THE CASE FOR INCLUSION

A NEW APPROACH TO DISABILITY IN LOW AND MIDDLE-INCOME COUNTRIES

Disability Africa
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DISABILITY AFRICA
CHANGING CHILDREN'S LIVES

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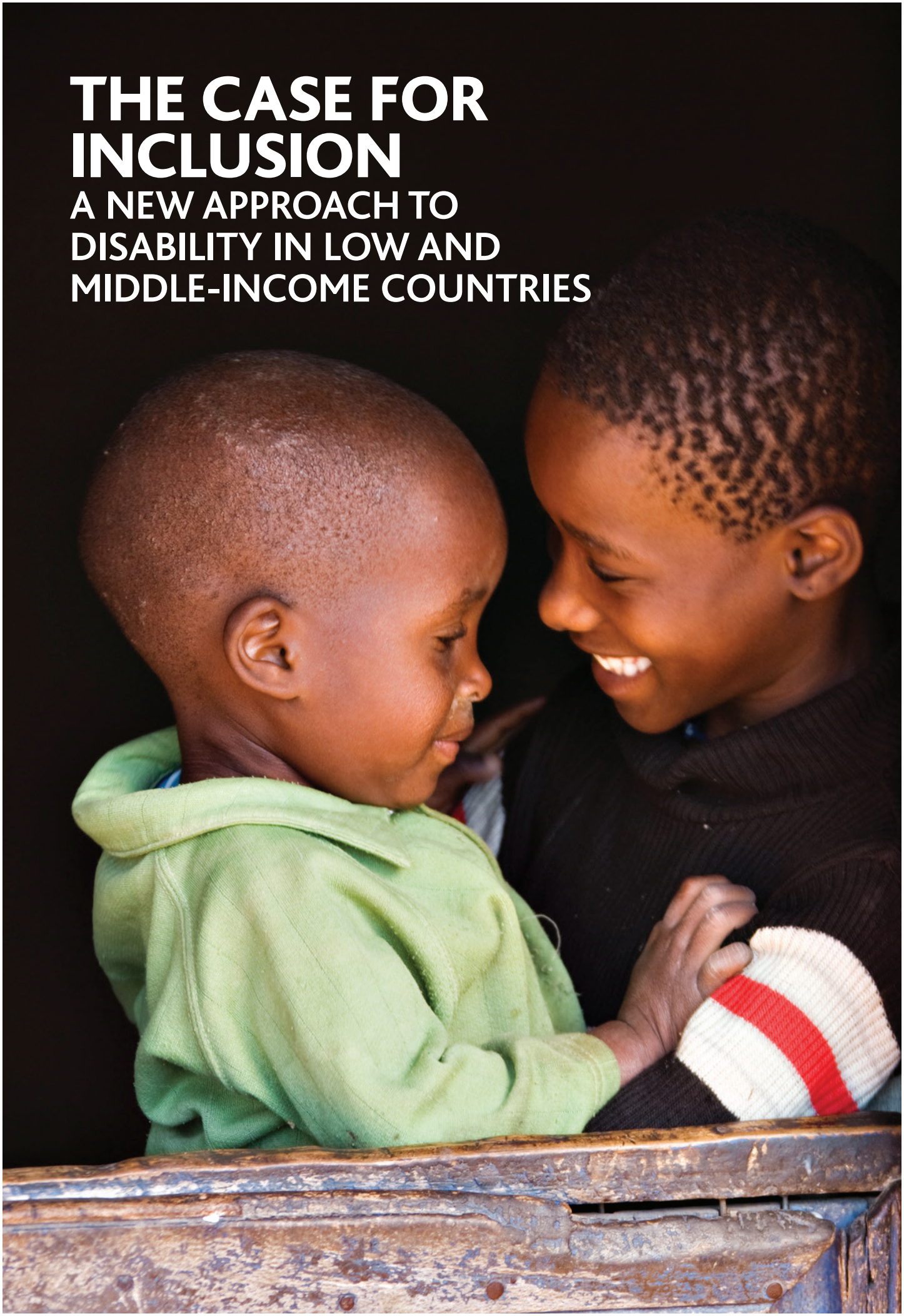

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Notes on Terminology

'Disabled People' vs. 'People with Disabilities'

Disability Africa uses the term 'disabled people' rather than 'people with disabilities' (which remains the preferred language of the United Nations and others). It is only the the expression 'disabled people' that captures the difference between 'disability' and 'impairment' in the social model understanding of disability (see Dis-abling Negative Attitudes below). It is also the preferred language of the disability movement in the UK.

'Disability Inclusion' vs. 'Inclusion'

Disability Africa understands why the term 'disability inclusion' is used to refer to the inclusion of people with impairments, but does not consider it to be a helpful term. Disability Africa understands that people with impairments are disabled principally by the non-inclusive attitudes and actions of non-disabled people. Therefore, when people with impairments are fully included in society they will no longer be disabled. As such, the term 'inclusion' alone is sufficient and with this understanding, 'disability inclusion' makes little sense since 'disability' is something to be eradicated rather than included.

Background and Purpose

It is increasingly recognised that disability has been, and remains, a neglected issue in international development. In 2014, the UK Department for International Development (DFID), published a new Disability Framework, in which it pledged to do more to include disabled people in development programmes. Following this, in 2015, The Institute for Development Studies (IDS) and The University of Birmingham produced a 'Topic Guide on Disability Inclusion' for DFID. The guide summarises some of the most rigorous available evidence on the key debates and challenges of disability inclusion in the fields of international development and humanitarian response.

The guide contains many points which strongly corroborate and validate Disability Africa's experience and understanding of disability in low and middle-income countries, the challenges faced by disabled people and the barriers to inclusion. This document collates existing research relating to disability in low and middle-income countries (LMICs) and links it directly to Disability Africa's (DA) template for Inclusive Community Development and other supporting evidence for its effectiveness. It summarises what is known about disability in Africa and how this has informed Disability Africa's programmes in response.

