Youth with Disabilities: Working Paper 23

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YOUTH WITH DISABILITIES[1]

INTRODUCTION

Of all groups of youth, the group about which we know the least are youth with disabilities.[2] In transition between childhood and adulthood, these are the years when all young people go through physical and psychological maturation, are expected to complete their education, acquire skills and assume a social identity that will enable them to fully participate in their communities and societies.

While issues faced by youth with disability have often been defined in terms of medical concerns, it is now clearly recognised that disability is a cross-cutting issue and that it is often not medical but rather social, economic and human rights issues that are key barriers in the lives of these young people. For this reason, the UN Convention on the Rights of Persons with Disabilities (CRPD; UN, 2008) identifies persons with disabilities as individuals who have long-term physical, mental, intellectual or sensory impairments which, when combined with negative attitudes or environmental barriers, prevents them from taking a full and active role in society.

It is easier to list what is *not* known about youth with disabilities, than what is. There has been little research on youth with disabilities as a distinct group in low- and middle-income countries and what information exists in the higher income countries focuses largely on formal educational or health systems, and transition to work programmes. The 2003 World Bank call for more attention to be paid to the wide array of issues that faced by youth with disabilities remains largely unanswered (World Bank, 2003).

Programmatically, youth with disabilities also often fall between the cracks; mainstream development programmes for youth rarely include young men and women with disabilities. Programmes for disabled populations, where these exist, are often no more inclusive, concentrating either on children with disabilities in

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[1] Document originally prepared for UN DESA by Professor Nora Groce
[2] The United Nations defines as "youth" as young people between ages 15-24. While the needs and concerns of a boy with a disability aged 15 may be very different than for a 23 year old young woman with a disability, in this paper, we concentrate on the large number of issues and concerns they share.

schools or on the employment and social integration of adults with disabilities. Few address the unique social, psychological, educational and economic needs of youth.

We do know that the needs of youth with disabilities are strikingly similar to those of their non-disabled peers: education, job training, employment, and inclusion in the social, cultural, religious and economic lives of their families and communities. What distinguish youth with disabilities are not their common needs, but the fact that these needs continue to go so largely unmet.

Legislation and policies

The rights of youth with disabilities are guaranteed by the CRPD, adopted in 2008 and now ratified by over 140 countries, which ensures that persons with disabilities are entitled to all rights enjoyed by all members of society – education, health care, the right to vote, the right to a family life and to participate fully in the societies in which they live. The human rights of youth with disabilities are further guaranteed by a number of UN instruments such as the UN Universal Declaration of Human Rights (UN, 1948) and the UN Convention on the Rights of the Child (CRC; UN, 1989). A host of regional, national and local legislation and policies that pertain to inclusion of persons with disabilities have been instituted in recent years, often in conjunction with national ratification of the CRPD.

Even in these documents however, the specific needs and concerns of youth with disabilities – as a distinct and vulnerable group – are assumed but rarely mentioned. Even the landmark UN document World Programme of Action on Youth (UN, 2010a) although it is assumed that all components of the World Programme of Action are equally application to youth with disabilities, only specifically cites youth with disabilities in a few sections (education, employment and ICT).

Prevalence

Currently, no reliable global data exists on the number of youth with disabilities (UN, 2012). Estimates nationally and globally vary widely due to differing definitions of disability and different data collection methods[3], as well as social stigma that in many

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[3] Initiatives, including work of the UN's Washington Group on Disability Statistics (http://www.cdc.gov/nchs/washington_group.htm) are currently underway to standardize and improve data collection efforts on national and global disability statistics.

countries make families unwilling to disclose the existence of a disabled family member to census and survey collectors (WHO/World Bank, 2011).

Estimates suggest, however that the number of youth with disabilities is significant - between 180 and 220 million youth with disabilities worldwide and nearly 80% live in developing countries (UNDESA, 2012).

Moreover, with half the world's population below 15, these numbers can be expected to rise markedly over coming decades, particularly in low and middle-income countries. This will not simply reflect a rising birth rate. Better medical interventions now allow growing numbers of disabled infants and children to survive into adolescence. Improved access to treatment for accident or illness allows many seriously ill or gravely injured children and youth to survive, but survive with a disability. Young people are also at increased risk of becoming disabled during their youth due to work-related injuries, risk-taking behaviour (including motor vehicle accidents, experimentation with drugs, and risk of violence). Members of military forces are disproportionately young and many below the age of 24 receive disabling injuries. Many chronic disabling illnesses and mental health conditions appear during adolescence. The sensory, physical and mental health impairments associated with HIV/AIDS will add millions of young people to the growing numbers of those who are disabled, and a lack of adequate reproductive health information places youth with pre-existing disabilities at increased risk of contracting HIV (UNICEF, 2013a).

