and the poor conditions from the hospitals and maternities are all real problems.* – Parent, Romania

The burning issue of transport needs to be flagged as a real barrier to implementation that requires cross-sector planning as it impacts on access to the services and activities of everyday living. Grut, et al. (2012) caution that the apparent non-compliance by families with the opportunities offered to them should not necessarily be interpreted as disinterest or neglect, but could result from impoverished circumstances. They recommend: 'When offering health services to people with disabilities living in resource-poor settings, services should take into consideration the person's history, the needs, and the resources and abilities of the family group.'

Action learning

Effective projects begin by looking at the community's needs and responding to them. It appears that Healthy Communities took the lead in identifying needs, rather than doing so as part of a consultative process with partners. Community ownership of programmes could be limited by this approach which, in turn, would affect sustainability.

The Healthy Communities projects incorporated action learning through the constant monitoring and evaluation used to inform further steps or adjustments to their programmes. However, these monitoring systems, rather than ones devised by external agencies such as funders or health service managers, need to be directly linked with service delivery. The health-screening tools



used by Healthy Communities projects are good examples of how information that is gathered can be used to monitor the health of individuals and improvements over time, and collated to give an overall picture of the health disparities among persons with intellectual disabilities. For example, male youth with intellectual disabilities were found to be significantly underweight in LMIC in Africa compared to other nations, with poor nutrition being a likely explanation (McConkey, et al., 2018).

Projects can be improved or spread their coverage as they learn from their successes and develop strategies to address mistakes or failures.

> *We've just reached part of Malawi and the districts; it's not like the whole district, it's just parts of the districts, so we need to go out more and roll it out, sensitise the community. We still have a long way to go.*
> – Healthy Communities coordinator, Malawi

Community action

Community action refers to the actions taken by the leadership and membership in existing communities towards achieving desired outcomes. Although consistent monitoring informs community action, it needs to be developed as an action in its own right. Community action can result in changes to policies, practices and programmes that are consistent with the project's mission. It is enhanced through awareness-raising events, conducting screening campaigns, and making use of volunteers. The premise of Healthy Communities is that community-instigated actions will result from the leveraging of partnerships in order to gain access to resources and health skills for local communities. Data gathered from Healthy Communities suggest that two sub-themes underpin community action:

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

Generating engagement and consultation

Any attempts to try to reduce health disparities should ensure community involvement in all discussions. It is the communities that possess the expertise and knowledge of local resources, so they have a right to engage, direct and influence initiatives that are aimed at addressing their health needs (George, et al., 2016; Addison, et al., 2015). In Malawi, engagement and consultation with community leaders was crucial in accessing families and athletes:

> *You need to engage the traditional leaders, let them know what you want to do, what you are trying implement, who is involved, what are you going to actually do in your implementation. If you go through the*

> *traditional leaders, even those from the education side, people will easily come and embrace activities, rather than you just going to the community without passing through the leadership.*
>
> – Healthy Communities staff, Malawi

Changes were evident in the attitudes and behaviours of community members in Malawi who were engaged through training processes. They mentioned how, through Healthy Communities, they too had been trained to take care of persons with disabilities within their communities. This approach had a knock-on, catalytic effect:

> *Our involvement as leaders is that, after the training, we also trained our people on how to help people with intellectual disabilities in daily living skills like bathing, self-care, especially for girls, eating habits, cleaning their surrounding places [sweeping].*
>
> – Community member: Malawi

While mention has been made of the need for good communication strategies, sometimes there has been inadequate communication within and between structures. Language barriers have also played a contributing factor, with some participants feeling that that cultural backgrounds were not taken into consideration:

> *The discomfort that I felt … We did a campaign in [village] and I felt limited by language, because people were [local language] speakers. Thankfully there were people in the project who spoke the language and helped translate things back to the families.*
>
> – Healthy Communities staff, Peru

Poor coordination and communication among partners can also have negative consequences; for example, participants may miss opportunities to attend leadership programmes because the timeframes and dates have not been communicated to them.

Complexity of multiple roles and responsibilities

As with other CBR programmes around the world, Healthy Communities mobilised personnel for their programmes through the recruitment of volunteers. However, this approach requires the delineation of volunteer roles and responsibilities, and their relationships to salaried staff. The combination of paid staff and volunteers is often not an easy balance to maintain.

> *Since the beginning of the project, there was a lot of stress about making the project sustainable. I know it's hard to say this in a volunteer organisation, but I think it needs securing a budget for the person who's going to run Healthy Communities. You have to have a salary for that*

> *person because it's very demanding and, even if you are a volunteer, you will burn out. So I think you need to compensate that person; there has to be a salary line for the person who's going to run Healthy Communities.*
>
> – Healthy Communities staff, Peru

Health Communities coordinators were often required to take on multiple roles and responsibilities in the absence of paid staff. To address this tension, staff supported each other by developing work schedules that clarified their roles and responsibilities related to the governance and management of staff, organising events, fundraising, marketing, and the coordination of other programme development.

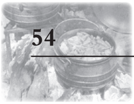
While partnerships enable project staff to achieve their goals through shared resources, it is volunteers who are often the backbone of community-based programmes and who generate a high degree of satisfaction through their engagement, leading to skills development and social interactions. Values clarification occurs at a deep level:

> *I think that working with them [athletes] is the most beautiful thing. They teach you how to value things that humans don't normally value … You begin to live with them, you value all you have from the moment you are born to the moment you go to sleep. I think this is my personal satisfaction as a coach and as a father, because most of them tell me that I am their second father; they basically live with me here.*
>
> – Coach, Peru

Healthy Communities volunteers range from skilled professionals to students studying to become health professionals. The universities are instrumental in providing volunteers and there is the expectation that, through their engagement as students, they will retain an interest in Special Olympics.

> *Even when the volunteer finishes studying, they can still come as a Special Olympics volunteer. I would like if that bond didn't disappear.*
>
> – Healthy Communities staff, Peru

Health professionals also volunteered their services and appeared to have a clear idea about their roles, which tended to be in line with their professional expertise. They expressed great satisfaction in working with Healthy Communities and many commented on how their perspectives had changed. However, in poorly resourced communities there may be limited scope for having volunteers as they expect to be paid. Programme managers need to be aware of the risk of exploiting poor people while they themselves receive a salary, although there have been attempts to address recompense by giving small incentives such as food and clothing. In Malawi, community home



visitors were recruited and trained to provide early intervention for families who had a child or children with intellectual disabilities. Bicycles were provided as a means of transport and payment was given in commodities, in lieu of currency (Kelly, et al., 2012).

Another outcome of volunteerism is that it may provide a path to further training and permanent employment.

> *I was invited to participate in Special Olympics in 2003 as a volunteer. Then I became the health director for Special Olympics group.*
>
> – Healthy Communities staff, Peru

In the Healthy Communities context, the overall impression is that community action was limited mainly to the recruitment and training of volunteers, facilitated and led by Healthy Communities staff. A similar scenario is found in many CBR programmes. In due course, the capacity of community partners to take on this responsibility needs to be developed through ongoing mentoring during the life of the project. In some cases, municipalities take some responsibility for providing services that support the goals of Healthy Communities, such as speech therapy. Experience in Thailand suggests that progress is possible.