Dis-abling Negative Attitudes

Disability Africa subscribes to the 'Social Model of Disability', which sees disability as a set of limiting social constructs imposed on people with impairments. Fundamental to the Social Model is an important distinction between the definitions of 'impairment' and of 'disability'.[1] DA believes that disabled people have been 'left behind' principally due to a lack of understanding about disability and associated negative attitudes, not so much due to impairments themselves. Whilst this issue is absolutely not unique to LMICs, studies have found that social attitudes towards disabled people in LMICs can be more extreme and the degree of stigma and shame can be greater than in higher income contexts.[2] Specifically, negative attitudes towards disability in LMICs can arise as a result of 'misconceptions, stereotypes and folklore linking disability to punishment for past sins, misfortune or witchcraft'.[3] It is now widely appreciated that attitudinal barriers, which result in stigma and discrimination, deny disabled people their dignity and potential and are one of the greatest obstacles to achieving equality of opportunity and social inclusion.[4]

Negative attitudes present barriers to the life chances of disabled children at various levels, e.g. at family level, community level, government level and internationally. Family members of disabled children can face discrimination by association, which can result in them developing negative attitudes towards their own disabled children or relatives.[5] Negative attitudes about disability especially disadvantage mothers in many cultures, who are often 'blamed' for having a disabled child.[6] Minimal understanding about impairments and disability can lead to family members holding low expectations of disabled children, which are damaging to confidence, aspirations and life chances.[7] Disabled people and their families also encounter negative attitudes

Footnotes

[1] *An 'impairment' is a condition/functional difficulty that a person has. 'Disability' is a construct that a person with an impairment experiences due to external social and environmental factors e.g. the attitudes of people who do not have impairments.*

[2] *Mont, D. 'Employment policy approaches and multisectoral implementation in low and middle income countries'. In: M. A. Stein & G. Moreno, eds. Disability and equality at work. New York: Oxford University Press (2014). p.24.*

[3] *Groce, N. & Kett, M. Youth with disabilities (Working Paper Series: No.23), London: Leonard Cheshire Disability and Inclusive Development Centre (2014); Rimmerman, A. Social inclusion of people with disabilities: National and international perspectives. Cambridge: CUP (2013) ; Burns, D; Oswald, K and The 'We can also make change' team. 'We can also make change': Piloting participatory research with persons with disabilities and older people in Bangladesh, s.l.: Sightsavers, HelpAge International, ADD International, Alzheimers' Disease International and Institute of Development Studies (2014). pp. 43-44.*

[4] *Wapling, L. & Downie, B. Beyond charity: a donor's guide to inclusion Disability funding in the era of the UN Convention on the Rights of Persons with Disabilities, Boston: Disability Rights Fund (2012). p.21; UNICEF. The state of the world's children 2013: Children with disabilities, New York: UNICEF (2013). p.11; Heymann, J., Stein, M. & Moreno, G. Disability and equality at work. New York: Oxford University Press (2014). p.6; Bruijn, P. et al. Count me in: Include people with disabilities in development projects - A practical guide for organisations in North and South, Veenendaal: LIGHT FOR THE WORLD (2012). pp.21-22.*

[5] *Burns, Oswald and 'We can also make change' team. 'We can also make change' (2014). p.39.*

[6] *Inclusion International. Hear our voices: A global report: People with an intellectual disability and their families speak out on poverty and exclusion, London: Inclusion International (2006). p.63.*

[7] *Mont, 'Employment policy approaches and multisectoral implementation in low and middle-income countries' (2014). p.24.*

[8] *Groce, et al. 'Disability and Poverty: the need for a more nuanced understanding of implications' (2011). p.1499; Burns, Oswald*

held by government officials, policy makers and community members.[8]

Exclusion, Isolation and Comprehensive Deprivation

Disability Africa's experience is that the result of these negative attitudes of non-disabled people is that disabled children and adults suffer social exclusion – they are isolated from mainstream social, cultural and political opportunities.[9] For disabled children, Disability Africa has consistently found that this social exclusion manifests as isolation at home with little or no participation in community life, or even in family life. Exclusion and isolation can begin at day one; stigma surrounding disability can lead to disabled children not being registered with local authorities and service providers at birth. This is a fundamental barrier to their participation in society and it increases their invisibility and vulnerability.[10] Negative social attitudes can lead to the families of disabled people, in particular children, keeping them hidden at home or sending them to institutions which also prevent their participation in society.[11] This may also place them at greater risk of sexual and physical abuse.[12] Disabled children are estimated to be at least three or four times more likely to be victims of violence and abuse.[13] At a possibly even greater risk are children with intellectual impairments[14] and disabled girls.[15] Attitudinal change resulting in greater social inclusion increases a child's protection against abuse. Abuse of disabled young people is commonly not seen as a crime, or less of an offence when the child's humanity is undervalued.[16]

Disability Africa understands that negative attitudes and stigma surrounding disability ultimately result in disabled children being comprehensively deprived of their fundamental needs. Disabled children who are excluded from their communities are likely to be deprived of healthcare, education, social interaction and even food. These various areas of deprivation and the multi-dimensional poverty that disabled children experience are explained and evidenced in the section below.

Disability, Exclusion and Multi-dimensional Poverty

Disability Africa regularly asserts that disabled children in Africa are 'some of the most disadvantaged and vulnerable people on our planet' or the 'poorest and worst-served group in the world'. DA draws an explicit link between disability, exclusion and multi-dimensional poverty, broadly arguing that;

- exclusion from society causes people with impairments to suffer comprehensive deprivation of needs and consequent multi-dimensional poverty
- disabled people in Africa are more likely to be among the poorest
- the poorest people in Africa are more likely to be disabled
- the lives of disabled people are made much worse by situations of poverty

and 'We can also make change' team. 'We can also make change' (2014). pp. 39-41; Groce & Kett. Youth with disabilities (2014). pp.10-11.