Stigma

Globally, one of the greatest impediments to youth with disabilities is stigma, which leads to social isolation and discrimination. Societal discrimination and negative attitudes arise from misconceptions, stereotypes and folklore linking disability to punishment for past sins, misfortune or witchcraft. Community members (family members, neighbours, community leaders, teachers, health workers and others) who hold such views, may distance themselves from children and adults with disabilities and their families and limit or prohibit their participation in community life. Families of children and youth with disabilities may respond by keeping them hidden at home or sending them to institutions – where these exist – both in response to such

prejudices and in an attempt to protect their children. Understanding and addressing stigma is a critical step to improving the lives of all persons with disabilities.

Poverty

While any family can have a child with a disability, disability disproportionately affects the poor. Lack of medical care, nutritious food, basic water and sanitation, adequate housing and safe neighbourhoods increases the risk that a child in a poor family will be born or will become disabled (Groce et al., 2011). Families with a disabled child are more likely to face poverty – not only through additional demands on household income for medical care and disability related expenses, but also because parents and family members may take on caregiving roles, which may entail one parent or family member (generally female) giving up income generating activities in order to stay at home and provide support. The result is that households with disabled members generally have lower incomes than other households and are more likely to live below the poverty line (Eide and Loeb, 2005; Mitra, Posarac and Vick, 2012).

Health

Access to healthcare is important for all youth – this is no less true for youth with disabilities. For these young people there are two areas of concern: lack of access to general healthcare; and, for some, lack of access to disability-specific care (rehabilitative services; assistive devices such as wheelchairs or hearing aids).

General healthcare is a problem because in many cases, health facilities are inaccessible – stairs block access for wheelchair users or a lack of sign language interpreters for people with hearing impairments. Healthcare workers are often unfamiliar with persons with disabilities and hesitate to take on routine care, mistakenly believing that specialist care is always needed.

Public health education programmes often are not designed to include youth with disabilities people (radio campaigns are inaccessible to Deaf individuals; witty, fast-paced advertisements for safer sex are lost on some young people with intellectual disabilities). This is a lost opportunity, particularly when a growing body of research clearly shows that youth with disability are at equal or greater risk for smoking, alcohol consumption and unsafe sex (Hollar, 2005; Groce, 2005).

Rehabilitative services are limited or non-existent in many countries, tend to be concentrated in urban areas and be prohibitively expensive. In societies where young women are not allowed to live away from home or travel unescorted, accessing such services is not permitted unless they are accompanied by a male relative, which has implications for the privacy and dignity of the disabled young person.

Assistive devices (artificial limbs, wheelchairs, hearing aids, eyeglasses, etc.) are often expensive and a growing adolescent will need a replacement every year or two. The issue is not simply cosmetic. A poorly fitting artificial limb carries the risk of increasing an impairment, but also has profound psychological and social implications for an already marginalised young person. A wheelchair that has become too small limits the ability of a young person to leave the house to attend school, work or establish any measure of autonomy.

Education

Lack of education is a key concern for most youth with disabilities. Lack of education often may reflects the belief that disabled children cannot learn, that they should not be put through the stress of learning, or that they are an embarrassment to their families and kept out of sight. In many countries children with disabilities are considered incapable of learning, no matter what their disability. Often a disabled child is considered a distraction to other students and simply sent home.

Awareness-raising and capacity-building programmes for teachers to adequately prepare them to teach children and adolescents with disabilities are rare. Lack of trained teachers or appropriate teaching materials or methods limits access to education for millions of blind, deaf and intellectually disabled children as well as young people with mental health difficulties.

There are physical barriers as well. If the school requires a long walk, or if stairs or doorways block access to school buildings or toilets, children with disabilities may not attend. Perhaps the primary reason these young people are so rarely in school, however, is that their families and societies may not perceive that they need an education. Where education for children with disabilities is not considered a priority,

spending money on school fees, books or uniforms may be considered unnecessary expenses for families, particularly if they are poor.