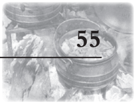
> *Today, almost three years later, we are seeing a lot of coordination between agencies and they're actually talking to each other. We're sitting at the same table, sharing experiences, and they're saying that we've never really have a discussion like this at all.*
>
> – Healthy Communities staff, Thailand

Key lessons

Community partnerships will occur to varying degrees during the life of a project and are usually formed with a specific focus, instead of addressing the more holistic needs of persons with intellectual disabilities and their families. The main challenge is that the implementing agency may own the problem rather than the communities in which the projects took place. This may be due to the type of innovation being piloted and the limited resources at the community's disposal.

Key lessons from the Healthy Communities and other CBR projects about community partnerships for sustained change include the following:

- In the initial planning stages of a project, identify possible partners both locally and nationally.
- Consult with community leaders for support as they will give a directive to other community members to take ownership and responsibility



for implementing the idea of health-promotion initiatives that will be culturally relevant using local resources.

- Build a critical mass through partnerships with non-governmental organisations and international agencies, locally and nationally, by involving them in the lobbying processes for improved access to health services and social development for persons with disabilities.

- Facilitate the formation of formal or informal associations with professional bodies or parent associations, in order to access resources and support for persons with disabilities and their families.

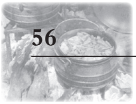
- Cross-sector planning helps to expand partnerships with relevant sectors such as: health, social development, education, sport and recreation, arts and culture, transport, and employment.

- Continuous monitoring and evaluation needs to be given high priority in planning, to facilitate improved strategies.

- Appoint a designated coordinator to maintain communication among partners, and to identify the types of services that persons with intellectual disabilities and their families need to access at any given time.

Conclusion

The relationship between health and disability is complex as these constructs often are intertwined and overlapping, as well as reinforcing (Kuper, et al., 2018:2). Community partnerships play an important role in the promotion of health programmes that are culturally competent. They enable the building of community capacity by reducing health disparities and creating sustainable change at all levels, thereby achieving the goal of improving health outcomes for persons with intellectual disabilities. Although the findings from the Healthy Communities study came from specific countries, their ideas can be used by other LMIC communities to address health disparities within their own contexts and cultures. Any health-promotion strategy or intervention needs to encourage the community to be a part of the process from the outset. It is imperative to focus on poverty-associated issues when addressing the social integration of persons with intellectual disabilities.



Chapter 5

Creating inclusive health systems for effective and sustainable social change

Theresa Lorenzo

This chapter explores factors that contribute to effective and sustainable social change in health systems that facilitate the inclusion of persons with intellectual disabilities. The training of health professionals to foster disability inclusion in service provision is a critical success factor. Many organisations need to consider the elements of organisational capacity when thinking and planning inclusive health-promotion programmes. Three themes are explored in this chapter: integrating disability inclusion and indigenous knowledge; building collaborative networks for disability inclusion and social change; and enabling inclusive health and quality of life.

Too often in low- and middle-income countries (LMIC), new projects or services are started that fade away when personnel and resources are no longer available. For similar reasons, local success and innovation is rarely followed by a national roll-out. Arguably the best use of government and donor funding is to work towards community sustainability. This approach is in keeping with international understanding on achieving better health for all citizens. Health-promoting initiatives must endeavour to become embedded and sustained by community partnerships, which requires key stakeholders' advocacy and advice from the project's inception.

Programme managers are encouraged to use Kaplan's (1999) theory of organisational capacity to identify factors influencing the sustainability of programmes (see Figure 5.1).

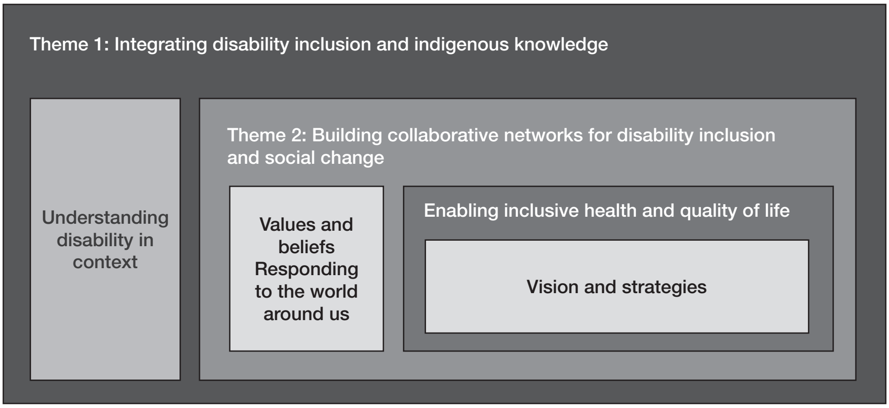


FIGURE 5.1: INTANGIBLE ELEMENTS OF ORGANISATIONAL CAPACITY

Three intangible elements are understood to ground organisations in a common understanding of purpose (context and conceptual framework), identifying common values and beliefs (organisational attitude), and creating a shared vision. These intangible elements contribute to sustainability, but are usually difficult to observe and measure. They can be ascribed to people's experiences and perceptions of community participation and social inclusion of persons with disabilities. The three tangible elements of organisational capacity, by contrast, are more observable and easier to measure.

Theme 1: Integrating disability inclusion and indigenous knowledge

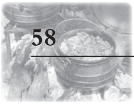
This theme explores how programmes and services are able to tap into local wisdom and practices, in order to integrate disability in social policy, and looks at identifying global policies for action at a local level.

Tapping into local wisdom and practices

Actively aligning health-promotion programmes with local policy processes contributes significantly to sustainability as it fosters community ownership.

Issues concerning children with disabilities were linked through a situational analysis of children generally to the local social policy. Co-ordinators also linked local initiatives to regional government departments for more support.

Grounding a programme in the recognition and respect of indigenous people integrates the influences of culture during the stages of planning and



implementation. Attitudinal barriers to inclusion are identified and removed, which leads to sustained change. Studies on the status of indigenous and vulnerable groups should include disabled persons to reach the most vulnerable population.

There was wide recognition that persons with intellectual disabilities are less seen and usually more marginalised in accessing services and opportunities. Surveys on the living conditions of persons with disabilities identified priorities related to exclusion, which informed how barriers are addressed and what partnerships were developed (Van Es, et al., 2015). Models need to be contextualised to be successfully implemented. It is important to learn about persons with intellectual disabilities, about their reality, to understand that they are like any one of us, who might also face barriers in accessing health care services. Barriers that make it difficult for health promotion programmes to be inclusive need to be addressed. We need to use evidence to integrate global policies into their programmes, which contributed to effectiveness.

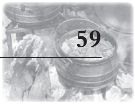
Identifying global policies for action at a local level

Aligning programmes with the international policies provides a contrast with existing rights and assesses their level of fulfilment by examining barriers in health, education, and protection against violence. The understanding of disability as an interaction of the person's impairment with environmental and attitudinal contexts need to be appreciated. It would be valuable for practitioners to critically analyse the International Convention on the Rights of Persons with Disabilities along with other UN Conventions to assess their level of fulfilment at local as well as national levels.

These conceptual and contextual matters also influence how the health services responds to the world around them, which is the second element of organisational capacity. Strong collaborative networks which reflect their collective values and beliefs will help to foster the social inclusion of persons with intellectual disabilities. The contribution of these networks to effectiveness and sustainability is explored in the next theme.