[9] *World Health Organisation and World Bank. World report on disability, Geneva: WHO (2011). p.263; Handicap International & Save the Children. Out from the Shadows: Sexual violence against children with disabilities (2011). p.v; Trani & Cannings. 'Child poverty in an emergency and conflict context: A multidimensional profile and an identification of the poorest children in Western Darfur' (2013). p.58.*

[10] *UNICEF. The state of the world's children (2013). p.41*

[11] *Groce & Kett. Youth with disabilities (2014). p.5.*

[12] *UNICEF. The state of the world's children (2013). pp.45-47; Human Rights Watch. Human rights for women and children with disabilities, New York: Human Rights Watch (2012). p.14.*

[13] *UNICEF. The state of the world's children (2013). p.44.*

[14] *Inclusion International. Hear our voices (2006). p.45.*

[15] *Human Rights Watch. Human rights for women and children with disabilities (2012). p.5; Burns, Oswald and 'We can also make change' team. 'We can also make change' (2014). p.52; Ortoleva, S. & Lewis, H. Forgotten sisters - A report on violence against women with disabilities: an overview of its nature, scope, causes and consequences (Northeastern public law and theroy faculty research papers series no. 104-2012), Boston: Northeastern University (2012). pp.16, 38-59; Barriga, S. R. & Kwon, S. R. 'As if we weren't human': Discrimination and violence against women with disabilities in Northern Uganda, New York: Human Rights Watch (2010).*

[16] *Ellery, F., Gerison, L. & Corrina, C. Out From the Shadows - Sexual Violence Against Children With Disabilities, London: Save the Children and Handicap International (2011).*

A growing body of academic evidence confirms that there is a link between disability and multi-dimensional poverty, and that exclusionary attitudes and practices are a key cause of this link. Studies and data are showing that disabled people in LMICs are 'poorer than their non-disabled peers in terms of access to education, access to healthcare, employment, income, social support and civic involvement'.[17] A systematic review of the relationship between disability and poverty in LMICs noted that 78 of 97 (80%) studies on the topic found a 'positive statistically significant association between disability and economic poverty'.[18] One study that used internationally comparable data from fifteen countries found that disability was 'significantly associated with higher multi-dimensional poverty as well as lower educational attainment, lower employment rates, and higher medical expenditures'.[19]

Disability Africa's programmes target disabled children as their beneficiaries and prioritise achieving inclusive behavioural change amongst non-disabled children and younger adults. This is because disabled children are assumed to be the most disadvantaged and disenfranchised[20], and because intervention in childhood stands to deliver greater benefits for life chances. DA believes that this approach has greater potential to create a sustainable change in how disabled people (and other marginalised groups) are served and treated by their communities.

DA believes that having an impairment strongly increases the likelihood of a child (and his or her family) in a low or middle-income country living in poverty and being amongst the poorest in their community. Academic enquiry into the relationship between disability and poverty has found that disability accentuates poverty because of 'systemic institutional, environmental and attitudinal barriers' that result in people with impairments being socially excluded and prevented from participating in society.[21] Disability increases poverty because of;

- discrimination, social marginalisation and isolation
- insufficient access to education, adequate housing, nutritious food, clean water, basic sanitation, healthcare and credit
- a lack of ability to participate in legal and political processes
- a lack of preparation for meaningful inclusion in the workforce[22]

Poverty and disability are said to be both a cause and consequence of each other, and therefore DA believes and asserts that the poorest children in a community are also more likely to be born with or acquire an impairment and become disabled. This assertion is also supported by academic study. Poverty has been found to increase the likelihood of disability by a number of studies – the link is particularly identifiable in terms of chronically poor people being at greater risk of ill health and injuries, and lacking access to healthcare – a phenomenon with which Disability Africa is frequently presented.[23] Poverty is also associated with malnutrition, inadequate access to public health services (e.g. immunisation), poor living conditions (e.g. lack of safe water), and environmental exposures (e.g. unsafe work or home environments), which can lead to health conditions and accidents

Footnotes

[17] *Groce, N., Kett, M., Lang, R. & Trani, J.-F. 'Disability and Poverty: the need for a more nuanced understanding of implications'. Third World Quarterly, 32(8), pp.1493-1513 (2011). p.1496.*

[18] *Morgon Banks, L. & Polack, S. The economic costs of exclusion and gains of inclusion of people with disabilities: Evidence from low and middle-income countries, London: CBM, International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine (2014). p.ii.*

[19] *Mitra, S., Posorac, A. & Vick, B. 'Disability and poverty in developing countries: A multidimensional study'. World Development, Volume 41, pp. 1-18 (2013). p.3.*

[20] *Handicap International & Save the Children. Out from the Shadows: Sexual violence against children with disabilities, London: Handicap International & Save The Children (2011). p.viii; Trani, J.-F., Biggeri, M. & Mauro, V. 'The multidimensionality of child poverty: Evidence from Afghanistan.' Social Indicators Research, Volume 112, pp. 391- 416 (2013). p.404; Trani, J.-F. & Cannings, T. 'Child poverty in an emergency and conflict context: A multidimensional profile and an identification of the poorest children in Western Darfur'. World Development, Volume 48, pp. 48-70 (2013). p.58.*

[21] *Groce, et al. 'Disability and Poverty: the need for a more nuanced understanding of implications' (2011). p.1497.*

[22] *Woodburn, H. 'Nothing about us without civil society: The role of civil society actors in the formation of the UN Convention on the Rights of Persons with Disabilities' Political Perspectives, 7(1), pp. 75-96 (2013). p.80; Groce, et al. 'Disability and Poverty: the need for a more nuanced understanding of implications' (2011). p.1497.*

[23] *Groce, et al. 'Disability and Poverty: the need for a more nuanced understanding of implications' (2011). p.1498; Mitra et al. 'Disability and poverty in developing countries' (2013). p.2.*

[24] *Mitra et al. 'Disability and poverty in developing countries' (2013). p.2.*

[25] *Groce, et al. 'Disability and Poverty: the need for a more nuanced understanding of implications' (2011). p.1498.*

[26] *Schulze, M. Understanding the UN convention on the rights of persons with disabilities, London: Handicap International (2010). p.173.*

that result in a permanent impairment.[24] In addition, poor people who become disabled are found to be more likely to descend further into poverty, with a significant effect on their entire household.[25] This provides evidence for the claims of DA and others that families in LMICs can become trapped in a 'vicious cycle' of poverty and disability.

'Leaving No One Behind'

Despite the increasing amount of available evidence that disabled people constitute one of the most marginalised and disenfranchised sectors of the global community, disabled people have been largely ignored by the international development agenda of recent decades. One study estimates that despite generally being amongst the poorest people in the world, just 4% of disabled people in LMICs benefit from any international cooperation programme.[26] Disability Africa firmly believes that disabled people in LMICs have been 'left behind', i.e. have not shared in development progress that has been achieved in most countries of the world.

The Millennium Development Goals (MDGs) focused on national averages which concealed whether the development outcomes targeted were inclusive or equitable.[27] The successes in poverty eradication etc. achieved against the MDGs were mostly felt by those that were easiest to reach as opposed to those most in need. The MDGs themselves did not even mention disability and so there was a lack of systematic inclusion of disabled people in programmes and policies.