Despite clear calls for universal education in the CRC and for universal education for children and youth with disabilities in UNESCO's Salamanca Statement (UNESCO, 1994), young people with disabilities continue to attend school at rates far lower than their non-disabled peers; they are more likely to drop out of school; and even those who complete their education often learn far less than their classmates due to a lack of resources, teachers untrained in how to best educate disabled children and low expectations held by educators, parents, and the young people themselves.

For many youth with disabilities the cumulative lack of adequate primary education results in poor performances on standardised exams, which blocks their ability to go on to higher education. By the time children with a disability reach early adolescence, the vast majority find themselves far behind the educational and skill levels of their non-disabled peers.

Gender further compounds inequities in education (Russo, 2003). Cultural bias against women in general, and reduced expectations for girls with disabilities in particular, further limits the resources that families and schools are willing to spend on their academic and vocational training.

Youth with disability who are successful in their education are also often restricted in what course of study they are allowed to pursue. In countries as diverse as Ireland and China, students with disabilities are not allowed to access a full range of academic courses (i.e. most sciences), assuming that the degree would be 'wasted' on a student unable to find work in certain fields (Shevlin, Kenny and McNeela, 2002). The issue of course, is not to deny qualified students admission, but to address why they would not be hired. At an age when non-disabled individuals are beginning to define themselves through their anticipated careers, most disabled young people enter the workforce strikingly unprepared.

Apprenticeships and job training are additional areas of concern. Unlike non-disabled youth, youth with disabilities find it particularly hard to get apprentices or job training that would enable them to enter the workplace. Should they not succeed in an initial

apprenticeship or be fired from their first job, those around them are quick to label them unemployable and refuse to let them try again.

Employment and financial independence

Formal education for most of the world's young people ends by mid-adolescence, after which most boys and many girls are expected to work. Young people worldwide are at significantly higher risk for unemployment, partial employment or full employment at lower wages than adult workers, particularly in the current economic climate.

Adolescents with disabilities are at even greater risk. Entering the job market with little education and few or no skills, youth with disabilities have difficulty competing. For some, specific physical or intellectual impairments may further limit their job options. For many, social prejudice and lack of understanding on the potential productivity of persons with disabilities makes employers hesitant to hire them.

Employment rates of youth with disabilities are rarely tracked (Kett, 2012). However, rates of unemployment among adults with disability on average tend to be 40-60% higher than for the non-disabled population (UN, 2010b). This is true even in developed countries with sophisticated school-to-work programmes and reserved employment schemes. The ILO estimates that the unemployment rate among people with disabilities in the developing world is as high as 80% in some countries (ILO, 2002). Unemployment among disabled young women in all societies averages 50% higher than unemployment among comparably educated disabled young men (itself is double that of non-disabled male peers).

Not only is their employment status in a continual state of flux, but young people with disability are also more likely to be hired for jobs that require little training and have few opportunities for advancement. Even when well educated, they take longer to find a position, have less job security and less prospect of advancement than do their non-disabled peers. Moreover they are often the last to be hired and the first to be laid off or fired. This is true even for individuals with disability who have received a university education (UNICEF, 2013b).Where vocational training is available, there is often a mismatch between the training on offer and the labour market (Kett, 2012).

Citing employment figures however, may be misleading, as they do not take into account unpaid labour. Millions of young people with disabilities worldwide do work in the family home, farm or workshop although officially 'unemployed'. They cook, clean, baby-sit, care for ailing and aged relatives, or tend gardens, fields and flocks. Millions more work doing odd jobs in the community or working as beggars (Groce et al., 2013).

Such work, even when of great significance to the household, may go unnoticed by economists, local communities and even by their own families. They receive little credit for the work they do and they have little or no control of what money they do bring in (UNICEF, 2013b).

Social inclusion and relationships

The years between 15 and 24, are developmentally critical for young people: it is the time that most begin to establish their identity and autonomy, forming relationships, moving from their parent's home and setting up households and families of their own. Yet many youth with disability are not included in activities that build fundamental social, educational and economic skills. Disabled young people are also often left out of both formal and informal 'rites of passage' - blocked from participating in cultural and religious ceremonies, joining sports teams, dating, learning to drive the family vehicle. This exclusion distinguishes young people with disability from other groups of young people in many societies.

In developed countries with established educational and support services for adolescents up to the age of 16 or 18, the sudden lack of individualised support services, and the need to apply for and often struggle to get into adequate housing, employment programmes or social protection schemes can leave young people in limbo. Many spend years at home, lost to the system while they and their parents struggle to get their children needed benefits and supports.