Theme 2: Building collaborative networks for disability inclusion and social change

This theme reflects the values and beliefs related to building collaborative networks for the social inclusion of persons with intellectual disabilities at two levels. Firstly, it identifies the need for service providers at different levels of government and non-governmental organisations (NGOs) to work



together. Secondly, it emphases the value of creating professional and family networks that contribute to the sustainability of programmes and services.

Finding allies at local and national level

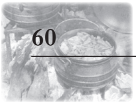
By becoming involved in and engaging with the policy processes of regional and local government, programme developers can help embed disability inclusion in programmes and services. Disability inclusion needs to be prioritised in public policy, national development plans, regional and local government management plans, and budgetary programming in health, education and social development. Empowerment can also be strengthened by networking with international organisations such as UNICEF, Save the Children Fund, and Disabled Peoples' International. The need to advocate and mobilise for disability inclusion is crucial. Although NGOs are often innovative in terms of programme design, and responsive to the needs of the communities they work in, it is a challenge to get government departments to upscale successful NGO programmes to benefit the wider populations.

Although some flexibility in decision-making enables health-promotion programmes to be responsive to priorities identified in local communities, which are often informed by their values and beliefs about disability, criteria for the successful implementation of programmes need to be identified and shared. Programme evaluators need to document community-based technical guidelines for inclusive health-promotion services so that experiences and available resources are maximised. Health professionals in Malawi highlighted a need to recognise ongoing development processes that contribute to new initiatives being sustained.

> *Disability has been there since the Creation. Why is it that only with a visit one would say things are moving in [village]? Healthy Communities cannot run without us.*
>
> – Health professional, Malawi

Creating professional and family networks

To ensure sustainability at a local level, values and beliefs related to building collaborative relationships need to be extended to professional and family networks. Curiosity and being open to learning more about persons with disabilities should prompt reciprocal learning among professionals and families. Conferences and seminars involving different ministries, local NGOs and parent organisations were organised annually by Healthy Communities, which strengthened collaborative efforts to improve health outcomes and social inclusion.



Community members in Thailand recognised the importance of building a network of stakeholders, that included international organisations such as UNICEF, to look at expansion and sustainability, and strengthening networks among NGOs, government and families. This type of systems-thinking approach contributes to sustainability, as evidenced in Thailand:

> *In terms of the expansion of the organisation, this project has an effect as there is collaboration among the concerned agencies, especially the social welfare department and the parents' networks, or family networks, which work together and have added into the system. So they can help the projects a lot in terms of the expansion of the activities.*
>
> – Healthy Communities staff, Thailand

Finding allies and creating different support networks ultimately lead to changes at individual, family and community levels, which generates sustained social change by creating supportive environments and reorientating the health services.

Theme 3: Enabling inclusive health and quality of life

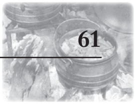
The values and beliefs of the Healthy Communities programme implementers and participants contributed to the vision of a more inclusive and enabling health system, and quality of life. Six strategies are proposed for reaching this vision:

1. Training trainers and leadership development;
2. Creating effective information and communication systems;
3. Influencing curricular changes in health professional education;
4. Networking with local and international organisations;
5. Research collaboration through partnerships; and
6. Prolonged partner engagement.

Training trainers and leadership development

Building capacity by training different categories of stakeholders and investing in human resource development is the crux of sustainable inclusive health services. However, training is more than transferring knowledge and skills; it involves inculcating the values and beliefs that form the foundations of health for persons with disabilities through accessible healthcare systems.

Healthy Communities staff in Thailand coordinate school programmes through principals and health teachers, offering training to teachers and to parents, given the strong family focus on developing individual skills, abilities and competencies. In Malawi, family health forums offered parents



opportunities to share their experiences and concerns about health. Training opportunities in advocacy and leadership also need to be made available to persons with intellectual disabilities. To ensure consistency across abilities, criteria to assess and select potential leaders can be developed collaboratively among disabled people's organisations (DPOs), NGOs and government.

Many community-based health services aim to increase their human resources to make programmes and projects inclusive of persons with disabilities. The absence of capacity building in community-based health and development committees has been reported in Malawi, Botswana and South Africa (Lorenzo, Van Pletzen and Booyens, 2015). Limited capacity could undermine ongoing coordination among schools, the provincial health office, district health offices, and community-based workers. Moreover, community rehabilitation workers identified the need for further training in information technology skills.

Creating effective information and communication systems

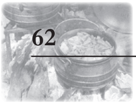
Effective information and communication systems are needed not only to enable the sharing of health information with individuals, but also for monitoring and evaluation. Information technology is also needed for marketing and fundraising. In LMIC, various information technology limitations and/or barriers have emerged as factors affecting programme sustainability. Future advances in information technology will hopefully offer better prospects for extending the reach of programmes nationally.

Policy-related research to monitor the progress of programme implementation has revealed how they could become more inclusive of persons with intellectual disabilities. The Healthy Communities project in Peru used public forums to share experiences of access and barriers to education, health, protection and participation, using a systems approach in decision-making processes.

Influencing curricular changes in health professional education

Another sustainability strategy used by Healthy Communities focused on curricular changes that would influence the training of health professionals. Partnerships among health services, NGOs, local universities or other higher-education institutions, and international organisations are facilitated by social responsiveness as a core function of universities. Lorenzo, Motau, et al. (2015) have argued that:

> *… service learning becomes an essential vehicle in collaboratively realising the outcomes of inclusive development. The possibilities exist for reciprocal collaboration between higher education institutions and*



> *community-based organisations through service learning, which would provide opportunities for fostering disability-inclusive youth development and developing accredited courses simultaneously.*

Indeed, community rehabilitation workers can identify the authentic needs of persons with disabilities that may be addressed collaboratively with the individual and their families. They contextualise matters and mediate misunderstandings between the real needs of a community and academics' understanding of these needs (Lorenzo, Motau and Chappell, 2012; Lorenzo, Van Pletzen and Booyens, 2015).

In Peru, following parent advocacy through Special Olympics campaigns, intellectual disabilities has been included in the undergraduate curricula of health professionals. Continuing professional development may also be needed to upgrade skills to improve the health of not only those with intellectual disabilities, but also the population in general. However, skills alone are insufficient. Healthy Communities staff in Romania cautioned that working with athletes with intellectual disabilities required a certain vocation and patience, empathy and repetition. Health professionals in Malawi felt that providing opportunities for students to gain practical experience – for example, in health-screening, and observing and interacting with children who have conditions such as autism, hyperactivity and attention deficit disorder – would build necessary knowledge, skills and values for promoting inclusive health.

The practical engagement of dentistry students with athletes left a strong impression of the value of their involvement with health-promotion programmes for children and youth with intellectual disabilities in Peru.

> *The students see it as entertainment, because all of them had a good time, and it was a good way for them to find their true heart. These are people who never thought about treating a child, but now they even treat children with autism. They see there is a need, so they tend to share a positive experience; no one can tell you the opposite.*
>
> – Healthy Communities staff, Peru

Barriers encountered in accessing inclusive health services included finding space in an already crowded curriculum for both undergraduate and postgraduate studies, while some institutions have no rehabilitation therapy programmes. Financial cost is another limitation in training professionals to develop inclusive services and programmes. Transportation to enable participation in events was also a major barrier. Options that could minimise costs include situating health-promotion campaigns in local municipalities or where universities organise practical learning placements for students.