Countries that are now classified as 'middle-income' largely comprise those in which poverty has reduced quite considerably in recent decades (and as a result of MDG efforts) for example certain countries in Africa and Southern Asia. Studies have found that the difference in economic well-being between disabled and non-disabled people is often more significant in middle income countries than it is in low-income countries.[28] Another study found that the gap in employment between non-disabled and disabled people is greater in middle-income countries than it is in low-income countries.[29] This evidence suggests that in middle-income countries that have generally experienced a decline in poverty, disabled people have not benefited nearly as much as their non-disabled compatriots. It seems to be in these countries, rather than the very poorest, that disabled people have been left the furthest behind, and therefore it can be argued that 'development' has been insufficiently inclusive.

The Power of Play

Disabled children have often been left so far behind and are so deprived of their diverse needs that no single intervention can remedy their situation. Disability Africa's projects adopt a holistic and inclusive approach which aims to both raise awareness of the rights and needs of disabled children and develop and deliver services to meet these needs. At its outset, the priority of a Disability Africa project is to promote disabled children's inclusion, thereby end their isolation, begin their participation in their communities and establish a local understanding of their needs. For this approach to be replicable and scalable across various African contexts it needs to be achieved in the absence of excessive resources and an abundance of expertise. Given these circumstances,

[27] *Vandemoortele, J 'If not the Millennium Development Goals, then what?' Third World Quarterly, 32(1), pp. 9-25 (2011). p.19.*

[28] *Mitra et al. 'Disability and poverty in developing countries' (2013). p.7.*

[29] *Mizunoya, S. & Mitra, S. 'Is there a disability gap in employment rates in developing countries?' World Development, 41 pp. 28-43 (2013). p.38.*

DA's primary intervention is 'Playschemes'.

Playschemes can be run easily, by local people, with little expertise, at a minimal cost. But they can make rapid progress in both of DA's project objectives:

1. Raise awareness of the rights and needs of disabled young people

2. Develop and deliver services to meet identified needs

In a context where dedicated services for disabled children are non-existent, disabled children are isolated in their own homes and the community has not considered their rights and their needs, a playscheme is a powerful initial intervention through which to pursue change.

Play is most specifically appropriate as a primary intervention for disabled children in LMICs because a playscheme can:

- Instantaneously end a disabled child's isolation
- Be an appropriately stimulating educational environment for a disabled child who has been socially isolated, under-stimulated, possibly for many years with resultant developmental delay
- Help disabled children with impairments develop vital social, coordination and communication skills
- Change the negative/exclusive attitudes and low expectations of family members and the wider community (which are the root cause of the exclusion of disabled children)
- Provide a context for assessment of educational and medical needs
- Provide a platform for development and delivery of previously non-existent community-based services
- Provide equitable access to existing community services e.g. medical support and physiotherapy
- Initiate collaboration with schools to deliver inclusive education, improve teacher skills relating to 'special education' and support the transition of a disabled child into mainstream education - particularly where Playschemes are run within schools.

Playschemes are particularly suited to typical 'resource contexts' found in low and middle-income countries because:

- They have a very high impact without the need for specialist or even additional facilities – making use of existing meeting halls, schools or religious buildings
- The skills required for playwork are inherently available in every community and the minimum of additional training is required
- They do not require input from medical or education 'specialist' staff who are seldom available (especially in rural areas of LMICs)
- They are perceived by the community to be achievable within their existing skill-set
- They require very little in terms of additional resource[30]

Footnotes

[30] *Brown, F., 'The play behaviours of Roma children in Transylvania'. International Journal of Play, 1(1), pp. 64-74 (2012). Whilst the link between poverty and disability is indisputable, there is little evidence to suggest a similar link between poverty and 'play deprivation'. One study of Roma children in Transylvania, some of the most materially deprived children in Europe, found that their access to quality play was extensive, which may account for their high level of happiness in spite of the poverty that they experienced. The suggestion is that poverty and other forms of disadvantage need not be a barrier to children accessing and benefitting from play, and thus play is a highly appropriate intervention for the resource context on LMICs.*

[31] *Singer, D. G., Golinkoff, R. M. & Hirsh-Pasek, K. Play = learning: how play motivates and enhances children's cognitive and social-emotional growth. Oxford/New York: Oxford University Press (2006).*

[32] *World Health Organisation. Community-based rehabilitation: CBR guidelines, Geneva: WHO (2010) pp.15-16.*

[33] *O'Connor, C. & Stagnitti, K. 'Play, behaviour, language and social skills: the comparison of a play and a non-play intervention within a specialist school setting'. Research in Developmental Disabilities, 32(3), pp. 1205-1211 (2011).*

[34] *Whitebread, D., Basilio, M., Kuvalja , M. & Verma, M. The importance of play, Cambridge/Brussels: Toy Industries of Europe (TIE) (2012); Fearn, M. & Howard, J. 'Play as a Resource for Children Facing Adversity: An Exploration of Indicative Case Studies'. Children & Society, 26(6), pp. 456-468 (2012).*

[35] *Brown, F. & Webb, S. 'Children without play'. Journal of Education, Volume 35, pp. 139-158 (2005).*

[36] *Taneja, V. et al. 'Not by bread alone': impact of a structured 90-minute play session on development of children in an orphanage'. Childcare, Health and Development, 28(1), pp. 95-100 (2002).*

[37] *Sense, 2016. Making the case for play: Findings of the Sense Public Inquiry into access to play opportunities for disabled children with multiple needs, London: Sense (2016). pp.10-14.*

- Through the involvement of young, non-disabled people as playmates and paraprofessional playworkers, long-term attitudinal change within a community can be initiated
- They are eminently sustainable and replicable because they can be established and run by local people in existing facilities at very little cost

The educational and developmental value of play for children in general has been extensively researched and is well understood. The educational and developmental value of play for children with impairments is also well recognised in the available literature.[31] Play is recommended by The World Health Organisation in its Community-Based Rehabilitation (CBR) guidelines[32] and some studies of play-based programmes in 'special educational contexts' have found them to be more successful than non-play based alternatives in terms of communication, language and social skill development.[33]