Young people with disability often have little or no say over where and with whom they will live, and the role that they will play within their families or communities. They are often denied the right to marry or to build families of their own. Indeed, in some countries, individuals with certain types of disability are unable to legally obtain a marriage license (World Bank 2003).

This does not mean that young men and women with disability are not involved in relationships, or do not engage in sexual activities, but it does mean that there is often no social acknowledgement, and a lack of information on relationships or sex education provided to them (UNFPA/WHO, 2009). This places adolescent girls and young women with disabilities at increased risk for pregnancy, and disabled young men and women at increased risk of abusive relationships and sexually transmitted diseases – including HIV/AIDS (UNFPA/WHO, 2009).

Social participation and civic engagement is also often limited or denied youth with disabilities. Civic groups, community associations or political activities are rarely designed to be accessible to youth with disability. And without inclusion in the social and civic life of their communities, young women and men with disabilities often lack a voice or a vote in how their communities are run or decisions that will affect themselves and their families in future.

Cross-cutting issues and disability-specific issues

Disability does not exist in isolation; it must be considered in conjunction with other pressing development issues. One area of particular concern is gender. In societies where girls are valued less than boys, the investment in education, health or job training that families are willing to make in young women with disability is often substantially less than for boys with disability or than for non-disabled girls (ESCAP, 1995). When these issues are compounded the result is often called 'double discrimination' (DFID, 2000).

Young people with disability who are members of ethnic and minority populations, and those who live in rural areas or urban slums, also face multiple disadvantages. These young people are less likely to be included in whatever mainstream or disability-specific services and programmes exist for youth with disabilities. In some cases this is because such services do not exist in the areas in which these young people live (remote rural areas, reservations) and in some cases, even if services are available nearby, they are provided in mainstream rather than local languages, they are not designed to address specific ethnic or cultural traditions (gender, food restrictions, schedules related to times for religious observances or important festivals and holidays) or they are run by professionals who are not welcoming to ethnic or minority populations. A further complication is that traditional beliefs and

prejudices held by ethnic or minority families towards disability may make families from these communities less willing to come forward to ask for assistance or seek inclusion of their children in mainstream programmes. Such marginalisation on the basis of ethnic or minority status compounds the discrimination already encountered because of an individual's disability. Young women with disabilities in such populations are at even greater disadvantage.

Violence and abuse is another area of great concern. Youth with disabilities are at significantly increased risk of violence and abuse (UNICEF, 2006). Not only have many young people been initially disabled through violence, either within the household or community, or as a result of warfare, child soldiering or landmines, but once disabled, these individuals are at significantly increased risk of being victims of physical and psychological abuse, domestic violence and rape. (World Bank 2005) They are also at increased risk of being trafficked into sexual slavery. (UNICEF 2006) Youth with disabilities are at increased risk because they are often unable to protect themselves, and because many abusers believe that these young people will be unable to report the abuse or will not be believed (World Bank 2004; UNICEF, 2006). Unfortunately, because many people in authority – such as social workers, police officers and judges – know little about persons with disabilities, these abusers are often correct in such assumptions. While discussion of violence against young people with disabilities is often framed as a gender issue, in fact, young men with disabilities are also at increased risk of violence and rape.

The social isolation, lack of education, poverty and discrimination faced by youth with disabilities sets up an interconnected pattern of problems. Millions of these young people end up on the street, unemployed and often involved in crime, sex work and drugs, frequently at the behest of others who see them as easy prey. It is estimated that at least one-third of all street children have a disability (UNICEF, 1999).

Institutionalization is another disability-specific area of concern. Although the CRPD as well as the CRC (UN, 1989) clearly sets out the right of all children – including children with disabilities – to a home and family of their own, hundreds of thousands of children with disabilities continue to live in institutional settings. And despite the fact that Article 23 of the CRC, addressing the needs of children with disability calls for facilitating 'the child's active participation in the community' and Article 19 of the

CRPD recognising the equal right of all persons with disabilities to live in the community (UN, 2006), children with disabilities still fare less well than their non-disabled peers. Violence and sexual abuse are of great concern for the significant number of these young people who continue to be institutionalised in schools, hospitals and mental health institutions (UNICEF, 2013b).