Leadership development was identified as a critical success factor by the Healthy Communities coordinator in Thailand. Getting management buy-in for new initiatives is time-consuming in both the education and health sectors, and in terms of influencing professional bodies. It presents a serious challenge to effectiveness as it drains energy and enthusiasm, often leading to discouragement. The training of health professionals was strengthened through networking across sectors and with international organisations.

Networking with local and international organisations

Establishing networks and collaborative partnerships was a successful strategy as ownership of the Healthy Communities programme was shared by local municipalities, national government and global initiatives. Healthy Community members in Peru and Thailand formed community forums at municipal level where international NGOs such as UNICEF and Save the Children Fund co-presented the results of surveys that were inclusive of children with disabilities. Collaboration with Special Olympics International gave a voice to children with intellectual disabilities.

Work with local agencies also contributed to the implementation of programmes that could be sustained; for example, communities experienced the benefits of health-screening for young people with locomotor and intellectual disabilities in poor, rural and isolated communities of Romania. The collaboration extended to Motivation, an international NGO that provides wheelchairs through local agencies. In rural communities, which are usually poorly serviced and under-resourced, community rehabilitation workers are able to extend access to health services, early childhood development and schooling (Lorenzo, et al., 2013).

Research collaboration through partnerships

Collaborative partnerships provided capacity to undertake research into the contextual factors influencing access to services for children and youth with disabilities, including intellectual disabilities. Such surveys contribute to a contextual understanding of disability to shape policy that enables government departments responsible for up-scaling community projects to reach more people. Innovative thinking by the Healthy Communities coordinator in Peru involved youth with disabilities as co-researchers to promote inclusive research and development. Ways need to be found to extend these strategies to health-promotion programmes and campaigns, as the engagement between researchers and programme implementers contributes significantly to sustained change and inclusion at multiple levels of policy development and implementation.

Prolonged partner engagement

Given the scale of the challenge of removing the health disparities faced by persons with intellectual disabilities, improvements will not come quickly, especially in LMIC that face many competing demands on their already fragile health and social-care services. Continuity of personnel within the partnerships is vital, coupled with effective succession planning so that when people leave, other like-minded individuals can replace them.

Even so, some progress is needed to maintain motivation and build hope that the vision of inclusive health services for persons with intellectual disabilities is attainable. A major threat to partnerships is the limited conceptual understanding of contextual factors, collective values and beliefs in sustaining inclusive health-promotion campaigns and programmes. Innovative strategies are needed to engage different stakeholders to contribute to the sustainability of programmes locally, that not only focuses on fundraising, but also involves the skills development for transformative leadership. Cost-sharing strategies and the involvement of schools, health departments, NGOs and corporations will contribute to programme sustainability and achievement of the vision.

Key lessons

The sustainability of inclusive health initiatives continues to challenge training institutions and health service-providers. Thinking about the intangible elements of organisational capacity that contribute to sustainability needs to be considered from the outset, when establishing new initiatives to promote access to inclusive health. This will ensure that sustainability is given priority in the planning and monitoring of project work. Key lessons for sustainability include the following:

- Create professional, community and family networks that integrate indigenous knowledge into the programme design and delivery.

- Recognise leadership development and self-advocacy as a potent catalyst for disability inclusion and social change locally, nationally and regionally across the continent.

- Develop consensus on approaches to disability inclusion among community partners based on occupational and social justice.

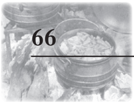
- Actively align the work of disability-inclusive development with local policy processes of the country to foster community ownership across the government, NGO and business sectors.

- Build collaborative relationships with public-private service providers, corporates, universities and international NGOs, as well as disabled people's organisations, to research and monitor inclusive policy implementation.

- Lobby universities and professional bodies to institute curricular changes to integrate disability into the training of all health professional.

- Local sites should develop partnerships with local businesses through corporate social responsibility.

- Where training and capacity building is limited, exchange programmes that facilitate the sharing of resources and personnel could be considered between countries.



Chapter 6

Looking to the future: Designing for inclusive health promotion and well-being

Dominique Brand, Roy McConkey and Theresa Lorenzo

In this chapter we bring together some of the key lessons to emerge from the various experiences recounted during evaluations conducted by Disability Innovations Africa (DIA) with organisations that specifically focus on engaging with persons with intellectual disabilities and the government, and grassroots organisations that provide services to this population and their support networks.

Investing in people to maximise health interventions

Social change interventions often make use of volunteers in a professional capacity, for example medical doctors, or community members working for change in their local context. Change is possible when projects invest in grassroots initiatives that are driven by site-specific agendas with a disability-inclusion focus. Projects with modest financial investments have shown huge returns if the project design and implementation focuses on investing in people. The types of volunteers, the reasons for using volunteers, and the expected outcome of using volunteers, need to be clear in the design, planning and implementation of a project and consider the specific context of the intervention. When grassroots-level project staff and volunteers are engaged and empowered, they use their time and energy effectively to drive implementation, often with scarce resources. By empowering them to troubleshoot implementation problems, they gain experience and take initiative to improve the overall sustainability of the project. Staff and volunteers have illustrated that they have exceptional capacity to generate in-depth understanding of their context and the challenges faced by persons with intellectual disabilities who are seeking access to health care.

The results of programme evaluations indicate that finding the right people with the right characteristics to fill volunteer positions is an essential ingredient for success. Volunteers are often formally employed in structures that already cater to persons with disabilities in schools, government departments or other NGOs that share a similar vision and mission, and have a professional and personal network.

Volunteers are often the most important deputies, who have the drive to engage with the community and will assist an organisation to reach its projected outcomes. The only way to fully support and utilise the skills and initiative of volunteers is to engage with them on a regular basis and to cater to their support needs, enabling them to keep the project agenda alive and in the minds of community members. Being clear about the context and the situation of potential volunteers is equally important in the monitoring and evaluation process. In LMIC, interventions often rely on volunteers to submit a constraint budget. Volunteers often struggle themselves financially, which makes them (understandably) unreliable as there are no financial gains to be had from volunteering. Any framework for evaluating health interventions using volunteers requires a broad lens, to look not only at health-related outcomes, but also at what volunteers bring to and gain from the intervention.

It is important to know whether the programme will be managed using a top-down or bottom-up (grassroots) approach. DIA has seen projects that rely immensely on the volunteer component to influence outcome and impact. If the project design has acknowledged a reliance on volunteers, and considers the potential support or guidance volunteers will need to achieve long-term outcomes, it can be a great grassroots project that is driven by key grassroots volunteers. The project's sustainability would be increased because project ownership was created through grassroots human resource engagement. The grassroots approach is frequently utilised by NGOs that do not have a large footprint, but want to access often isolated community members, including persons with intellectual disabilities.

When recruiting volunteers, be mindful of the following points that are important for successful community engagement:

- Recruits need to see the importance of building relationships with the community and organisations serving the community.

- Recruits must create relationships with persons with disabilities that allow them to voice their opinions. Even if this is not possible at the beginning or throughout the project, ensure that there is an opportunity and platform for persons with disabilities to speak and be heard.

- Include parents of persons with disabilities in the process by regularly sharing information and inviting them to participate in events.

- Seek to partner with organisations that share similar values and conduct similar activities in a shared community.