There is also evidence to support the claim that play is the most appropriate remedial intervention for a disabled child who has been socially isolated, and under-stimulated for a number of years, which is likely to result in developmental delay and a severe impact upon mental health.[34] One study used play as a therapy for children who had suffered appalling deprivation in institutional care in Romania, and documented extremely impressive results.[35] Another study in India, found that the introduction of a play-based programme was of great developmental benefit to children in institutional care who were otherwise physically healthy. Contrary to the assumptions of staff, workloads caring for the children were reduced as a result of a programme of regular 90-minute play sessions.[36] It has also been observed by experts in the UK that play is an excellent context within which to assess a child with an impairment.[37]

Education and Child Development

Many studies across the world have found that disabled children are far less likely to be enrolled in education than their non-disabled counterparts, and those that do go to school are more likely to drop out.[38] Scarce data about disabled children and education means the 'scale of the challenge is likely underestimated'[39], but most studies of enrolment rates suggest that fewer than 10% of disabled children in LMICs are in education.[40] Within this, children with physical impairments are generally more likely to be enrolled than those with intellectual or sensory impairments[41] and disabled girls are less likely to receive an education than disabled boys.[42]

The impacts of the majority of disabled children in LMICs not attending school go beyond academic educational outcomes. Some studies estimate that literacy rates for disabled adults in LMICs are as low as 3% overall and 1% for disabled women, although little academic attention has been paid to this issue.[43] More attention has been paid to disabled adults access to the labour market, which is very poor[44] and this is highly likely to be a direct consequence of disabled children's exclusion from education.

[38] *Groce, et al. 'Disability and Poverty: the need for a more nuanced understanding of implications' (2011). p.1498; Morgon Banks & Polack. The economic costs of exclusion and gains of inclusion of people with disabilities: Evidence from low and middle-income countries (2014). p.26; Groce & Kett. Youth with disabilities (2014). p.8; WHO & World Bank. World report on disability (2011).p.206; UNICEF. The state of the world's children (2013). p.27; Human Rights Watch. Human rights for women and children with disabilities (2012). p.10; Trani, J.-F., Kett, M., Bakhshi, P. & Bailey, N. 'Disability, vulnerability and citizenship: To what extent is education a protective mechanism for children with disabilities in countries affected by conflict?' International Journal of Inclusive Education, 15(10), pp. 1187-1203 (2011).*

[39] *Education for All (EFA). Education for all 2000-2015: Acheivements and challenges (EFA Global Monitoring Report), Paris: UNESCO (2015).*

[40] *Groce, N. & Bakhshi, P. 'Illiteracy among adults with disabilities in the developing world: a review of the literature and a call for action' International Journal of Inclusive Education, 32(8), pp. 1153-1168 (2011). p.1156; Srivastava, M., de Boer, A. & Pijl, S. J. 'Inclusive education in developing countries: A closer look at its implementation in the last 10 years' Educational Review, 67(2), pp. 179-195 (2015). p.189.*

[41] *WHO & World Bank. World report on disability (2011).p.207; Inclusion International. Hear our voices (2006). pp.32-35; Trani, J.-F., Bakhshi, P. & Nandipati, A. 'Delivering' education; maintaining inequality. The case of children with disabilities in Afghanistan'. Cambridge Journal of Education, 42(3), pp. 345-365 (2012). p.355.*

[42] *Trani, J.-F. & Loeb, M. 'Poverty and disability: a vicious circle? Evidence from Afghanistan and Zambia'. Journal of International Development, 24(S1), pp. S19-S52 (2012). p.32; Education for All (EFA). Education for all 2000-2015: Achievements and challenges (2015). p.101; WHO & World Bank. World report on disability (2011).p.206; Trani et al. Disability, vulnerability and citizenship: To what extent is education a protective mechanism for children with disabilities in countries affected by conflict? (2011). p.1198.*

[43] *Groce & Bakhshi, 'Illiteracy among adults with disabilities in the developing world' (2011). pp.1153, 1158-1159.*

[44] *Mizunoya & Mitra. 'Is there a disability gap in employment rates in developing countries?' (2013). p.38.*

Exclusion from education also denies disabled children an opportunity for social networking and community participation, as well as access to many medical, social, nutritional and development resources which can lead to isolation, decreased autonomy and lower quality of life.[45] Without school, many parents say that they have no choice but to lock up or tie up their disabled children while they go to work or attend to daily chores.[46] Exclusion of disabled children from mainstream education can also play a role in propagating discriminatory attitudes at societal level, which creates further barriers to participation in other domains and perpetuates exclusion.[47]

Disability Africa aims to improve the almost non-existent participation of disabled children in education with its programmes. But we recognise that inclusive education is about much more than the simple presence of disabled students in schools – this will not automatically lead to positive outcomes; either academic or social.[48] However, many programmes, and government policies, have ended up at this minimum standard due to a 'lack of resources, teacher training and expectations, and expertise, as well as persistence of negative social attitudes leading to discrimination and exclusion'.[49]

Recognising this, Disability Africa is committed to exploring and addressing the reasons why disabled children are not receiving an education and to developing programmes which are child-centred; offering every individual disabled child the most appropriate available educational experience. We understand that the reasons for disabled children not accessing a quality education are wide-ranging and complex, they include:

- Discriminatory attitudes of non-disabled students and staff
- Negative attitudes and expectations of parents and family members
- Absence of key resources in mainstream schools
- Large class sizes and didactic teaching methods
- Insufficiently knowledgeable and trained staff
- Inaccessible systems for assessment
- Inappropriate school curricula
- Costs of enrolment – fees, books, uniforms – unaffordable or not prioritised
- Transport challenges and inaccessible buildings
- Narrow definition and understanding of what constitutes 'education'

As such, Disability Africa believes in a holistic approach to delivering inclusive education which simultaneously addresses all of these challenges. Our programmes aim to work with schools and with the communities that surround them. We aim to deliver:

- Community-based education – Playschemes deliver a wide range of educational benefits. They can serve as a bridge between isolation at home and formal education, or for some children they can represent the most appropriate available educational experience
- Playschemes can facilitate and support the implementation of other educational initiatives in

Footnotes

[45] *Morgon Banks & Polack. The economic costs of exclusion and gains of inclusion of people with disabilities: Evidence from low and middle-income countries (2014). p.34; Trani et al. Disability, vulnerability and citizenship: To what extent is education a protective mechanism for children with disabilities in countries affected by conflict? (2011). p.1200; WHO & World Bank. World report on disability (2011).p.205.*

[46] *Human Rights Watch. Human rights for women and children with disabilities (2012). p.10.*