One additional area of particular concern – and potentially of great promise – to youth with disabilities, are new information and communication technologies. Computers, cell phones and tablets allow many youth with disabilities to communicate for the first time with the world around them, linking them to social networks and allowing them to access information even if they are unable to leave their room. However, evolving technologies must be designed to be disability accessible – and youth with disabilities must have the literacy skills and technological training to understand how to use this technology and the resources to be able to purchase and maintain it.

WHAT CAN BE DONE?

There is a need to include youth with disabilities in all mainstream development efforts that target young people. However, there is also a strong need for disability-specific efforts. While there are an increasing number of programmes that address the specific needs of youth with disabilities, organised by government agencies, community-based rehabilitation programmes, non-governmental organisations, religious and community groups, globally the number of such programmes remains small[4] .

Disabled people's organisations (DPOs) run by and for people with disabilities exist in all countries and are a powerful advocacy base for change. But few DPOs have organised systems of youth groups or internship or training programmes whereby young people with disabilities are brought into the organisation to represent the voice

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[4] For example, Mobility International USA (MIUSA) brings young women with disabilities from around the world to leadership training programmes at its home base in Eugene, Oregon https://www.facebook.com/mobility.international;
Leonard Cheshire Disability runs the Young Voices Programmes in which brings together over 1,200 youth with disabilities from countries around the global to campaign both nationally and internationally for disability rights. http://lcdyoungvoices.tumblr.com/

and concerns of youth with disabilities or are trained to begin to assume leadership roles in future. More systematic outreach to youth with disabilities would add an important and currently poorly represented component to effective disability advocacy, and such efforts must be fostered and funded.

Need to listen to young people with disabilities

In 2013, DESA undertook a consultation with the Leonard Cheshire Disability Young Voices Programme, to survey young disability advocates, aged 16–25 years from countries around the world (UN/LCD, 2012). The 75 young adults who took part in the consultation reflected the global Young Voices membership – a balanced number of males and females having a range of disabilities (physical, hearing, visual, intellectual, and persons with albinism).   These young people responded with their ideas, stories, photographs and comments and raised many issues and concerns. Their call for action focused on a series of key requests:

1. Treat young people with disabilities with respect: Disability is not inability.

2. Support young people's efforts to raise awareness on the rights of people with disabilities and create opportunities for them to join in all activities. Help them to lobby and advocate for the implementation of the CRPD and to challenge the negative attitudes which perpetuate their exclusion.

3. Pay attention to the environmental barriers that stop young people with disabilities from participating. Find out what the barriers are and try to remove them. A lack of participation by young people with disabilities does not mean they don't want to take part – it means they can't because something is stopping them.

4. Acknowledge that girls and young women with disabilities can be at very high risk of abuse and exploitation. Raise awareness around their vulnerability, reinforce laws to protect them, and support efforts to empower them so that they can speak out for themselves.

5. Education for all means just that – give young people with disabilities a chance to reach their potential by supporting schools and families to accept the value of education for children and young people with disabilities.

6. Make sure young people with disabilities are brought into decision-making forums and that their ideas and suggestions are given equal consideration to those of their non-disabled peers. Don't assume they are only interested in disability issues – make sure they are able to contribute their ideas and views in all areas of debate.

7. Create inclusive opportunities for young disabled people to take part in sports and other recreational activities. Sport in particular can be a powerful mechanism to challenge negative stereotypes and promote the integration of young people with disabilities into their communities. It's also fun and helps build friendships and peer groups.

8. Support the development and promotion of accessible technology because it is clear that it is already having an impact on the ability of young people with disabilities to participate.

9. International development is important. The Millennium Development Goals (MDGs) are unlikely to be achieved if the needs and capabilities of people with disabilities remain on the fringes of development policy and practice. Make sure all development programmes take proactive measures to include people with disabilities, including young people.

10. Celebrate diversity. Recognise the important role that young people with disabilities play in creating richer, more dynamic, resourceful and respectful communities.

These recommendations provide an important starting point to ensure that youth with disabilities are included in all efforts to improve the lives of young people globally. And these points underscore the fact that such efforts cannot and should not move forward unless young people with disabilities themselves are brought into the process.

Unless these millions of youth with disabilities are included in all development efforts including the forthcoming Sustainable Development Goals (SDGs) now being considered in the post-2015 agenda, the rights delineated in the CRPD will not be realized and the economic and social benefits sought for all through the MDGs and the SDGs will not be met.

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