- Assist partners to make their interventions fully inclusive.

- Think about the intangible elements of sustainability within the community when activities are being planned.

- Create supportive networks for volunteers within the leadership of schools and services to support project agendas.

- Select recruits who show the ability to be reflective, non-defensive, self-critical and resilient.

These characteristics were observed in volunteers who participated in the evaluation of a project that used sport to mainstream a healthy lifestyle message. Each volunteer operated in a different way and utilised resources in a unique manner. As key community figures, they already felt the responsibility of being a leader and guiding the way in which people engage with persons with intellectual disabilities. Engagement with these types of interventions gave the volunteers some direction and a plan for guiding attitudinal change through inclusion and integration (Lorenzo, et al., 2016; Fischer Mogensen, et al., 2017; Brand, et al., 2017).

How can health initiatives be extended?

Six strategies were identified from various evaluations of disability inclusion in community-based initiatives:

1. Relationship building
2. Integrating sport and health
3. Project planning with local and national stakeholders
4. Matching strategies to context and environment
5. Leveraging technology
6. Encouraging advocacy and empowerment.

Relationship building

Amid the focus on actions and activities, it is easy to forget that it is the nurturing and valuing of human relationships that contributes most to improved physical, emotional, mental and spiritual well-being. This is true for all the stakeholders – be they parents, professionals or community volunteers – as well as for persons with intellectual disabilities. Thus, the personal qualities of the leaders in community projects take on added significance over and above any qualifications and experience they may have. Do they have the personal talents and attributes needed to build relationships? Talents such as listening rather than telling; supporting ideas rather than criticising; good humoured rather than complaining; and seeing the glass as half-full rather than half empty. Ideally they will have knowledge of, and empathy with, the communities they aim to serve. They need to be 'friend-raisers' as well as fund raisers, and able to relate to people at different levels, be they government officials, medical specialists, community workers or family members. We still have much to learn about how to nurture such personal qualities in the training programmes provided for healthcare professionals and community workers, but recognising the need to do so is a vital first step (Lorenzo, et al., 2016; Fischer Mogensen, et al., 2017; Brand, et al., 2017).

Integrating sport and health

Many mainstream and disability-focused programmes have chosen to promote the relationship between sport and health. In a recent evaluation by BFM and DIA, two prominent international NGOs collaborated to combine their programmes. One organisation brought to the foreground its curriculum of using sport as a tool to educate, inspire and mobilise young people to live healthier lives. This programme was implemented in three countries – Namibia, Nigeria and South Africa – and the collaborative process led to the development of an inclusive curriculum focused on using a sport-based health and lifeskills curriculum that addresses issues of HIV, sexual and reproductive health, rights, and drug and alcohol use among youth.

These programmes have also created the opportunity to integrate non-disabled and persons with disabilities into combined groups. This integration has enhanced the learning process as learners are challenged to engage with persons with disabilities and realise that they face similar life challenges. This process of understanding and engagement then continues on the sports field. In an evaluation conducted by DIA, many youth related how they previously did not engage with children from special schools, but now they do. Coercing integration is not an easy activity, but integration on the sports field was successful when special schools and mainstream schools created a space for lifeskills training through a sport-based curriculum (Lorenzo, et al., 2016; Fischer Mogensen, et al., 2017; Brand, et al., 2017).

Project planning with local and national stakeholders

The planning and roll-out of any health or livelihood intervention needs to begin by consulting stakeholders, the most important of whom are persons with intellectual disabilities and their families. It cannot be assumed that the needs in one locality are the same in another. There are various strategies for consulting communities of users, such as consultation workshops using participatory processes that enable visions and goals to be clarified, and drawing up action plans and continuous reflection to identify lessons learnt. A more detailed analysis of the context in which the project will be based will help to identify potential risks, such as differences in cultural understanding and responses to disability. Initial planning should inform decisions about how best to respond to specific health needs.

Since disability is multi-sectoral, involving a range of stakeholders, it is essential that community leaders buy into any proposed health or livelihood strategy and are empowered to take responsibility for disability issues within their own locality. The involvement of community leadership can be expanded through the development of local health and livelihood committees, where relatives of persons with disabilities can be recruited as members. In many LMIC there are community health workers and/or community development workers who could also join health and livelihood committees.

Additional community stakeholders may include government officials, other service providers, disabled persons' organisations, NGOs, schools and colleges, and service clubs. Decisions about who should be included will depend on local availability and the action plan that evolves from community consultations. A shared vision among the partners will make it easier for them to buy into common programmes and sustain their implementation. Formal partnership agreements will further clarify the terms of reference for the partnership, and the roles and responsibilities of each partner (Lorenzo, et al., 2016; Fischer Mogensen, et al., 2017; Brand, et al., 2017).

Matching strategies to context and environment

An ever-present risk in development projects funded by international organisations is exporting strategies that work in more affluent countries and trying to apply them to poorer nations, without sufficiently taking into account local conditions. Many development projects fade away when international monies are withdrawn. It is important for new interventions to show awareness of the need to match strategies to context by granting leeway to grassroots volunteers within the project structure and encouraging operations and information sharing among all the local projects. There is also the tendency to under-utilise knowledge and experience from less affluent countries, which is often not documented in international literature.

One main difference between LMIC and high-income nations is the relative lack of a professional healthcare workforce to adequately meet the primary healthcare needs of the population, let alone the needs of persons with disabilities. Unfortunately, the financial resources to provide such a workforce will be beyond the reach of most nations for the foreseeable future. An alternative strategy is to mobilise existing resources within communities and use scarce healthcare professionals to train and support community personnel. More attention needs to be given to the roll-out of projects in rural areas, which are often under-serviced and under-resourced (Booyens, 2015). Here, community health workers or community rehabilitation workers are key in building bridges between families with persons with disabilities and government services as they have in-depth understanding of contextual and cultural matters (Lorenzo, Van Pletzen and Booyens, 2015).

An initial strategy is to map the existing health capacity of a local community. This mapping could follow an asset-based, community-development approach, where a survey of community assets – personnel, facilities, services, and funding – that contribute to health could be determined. The challenge is to integrate the health needs of persons with intellectual disabilities and their families into this map. Significant gaps in community assets will also be identified and plans can be made for how these could be overcome. These local analyses can be collated to inform the development of national policies and services that are inclusive of persons with intellectual disabilities. Public transport difficulties related to inaccessible vehicles and the attitudes of drivers and other passengers will invariably arise and local solutions will need to be explored.

Innovative funding strategies in local contexts also need to be created. Local committees could be assisted to write funding proposals to charities or government agencies, perhaps in alliance with other community initiatives such as income-generation or rehousing schemes. Community partnerships could include businesses and service clubs that provide donations in kind, such as relevant services, products and technology, and undertake fund-raising (Lorenzo, et al., 2016; Fischer Mogensen, et al., 2017; Brand, et al., 2017).

Leveraging technology

Information technology, be it mobile phones, the Internet and electronic information exchanges, holds promise for improving people's health, but its use needs to be adapted to the local context. Evaluation of grassroots projects has raised issues around user capacity and engagement with technology needing to be coupled with considerations of cost and bandwidth, especially in low-income countries. This requires being creative about how technology innovations are used. For example, health-promotion programmes can be offered in particular locations, rather than targeted at individuals. Video conferencing, webinars and/or Skype meetings are held with groups of participants who have the experience mediated for them by a local facilitator or health coach. This approach would help to address the costs and technical issues of bandwidth.