[47] *Morgon Banks & Polack. The economic costs of exclusion and gains of inclusion of people with disabilities: Evidence from low and middle-income countries (2014). p.34; UNICEF. The state of the world's children (2013). p.27.*

[48] *Srivastava et al. 'Inclusive education in developing countries: A closer look at its implementation in the last 10 years' (2015). p.190; WHO & World Bank. World report on disability (2011).p.233: Bakhshi, P., Kett, M. & Oliver, K. What are the impacts of approaches to increase the accessibility to education for people with a disability across developed and developing countries and what is known about the cost effectiveness of different approaches?, London: EPPI-Centre (2013). p.6.*

[49] *Bakhshi, Kett & Oliver. What are the impacts of approaches to increase the accessibility to education for people with a disability across developed and developing countries and what is known about the cost effectiveness of different approaches? (2013). p.7.*

[50] *See: https://www.disability-africa.org/blog/2017/2/20/z79ogf5cmo0j391ivmurw7tphwptlu*

[51] *Morgon Banks & Polack. The economic costs of exclusion and gains of inclusion of people with disabilities: Evidence from low and middle-income countries (2014). p.47.*

[52] *Ibid. pp.48-49; WHO & World Bank. World report on disability (2011). pp. 62-63, 70-72, 77; Burns, Oswald and 'We can also make change' team. 'We can also make change' (2014). p.34.*

[53] *Groce & Kett. Youth with disabilities (2014). p.6; WHO & World Bank. World report on disability (2011).*

[54] *Inclusion International. Hear our voices (2006). p39.*

collaboration with schools[50]:

- Workshops for teachers, where they can learn about disability and inclusion and learn how to include disabled children in mainstream classrooms
- Classroom support delivered by project volunteers or employees. Playschemes provide an excellent context in which to engage volunteers and 'train' them as classroom assistants for disabled children
- Child-to-Child initiatives – educating and organising non-disabled students to support the inclusion of their non-disabled peers. Similarly, playschemes can engage non-disabled children and assist the development of effective child-to-child support in the classroom.
- Community awareness-raising activities

Healthcare

Disabled children in LMICs largely do not receive the healthcare services that they require. An absence of specialist healthcare services that are specifically for disabled people is a strand of this problem. However, of much greater importance are the inequities of access and quality and delivery of care in existing mainstream healthcare services that disabled adults and children experience.[51]

Health facilities are frequently inaccessible and information is not available, or communicated properly, to disabled people or parents of disabled children. Facilities might be remotely located and transport options not available, accessible or affordable. Misconceptions and stigma around disability often prevent families from seeking the healthcare that disabled children need and discrimination by healthcare providers might also limit the provision of services.[52] Healthcare workers are often unfamiliar with conditions presented by disabled children and adults. They may hesitate to take on routine care in the mistaken belief that specialist care is always needed.[53]

The result of this situation is that mortality rates for disabled children remain much higher than for their non-disabled peers. In 2006, Inclusion International estimated that infant mortality for disabled children might be as high as 80 per cent in some countries where under-five mortality as a whole had decreased to below 20 per cent - this cannot be solely ascribed to genetic or bio-medical factors.[54]

Disability is much more than a medical issue and therefore Disability Africa is not a medical charity. However, a lack of access to healthcare for disabled children is major challenge that has to be remedied. Therefore, Disability Africa programmes aim to achieve equity of access to healthcare for disabled children by:

- providing solutions to access barriers such as travelling distances and costs
- providing medical information and basic education about impairments to parents in order to improve healthcare at home
- establishing appropriate community-based medical services for disabled children e.g. physiotherapy, health worker home-visits, outreach clinics etc.

Gender and Household Poverty – Support for Parents

Some studies have found that households in LMICs with disabled children or disabled family members had a lower mean income and fewer assets.[55] There are obviously costs associated with disability at the household level and these can be divided into three types:

- Direct costs – for medical treatment and travel
- Opportunity costs – loss of income
- Indirect costs – the provision of care provided by family or community members.[56]

Furthermore, several studies confirm what many might intuit – that it is largely women and girls, more than men, that bear these costs and are therefore disadvantaged as a result of having a disabled child. Those caring for disabled children are generally female, and they often give up income- generating activities to do so.[57] Mothers are at a particular disadvantage at the hands of negative attitudes and superstitions, this combined with them bearing the majority of caregiving responsibilities can leave them almost as isolated within their community as the children that they care for.[58]

On the basis of this evidence Disability Africa programmes should offer both direct and indirect benefits to parents and the families of disabled children, and have the potential to mitigate all of the types of cost associated with having a disabled child (above).

Medical support programmes which provide community based services and transport solutions to other facilities for treatment will relieve families of the direct costs of medical care (both conventional and often equally expensive traditional medicine) and transport.

Disability Africa programmes in general aim to encourage and empower local communities to include disabled children and care for them, thus relieving the care burdens of parents. They will do this directly with the provision of playschemes and increasing access to formal education which will provide respite to caregivers. If programmes are successful in changing negative attitudes towards disability then community members and groups might also begin to play a role in reducing the burden of care placed on the parents of disabled children (primarily mothers). These interventions will reduce the opportunity costs and indirect costs of care that female carers for disabled children typically shoulder. Women and girls might have new opportunities to engage in the labour market, in education, or other income-generating activities. Although it must be recognised that childcare burdens are far from the only barriers that women face when attempting to engage in economic or educational activities in many societies where DA works.

Parent Support Groups are also a key element of DA programmes. They aim not just to improve the wellbeing of disabled children but also of parents, by providing a safe forum in which to receive reassurance, social/emotional support, to share experiences, and be reconnected with the community. These groups

Footnotes

[55] *Groce, et al. 'Disability and Poverty: the need for a more nuanced understanding of implications' (2011). pp.1501, 1503; Mitra et al. 'Disability and poverty in developing countries' (2013). p.3; Woodburn, H. 'Nothing about us without civil society' (2013). p.80; WHO & World Bank. World report on disability (2011).p.10.*

[56] *Groce, et al. 'Disability and Poverty: the need for a more nuanced understanding of implications' (2011). p.1503; UNICEF. The state of the world's children (2013). p.14.*

[57] *Cordier, S. 'Caring for people with intellectual disabilities in poor rural communities in Cambodia: experience from ADD International'. Gender and Development, 22(3), pp. 549-561 (2014). p.554; Groce & Kett. Youth with disabilities (2014). p.6; UN-ESCAP. Disability, livelihood and poverty in Asia and the Pacific: An executive summary of research findings, Bangkok: ESCAP (2012).*

[58] *Inclusion International. Hear our voices (2006). p.63.*

[59] *Groce, N. et al. 'Inclusive nutrition for children and adults with disabilities'. The Lancet Global Health, 1(4), pp. e180-e181. (2013). p.180.*

[60] *Ibid.*

[61] *Ibid. pp.180-181; UNICEF. The state of the world's children (2013). p.25.*

[62] *Rohwerder, B. Disability inclusion in social protection (GSDRC Helpdesk Research Report 1069), Birmingham: GSDRC. (2014). p.5.*

might also have the potential to develop into small community-based organisations which advocate for their children's rights and might organise to collectively generate income and/or save collectively to 'insure' against unforeseen medical costs etc.