The use of technology for record keeping is an important future development that is currently hindered by the cost and availability of hardware. However, with advances in mobile phone technology and software that are becoming available, there will be greater scope for creating personalised health records and associated health-promotion messages. Health professionals of the future will need the knowledge and skills to apply this technology in their work with persons with intellectual disabilities so that they too have equitable access to new approaches to health promotion (Lorenzo, et al., 2016).

Encouraging advocacy and empowerment

Internationally, the focus of many initiatives has been to make life better for persons with disabilities. Arguably, this focus has been present in community development, with the aim of changing communities. More recently, though, the emphasis has shifted from a betterment approach to an empowerment approach, through which persons with disabilities and local communities are empowered to address to their own needs (Fawcett, et al., 1995).

Using the empowerment model, the project agenda arises from the community and is owned by the community in its purpose and process. When it comes to advocacy and empowerment, it is worth noting that community is not necessarily a geographical area, but could be a community of practice that has common vision and purpose. Such communities would include national disabled peoples' organisations (DPOs), parent organisations and their local branches. The reach of disability-inclusive initiatives could be expanded through local advocacy groups, especially parent associations, to advocate for a family-centred approach to improved access to health services in their locality. Support for parents is required for them to become advocates for the rights of persons with intellectual disabilities at different levels. National organisations led by parents are ideally placed to offer such support and training, and the formation of parents and friends associations, if none exist, may be an important action for future disability-inclusion initiatives (Lorenzo, et al., 2016; Fischer Mogensen, et al., 2017; Brand, et al., 2017).

At national level there is a need to engage further with other national advocacy organisations in lobbying politicians to take up and/or integrate disability into local and national policy. If a country has signed and ratified the United Nations Convention on the Rights of Persons with Disabilities (2006), its government is required to submit a report every five years to the United Nations Special Rapporteur on Disability (Mittler, 2012).

There is a need for DPOs and NGOs to come together to discuss monitoring strategies and indicators. Through a unified and stratified effort to monitor data, information could be shared with NGOs and DPOs to provide an accurate base for writing a shadow or alternate report on the implementation of the Convention in their country. The empowerment component of the CBR Guidelines (WHO, 2010) provides other examples of operational strategies for use locally and nationally.

Key actions for extending health initiatives

- Professional and family networks should be developed and supported as there is evidence that peer support and reciprocal learning has improved the emotional and mental well-being of individual family members and carers. They have also capacitated health professionals to address the needs of persons with intellectual disabilities.

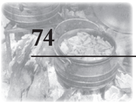
- DPOs and parent organisations need to be recognised as critical partners that will contribute to leadership development, and policy implementation and monitoring.

- NGOs and DPOs should communicate and collaborate when planning new interventions so that indicators and monitoring data can be shared to build capacity to report on the implementation of the UNCRPD in their community or country (if their government has ratified the UNCRPD).

- In countries where there are community-based health and rehabilitation workers, they should be utilised to bridge gaps in service delivery so there is a better continuum of care and supportive environments are created.

- If sport is used to mobilise health education, health coaches could be recruited to work alongside sports coaches. They would reinforce collaborative efforts among the health, education, social and livelihoods sectors, thereby addressing social and economic well-being at a population level.

- Strengthening partnerships among programmes and NGOs that have a shared vision and mission, and common key objectives, can assist in making community outreach programmes more inclusive.



- Strengthening partnerships among programmes, health services and universities so as to engage undergraduate and postgraduate students as health-screening volunteers. Their involvement could influence curriculum changes to make health services more inclusive.

- Research partnerships with universities and global organisations have helped to build capacity for evidence-based advocacy campaigns.

- Information technology and social media can be used to publicise 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 youth who need to find opportunities to become economically active. The link between work and improved health outcomes is well known.

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

Some NGOs rightly place emphasis on local, community-based initiatives as the way to improve the health and well-being of persons with intellectual disabilities. However, using this approach alone may fall short of achieving the vision of Health for All. For example, some localities remain under-served as resources are focused on areas where programmes are strongest. Some issues cannot be addressed at community level and require national action, such as the training and deployment of healthcare professionals. The health of persons with intellectual disabilities must be included in national policies and health services as a means of supporting and extending the community-based approaches upheld by local community health workers and NGOs. Changing and implementing policies, and influencing health professionals, are two strategies that hold some promise.

Changing and implementing policies

Where there are gaps in national policy that ignore disability issues, these need to be targeted. Frameworks have been devised for reviewing policy statements on health to establish the extent to which disability features in them, if at all (Eide, et al., 2015). Comparisons can also be drawn with neighbouring countries as another way of levering change.

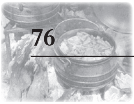
Advocates have a key role to play in promoting international conventions on the rights of children and persons with disabilities, and using the mechanisms by which the United Nations holds national governments accountable for their implementation of the UNCRPD. As these are rarely translated into local languages, national advocacy organisations have a vital role to play not only in lobbying politicians and government officials, but also in communicating with local communities. More basically, new understandings of disability need to be promoted as many policies are based on outmoded medical models of disability. The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) provides a common language for understanding the social and environmental influences that compound the impairments and limitations on participation experienced by persons with intellectual and other disabilities. A common assessment framework will guide policy making and should assist in establishing entitlements to financial and other support. It will also provide better monitoring of changes in people's health and well-being and, ultimately, be used in determining the cost-effectiveness of support provided.

The seventeen United Nations Sustainable Development Goals (United Nations, 2015) provide a further basis on which advocacy and the lobbying of national governments can take place. These goals will only be achieved if they embrace persons with disabilities. For marginalised groups, mobilisation is best done through alliances that may extend beyond disability interests. The goal is to ensure that policies and practices are implemented and monitored to identify progress made. Once again, national organisations have a responsibility to ensure local communities are made aware of the international developments to which their governments are signatories.

Influencing health professionals

Changes in curricula for undergraduate and postgraduate health professionals are starting to happen in some places, which could serve as models for other course leaders to emulate by either extending the revised training to other healthcare professionals within the same institution, or by sharing new courses with other institutions. Certainly there is growing evidence of the benefit this training brings to students, as well as the impact it can have on making health services more accessible.

Government policy and the funding provided for training will also influence the style and content of pre-service training provided for healthcare professionals and their opportunities for post-training experience, which at present is often limited in LMIC. National associations of doctors, nurses and therapists also determine the core practice of various professionals, so they too need to be engaged in how their professions meet the needs of persons with intellectual disabilities and their families. The associations can help to strengthen community involvement in training initiatives.



Personnel exchange programmes within and across LMIC have been a productive way of sharing expertise and appropriate to low-resourced settings, rather than sending personnel to higher-income countries for training and from where they may not return. The use of information technology would assist in maintaining and extending these exchanges (Lorenzo, et al., 2016; Fischer Mogensen, et al., 2017; Brand, et al., 2017).

Key actions for inclusive policy processes

In summary, the following key actions will help to shape national policies and services – a process that is well underway in more affluent countries, but has yet to begin in many LMIC.

- Focus needs to shift from services designed around individual health assessments and treatments, to effective population approaches to improving health outcomes for marginalised groups.