Nutrition

A few studies have found that the nutritional needs of disabled children and disabled adults in LMICs are rarely addressed, due to;

- less access to health and social services
- a lack of public awareness
- ineffective communication on the part of health and development professionals
- public health campaigns that do not consider the needs of disabled people[59]

Disabled people can sometimes be omitted from nutrition outreach efforts as their lives are less valued, and within the family unit disabled members might be denied food or offered less food than others.[60] Children and adults with severe physical impairments, for example cerebral palsy, often suffer from undernutrition due to poor knowledge and stigma among those that care for them.[61]

Disability Africa recognises that undernutrition in disabled children is more usually caused by stigma, lack of understanding and prioritisation, rather than by economic necessity and food security. Whilst some DA programmes do provide meals at playschemes etc. their aim is more to incentivise attendance and enable whole day activities to be delivered. Our programmes provide support and information for parents on how to feed children with severe physical impairments and help them feed themselves. Ultimately, if negative attitudes surrounding disability can be challenged and altered then disabled children will be far less likely to be at a nutritional disadvantage.

Social Protection – Support from Government

A growing number of countries have social protection programmes that target disabled people or claim to mainstream disability. But both statistical and anecdotal evidence shows that many disabled people are not reached by these programmes due to a variety of barriers. It should also be highlighted that social protection programmes alone will not eliminate the vulnerabilities that disabled people face; complimentary programmes with an emphasis on inclusion are needed to create a truly enabling environment.[62]

Disability Africa has found that social protection schemes for disabled children in African countries rarely exist. Where they do exist they generally do not reach their targets due to a lack of information and difficulties accessing impairment assessment to be classified by the authorities as 'disabled'. Disability Africa programmes will compile accurate registers of disabled children, therefore enabling relevant data to be presented to governmental authorities in order for the beneficiaries of our programmes to be assessed and access any social protection/cash transfers to which they are entitled.

Improving Data

Across the world there is a paucity of data on disabled people, meaning that policy-makers are more likely to put disability aside.[63] Disability has been largely absent from data collection and monitoring mechanisms in international development[64] and disabled people have been invisible in the mainstream development narrative. Studies have confirmed that this has resulted in development interventions which unintentionally leave disabled people out of their target groups.[65] The lack of data has also contributed to a false impression that disabled people represent a very small group, reserved for the specialist attention of health professionals and beyond the scope of international development.[66] Researchers and policy-makers are largely agreed that disability data must be improved in order to better include disabled people in international development programmes.

In this context, a key primary challenge for programmes that aim to improve outcomes for disabled children is to identify them. Identifying disability is not straightforward. The concept of 'disability' is complex and can be understood in many ways. It can also be a loaded term that is surrounded by stigma. Disabled people have been found unwilling to identify themselves as such for fear of becoming labelled and marginalised.[67] Disability Africa has adopted a methodology for disability data collection developed by The Washington Group on Disability Statistics (WG) - a UN city group established under the United Nations Statistical Commission. The WG was constituted to address the urgent need for cross-nationally comparable population-based measures of disability.

Whilst national censuses have typically returned data that classifies approximately 1-3% of people as 'disabled', some trials of the WG questions have found 15% of respondents reporting severe difficulties in functioning – much closer to the World Health Organisation's estimates of the numbers of people in the world that live with impairments. In November 2016, the Inter-agency Expert Group on Sustainable Development Goal Indicators unanimously recommended Washington Group tools be used for SDG data disaggregation.[68]

Whilst great progress has been made in the development of question sets which are very successful in identifying disabled adults, identifying disabled children is a much greater challenge. Children develop at different speeds, which makes it difficult to assess functioning and distinguish significant limitations from variations in typical child development.[69] The WG question sets on adult functioning can identify many children with functional difficulties but they do not address all areas of functioning or allow for variations in child development. WG and UNICEF have collaborated to develop further question sets for children aged 2-4 and 5-17. These questions often encourage respondents to focus on the functioning of the child in reference to the child's cohort.

The number and complexity of the questions in the WG and UNICEF sets has inspired Disability Africa to attempt to develop a single short question set that can be asked to caregivers to identify a full range of impairment across an age range of 9 months to 17 years. Responsibility for data collection must be given

Footnotes

[63] *Groce, et al. 'Disability and Poverty: the need for a more nuanced understanding of implications' (2011). p.1501.*

[64] *Mitra, S. 'A data revolution for disability'. Lancet Global Health, 1(4), pp. e178-e179 (2013). p.e178.*

[65] *Bruijn, P. Count me in: Include people with disabilities in development projects (2012). p.20.; Al Ju'beh, K. Disability Inclusive Development Toolkit, Bensheim: CBM (2015). p.50.*

[66] *Mitra et al. 'Disability and poverty in developing countries' (2013). p.1.*

[67] *Kett, M. & Twigg, J. 'Disability and disasters: Towards an inclusive approach'. In: World disasters report - focus on discrimination. Geneva: IFRC, pp. 86-111 (2007). p.97.*

[68] *http://www.washingtongroup-disability.com/wp-content/uploads/2016/01/Joint-statement-on-disaggregation-of-data-by-disability-Final.pdf*

[69] *UNICEF. The state of the world's children (2013). p.63.*

[70] *Morgon Banks & Polack. The economic costs of exclusion and gains of inclusion of people with disabilities: Evidence from low and middle-income countries (2014). pp.34, 46.*

[71] *Ibid. p.34*

[72] *WHO & World Bank. World report on disability (2011).p.169.*

to community members with limited training, and therefore considerations of simplicity and usability must be paramount. The feelings of the responding caregivers need to also be considered – conducting lengthy interviews of many questions for no apparent or obvious reason may impact on the quality of the responses and has the potential to do harm.