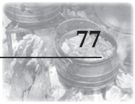
- Sensitising community programmes and partners on global policies affecting the health, well-being and inclusion of persons with disabilities.

- Mobilising 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 make explicit mention of disability in all their policies and to fund specific service improvements, in line with global policies based on the insights and information gained from experiences in community-based rehabilitation.

- Engaging with policymakers across different sectors on the implementation of international accords and adapting mainstream services to meet the needs of persons with intellectual disabilities.

- Ensuring that the training offered to healthcare professionals includes the needs of persons with intellectual disabilities and how best to respond to those needs.



Appendix

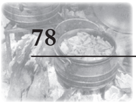
Evaluating interventions

Dominique Brand, Karina Fischer Mogensen,
Theresa Lorenzo and Roy McConkey

In this Appendix, we describe monitoring and evaluation (M&E) approaches that are useful and appropriate for health and livelihood interventions for persons with intellectual disabilities, especially in low- and middle-income countries (LMIC). We advocate for viewing M&E as a learning and capacity-building process that includes and empowers evaluation stakeholders and participants. This approach is particularly important as the general M&E capacity in the disability and health sector is low, and the focus is often on quantifiable results rather than actual change in people's lives. We also suggest approaches to evaluating interventions that rely on volunteerism, which is often used as a way of activating programmes at grassroots level. Creating an effective and sustainable grassroots programme has a fine line to balance between staff and volunteers, and autonomy and isolation, compared with a support system structured around key volunteers.

Participation and utilisation-focused evaluation

Working within the disability sector, we have experienced the clear need for capacity building in M&E to ensure successes and challenges are documented, and to enhance learning within organisations. M&E should not be seen as stand-alone activities, but rather as critical components of reflection on action that enables deeper learning to inform planning of the next action cycle, and the continuous monitoring of implementation and changes that occur (Taylor, et al., 1997). Within this view, the participation and utilisation-focused evaluation approach developed by Michael Quinn Patton (1996) is particularly useful. The approach has two essential elements: Firstly, the evaluation's primary intended users must be clearly identified and, from the beginning of the evaluation process, they must be engaged to ensure they are identified and addressed in the evaluation. Secondly, evaluators must ensure that the identified intended uses guide the evaluation process, including the design, identification of evaluation participants, and data collection and analysis.



A participation and utilisation-focused approach involves funders, project staff and project target group/s in research and evaluation. M&E is an integral part of the action learning approach, and should be designed to provide stakeholders with useful information that will assist them in decision-making at each step of the project cycle. All programme stakeholders should be involved in the evaluation process to collaboratively identify methods, design instruments, determine data collection protocols, and select reporting formats. At its core, the participatory approach seeks involvement from all influencers; however, the type and level of stakeholder involvement will necessarily vary – for example, between a local-level impact evaluation and an evaluation of policy changes (Gujit, 2014).

It is also important to consider why certain stakeholders should be included in the evaluation. Working closely with project staff provides opportunities to gain cultural and contextual understanding, build M&E capacity, establish and explain causality, and sustain organisational learning and growth.

The involvement of the project target group/s, or beneficiaries, is also important, with projects targeting persons with intellectual disabilities posing some challenges to traditional evaluation approaches. According to Robinson, et al. (2014), it is important to involve persons with intellectual disabilities in evaluations of disability interventions for the following reasons:

- People have the right to be involved in finding out about their lives.
- It changes the way people think about people with cognitive disability.
- It proves to people that you can do it, and you get the chance to do it.
- People with cognitive disability have a different way of doing things – they understand the way evaluation should be put together differently; they come at it from a different angle.
- People's experience is valuable as they provide a lived experience.
- Persons with disabilities may feel more comfortable talking to someone who has/had the same kind of experiences.
- You get different information from people when someone with cognitive disability asks them.
- People can understand what they are being asked because you don't use too many big words; it makes it easy.
- More people find out about evaluation and research, and get more involved (i.e. those with and without cognitive disability).

Healthy Communities evaluators pursued the involvement of youth with intellectual disabilities in data collection. Peer-to-peer interviews were used at three evaluation sites and data collectors with disabilities were trained to use research tools under supervision. This approach was well received by the athletes who participated in the interviews both as interviewer and interviewee. The approach created a sense of belonging for athletes and inclusion in the evaluation process (Lorenzo, et al., 2016).

Changing people's lives: qualitative impact

Methodologies that work well for impact evaluations with a qualitative focus include Most Significant Change (MSC) and Appreciative Inquiry (AI). These approaches complement each other as they share a focus on generating rich stories with an emphasis on best practices.

The MSC approach focuses on collecting stories of change. There are three basic steps to follow when using the MSC approach:

- Collecting stories of change.
- Selecting the most significant stories (for example, on health or teaching practices, levels of empowerment, or stigmatisation).
- Sharing stories with key stakeholders and analysing them to understand their value.

AI is an approach to organisational change. Often organisations that engage with an evaluation for the first time harbour an array of fears that could negatively influence their engagement with the evaluation process and the benefits that could be gained from this experience. The AI approach is a method that is often used to disarm organisations' initial fears, and to create an atmosphere that is non-threatening and rooted in a learning space. The AI space focuses on identifying strengths rather than weaknesses. This approach draws on the platform of the participatory approach, where there is cooperation between the evaluator and the organisation. Organisational staff is seen as key to the evaluation as they will help the evaluator understand contextual complexities and how these influenced the project outcomes. The AI approach helps organisations to evaluate their work by identifying what was successful and effective, what did not work, what can be built on, and what needs to change for it to be more successful in the future.

Evaluation often relies on quantitative data to indicate whether the project achieved its short- and long-term outcomes. Quantitative data is also useful for answering questions about short-term outcomes, but will not give much insight on whether long-term outcomes or impact have been achieved. Qualitative methodologies and indicators are needed to answer these questions.

Developing qualitative indicators is not always an easy process, but the Theory of Change (ToC) can be used to mitigate this planning challenge. Following the planning and action phases, M&E data can be used to test whether the theory was correct: Did the desired change/s occur as a result of the action/s? To what extent? Why did it work or not work? This analysis will result in a deeper understanding of what works and what does not work, and the organisation can then integrate this back into their planning (a new ToC) before moving forward with an amended set of actions.

If ToC is applied at the beginning of a project, it challenges project developers and stakeholders to verbalise the change they want to see, the level of change to be achieved, and the causal pathways that will lead to this change. Mapping change pathways allows for clearer identification of qualitative indicators that will assist with monitoring for change. Although this is always advocated, deciding on how many qualitative indicators should be collected will probably be guided by the resources available for continuous monitoring.

Biopsychosocial focus

Bronfenbrenner developed the ecological systems theory to explain how the inherent qualities of a child and his/her environment interact to influence how he/she will grow and develop. This is a good framework to use to analyse context, especially for programmes that are developed to reach a certain population group that are often isolated within communities. Ecological systems theory focuses on the importance of observing a child within the context of multiple environments to understand his/her potential development. A child can often be enmeshed in multiple expansive ecosystems – from home to school, societal and cultural ecological systems (Bronfenbrenner, 1994).

Asset-based community register

Asset-Based Community Development (ABCD) is understood to be a methodology for evaluating the sustainable development of communities, rooted in their strengths and potential. It involves assessing the resources, skills and experience available in a community; organising the community around issues that move its members into action; and then determining and taking appropriate action. This approach uses the community's own assets and resources as the basis for development, empowering people by encouraging them to utilise what they already possess (Haines, 2009). Thus, the approach is well suited to LMIC and programmes that use community volunteers as assets.

Community-based rehabilitation

The World Health Organization's Community-Based Rehabilitation (CBR) framework (WHO, 2010) is an appropriate framework to use for evaluations that focus on disability-inclusive development. CBR has changed from a medical-orientated, often single-sector service-delivery approach, to a comprehensive, multi-sectoral, rights-based one. CBR is defined as community-based inclusive development that involves everyone, but especially those who are marginalised and often discriminated against. Persons with disabilities and their families, particularly those living in rural or remote communities, or urban slums, often do not benefit from development initiatives. Disability-inclusive development is, therefore, essential to ensure that they can participate meaningfully in development processes and policies (WHO, 2010; IDDC, 2012).

CBR uses a 'twin track' approach to achieve the goal of community-based inclusive development by:

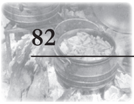
- Working with persons with disabilities to develop their capacity, address their specific needs, ensure equal opportunities and rights, and facilitate self-advocacy; and

- Working with the community and society at large to remove barriers that exclude persons with disabilities, ensuring the full and effective participation of all persons with disabilities in all development areas on an equal basis with others.

Evaluators use the CBR Guidelines as a framework to assess how the project has been designed, planned and implemented within a community-based, inclusive-development approach. Using the principles of the UNCRPD is also a good foundation to use for any evaluation design working with vulnerable groups.

Kaplan's elements of organisational capacity

Kaplan (2000) claims that development is not about things but the way in which somebody develops their thinking. DIA evaluators used the elements of Kaplan's theory of organisational capacity to look at how the organisational



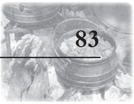
capacity of NGOs and DPOs influence project implementation and sustainability (Fischer Mogensen, et al., 2017; Brand, et al., 2017).

It is described as an open system comprising six interlinking and interdependent elements that form a hierarchy of importance. The elements can also be divided into two realms: The tangible (material) elements, at the bottom of the hierarchy, are easier to observe because they are quantifiable, measurable elements of capacity that can be easily grasped and worked with. Intangible elements belong to the invisible realm and are, to a large extent, observable only through the effects they have.

The theory is a lens that can be used to view the organisational capacity of a project and frame recommendations that allow the organisation to observe and learn about factors that might influence its future organisational capacity – something that needs to be managed and developed as the organisation grows and matures.

Creating social capital

Many NGOs and DPOs rely heavily on recruiting volunteers to assist and, at times, take responsibility for vital activities. When such programmes are being evaluated, a specific lens should be used to look at programme designs that creates social capital and unified responsibility, and increases volunteerism among community members. A social capital lens would also need to look at how programmes are designed to support volunteers to reach their target audiences and deliver key activities without the direct involvement of programme staff. This method of grassroots activation of volunteers has proved successful, especially when programmes need to reach an isolated population group. Evaluations should look at how programmes are designed to guide, train or support volunteers as they are often key to achieving long-term outcomes and impact (Evans, 1996).



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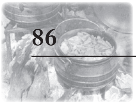

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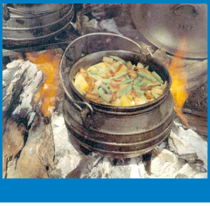
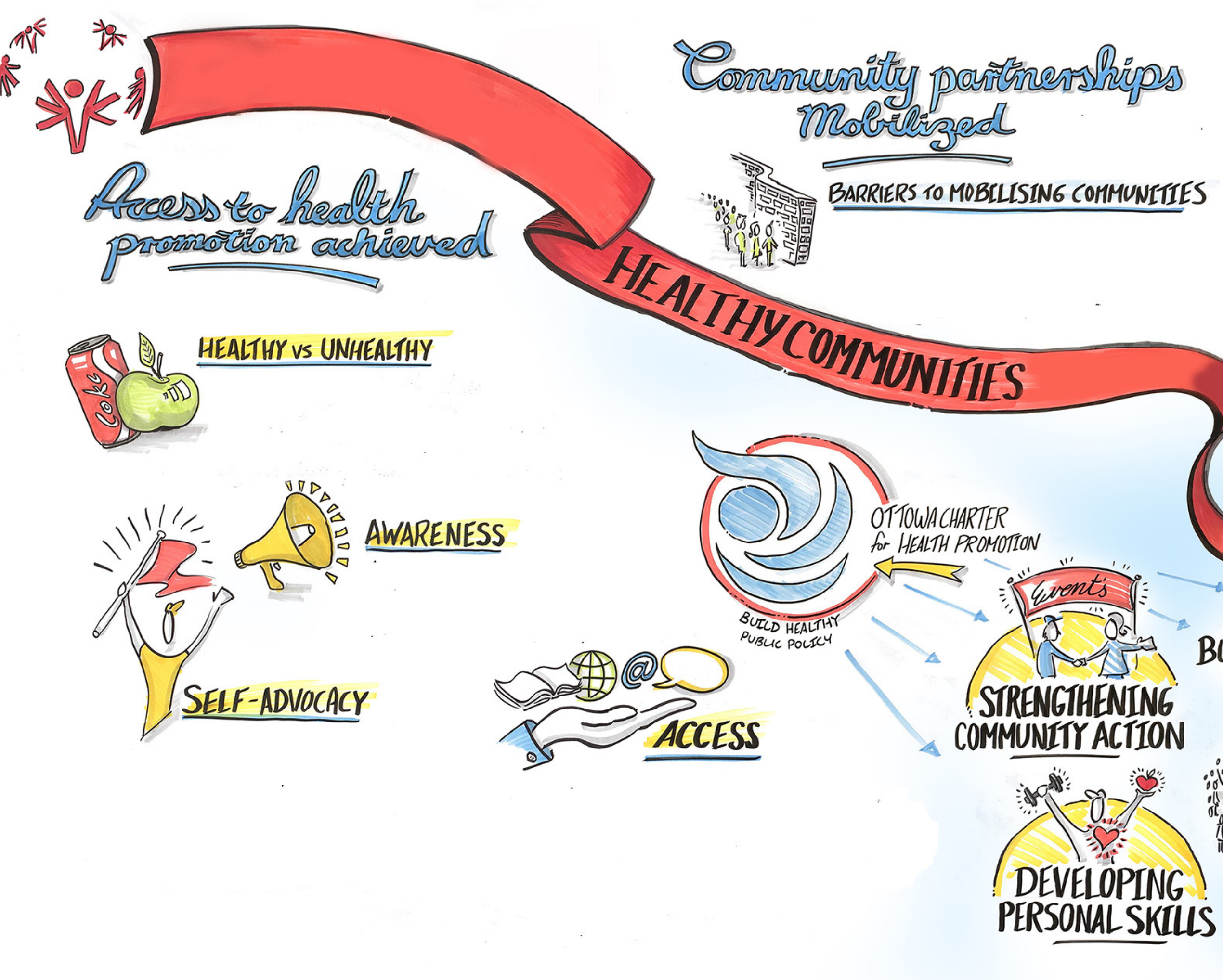


Implementing Inclusive Population Health for Youth



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