Based on the WG Short Set and UNICEF Child Functioning models, Disability Africa has developed a new, simple set of ten questions to identify impairment in children. The questions are designed to be asked to a mother/caregiver, and encourage respondents to assess their child's functional difficulties in relation to the rest of their peer group. By encouraging this consideration of age, the single set should be appropriate for infants of 9 months or older up to youths nearing adulthood (16/17 years). The questions focus on five areas of functioning:

1. Sensory
2. Core strength and physical mobility
3. Intellectual
4. Fine and gross motor skills
5. Social interaction

Inclusive Societies Benefit Everyone

The basis of Disability Africa's work is a commitment to 'inclusion'. Inclusion may seem to be an ideal that delivers benefits to excluded minorities – it does. However, inclusion has a much wider meaning. Disability Africa believes that more inclusive societies benefit everybody in that society, by definition and in practice. The reasoning for this position is that if the most disenfranchised group in a given community can be identified and the necessary steps taken to ensure that this group of people are included within their community, then by default the necessary steps will have been taken, and adjustments in attitudes made, to include any disadvantaged person in that community.

There is academic support for Disability Africa's assertion that inclusion of the most marginalised disabled people in a community will have much wider societal benefits. Inclusion of disabled people in education and in employment is understood as having the potential to encourage 'greater acceptance of diversity and the formation of more tolerant, equitable and cohesive societies'.[70] Efforts to increase the quality of education to ensure effective learning for disabled children arguably has the potential to improve teachers overall abilities and improve educational outcomes across the board.[71] The creation of accessible community environments benefits a very broad range of people including elderly people, pregnant women, parents with young children, people with less education or speakers of a second language.[72]

Disability Africa was founded to support a client group who are understood to be disenfranchised in a minimum of three dimensions:

1. Children have less power, presence and influence than adults
2. Africa is the world's poorest continent, in which conditions for children are the worst

3. Those with impairments (physical, sensory, intellectual) are some of the most disadvantaged children in Africa

There is much evidence to support these assumptions in this paper and elsewhere.

The case for the inclusion of disabled children and adults is, above all, moral. But a key barrier to the inclusion of disabled people in international development remains the perceived economic costs, which are commonly assumed to be high.[73] Other excuses relate to concerns that inclusion of disabled people is too difficult and requires specialist knowledge, or disabled people require special programmes.[74] However, studies suggest that an estimated 80 per cent of disabled people can be included without any specific additional intervention, or with low-cost and simple community-based interventions such as playschemes for disabled children which do not require specific expertise.[75] There is also a growing body of evidence to suggest that the quantifiable costs of exclusion are far greater than the small additional costs of including disabled people in international development. The exclusion of disabled people involves significant 'losses in productivity and human potential'.[76] The International Labor Organisation has estimated that exclusion of disabled children from education and the subsequent exclusion of disabled adults from the labour market, costs LMICs up to 7% of their annual GDP.[77]

Conclusion

The primary aim of international development has always been the reduction or eradication of extreme poverty; the sector exists to assist the very poorest and most disadvantaged people in the world. But it can be argued that an historically narrow interpretation of poverty and its solutions have systematically and serially excluded disabled people. Given the strong links between disability and multi-dimensional poverty, international development's overall failure to reach and include disabled people has been contradictory to its overarching aims. The Global Goals for Sustainable Development (SDGs) for the period of 2015 to 2030 recognise that poverty eradication efforts and successes have had less impact upon the most marginalised sections of the global population, including disabled people. The development community now pledges to 'Leave No One Behind'.

If international development is to successfully assist and include disabled adults and disabled children in the SDG era it must fully understand what has caused disabled people to be left behind and the complex nature of the situations that disabled people face. It must also overcome misconceptions about disability which remain commonly held at many levels. Disability must be understood to be a complex construct that arises from the interaction of a person's impairment with a non-inclusive environment, rather than a 'fixable' or 'correctable' medical issue. International development must address these causes of disability where they are primarily found – at community level, and undertake holistic programmes which aim to deliver social inclusion in every sphere of life.

This is, without doubt, a formidable task. But, for disabled children, many of whom will have been

Footnotes

[73] *Coe, S. & Wapling, L. 'Practical lessons from four projects on disability-inclusive development programming'. Development in Practice, 20(7), pp. 879-886 (2010). p.884.*

[74] *Bruijn, P. Count me in: Include people with disabilities in development projects (2012). p.20*

[75] *Ibid. pp.23,76.*

[76] *DFID. Disability, Poverty and Development, London: DFID (2000). p.4.*

[77] *International Labor Organisation. The price of exclusion: The economic consequences of excluding people with disabilities from the world of work, Geneva: ILO (2009).*

isolated and deprived of their needs, playschemes represent an appropriate and powerful primary intervention through which to pursue the significant social change that is required. Playschemes are affordable, accessible, achievable, scalable and sustainable across LMIC contexts. They can deliver rapid changes in attitudes towards disability and begin to meet the needs of the most marginalised young people in any LMIC community.

Playschemes can develop into inclusive community projects which successfully advocate for the rights of disabled children and deliver accessible services to meet their needs. Disabled children in LMICs suffer multiple deprivations and their families experience many disadvantages, for example lack of access to information, education, healthcare, social protection, nutrition and a greatly increased likelihood of household poverty. In most cases these deprivations and disadvantages can be remedied and eliminated in full or in part by low-cost community-based programmes that deliver equity of access to already existing services, resources and opportunities. Community-based initiatives must not be overlooked by development actors; indeed, they should comprise the majority of programmes in the growing disability and development sector, with more 'specialised' and 'top-down' initiatives also playing a role.

This paper shows that Disability Africa has a comprehensive understanding of the evidence of the unmet needs of disabled people in LMICs and the major barriers to inclusion, based on experience of programme delivery and the best available academic research in the field. Disability Africa is piloting a template for 'Inclusive Community Development' to improve outcomes for disabled children and young people (0-18 years) across a range of socio-cultural contexts in African countries. This template is informed by evidence of need and delivers responses which are appropriate for the context in LMICs. It specifically addresses and delivers on the key outputs that have been identified as required for the inclusion of disabled people in international development by the best available research in the field, and recognised by DFID.

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