YOUTH WITH DISABILITIES



HIGHLIGHTS

- Estimates suggest that there are between 180 and 220 million youth with disabilities worldwide and nearly 80% of them live in developing countries¹.
- The unemployment rate of persons with disabilities is over 80% in some countries across continents².
- Youth with disabilities face dual disadvantages as individuals with disabilities are more likely to live in poverty even in developed countries such as the United States³.
- Children with disabilities have lower probability of entering school as well as staying and advancing in school as children without disabilities⁴.

disabilities Youth with often face marginalization and severe social, economic, and civic disparities as compared with those without disabilities due to a range of factors from stigma to inaccessible environments. As countries look towards the post-2015 era to ensure poverty reduction and equitable development, it is essential to ensure that all youth have equal opportunities to become productive and contributing members of their society and enjoy all rights and privileges of citizenship, including youth with disabilities.

It is important to understand the life cycle of disability-based marginalization that impacts persons with disabilities in their youth. Youth with disabilities are impacted by their experiences as they transition from childhood into adulthood and similarly spillover into the remainder of their adult lives. For many young people with

¹ Groce, N.E. (2003). HIV/AIDS and people with disability. *The Lancet, 361*(9367), 1401-1402.

Roggero, P., Tarricone, R., Nicoli, M., & Mangiaterra, V. (2005). *Employment & Youth with Disabilities: Sharing Knowledge and Practices*. Washington, D.C.: World Bank.

² International Labour Organization. (2002). Information Note. ILO/Japan Technical Consultation Meeting on Vocational Training and Employment of People with Disabilities in Asia and the Pacific. 14-16 January 2003. Bangkok. Available at: <u>http://www.ilo.org/public/english/region/asro/bangkok/ability/</u>

Mitra, S., Posarac, A., & Vick, B. (2013). Disability and poverty in developing countries: a multidimensional study. *World Development*, *41*, 1-18.

³ U.S. Census Bureau, 2008

https://www.census.gov/newsroom/releases/archives/facts for features special editions/cb08-ff11.html

⁴ World Health Organization and World Bank, *World Report on Disability* 29 (2011), available at <u>http://www.who.int/disabilities/world_report/2011/report/en/</u>







disabilities, exclusion, isolation, and abuse, as well as lack of educational and economic opportunities are daily experiences. Disparities in education, employment, and relationships are more pronounced in youth with disabilities. Like adults with disabilities, youth with disabilities do not enjoy the same human rights or equal access to goods and services as peers without disabilities. Children with disabilities may lack opportunities to receive an education due to inaccessible school systems, which will in turn impact their vocational skills and ability to accumulate capital and social assets as adults (Mitra, Posarac & Vick, 2013). Without equal opportunities to get and retain employment and economic self-sufficiency, youth with disabilities will have to be highly dependent on other household members or Government welfare which negatively impacts household assets (Mitra, Posarac & Vick) and in turn a country's economy.

Youth with disabilities also face severe challenges in exercising their basic rights and for most, full societal acceptance is often out of reach. Youth with disabilities face political and civic disenfranchisement and may experience barriers in youth-driven or youth-focused political and civic participation activities due to the inaccessibility of physical and virtual environments.

The Convention on the Rights of Persons with Disabilities (CRPD)⁵ recognizes the importance of ensuring that all persons with disabilities, irrespective of age, enjoy the same human rights as everyone else and provides a framework for legal, civic, and socioeconomic empowerment (Lord, Samant Raja & Blanck, 2012). Effective implementation of the Convention requires a focused effort by all sectors to guarantee that young people with disabilities participate in mainstreamed as well as in disability specific programs on an equal basis with others.

Youth and disabilities: Prevalence

There is a significant shortage of empirical research on prevalence of disabilities among the youth (between ages 15-24 as per the United Nations) and their living conditions. Estimates suggest that there are between 180 and 220 million youth with disabilities worldwide and nearly 80% of them live in developing countries (Groce, 2003; Roggero, Tarricone, Nicoli & Mangiaterra, 2005; United Nations 1990). Variations in definitions of disability, data collection methods, and sophistication of statistical analysis make international comparisons difficult. Additionally, questions on disability are often excluded from national surveys such as the census or when included may be too narrow to gather holistic information about the economic and social living conditions of persons with disabilities (Eide & Loeb, 2005). Although the actual figures are uncertain, it is clear that individuals with disabilities form a significant proportion of the youth population in every society. The number of youth with disabilities is likely to increase due to youthful age-structures in most developing countries and medical advancements which promote higher survival rates and life expectancy after impairment-causing diseases, health conditions, and injuries. Youth itself can be a contributing factor, as young people are at an increased risk of acquiring a disability through such incidents as road traffic accidents, injuries from diving and other sport activities, violence and warfare (Aito et al. 2005, Cripps 2003, Karacan et al. 2000).



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⁵ <u>http://www.un.org/disabilities/convention/conventionfull.shtml</u>





For example, statistics from several countries show that the incidence of spinal cord injury is highest among youth. In Canada, for example, over half of those with spinal cord injury were aged between 15 and 24 at the time of their accident (Canadian Paraplegic Association, 2003). In Australia, the incidence rates of spinal cord injury are highest for those aged between 15 and 24 (Cripps 2006). Youth are also increasingly involved in war and conflict – approximately 250,000 individuals under 18 years of age are participating in armed conflicts (United Nations Children's Fund [UNICEF], 2006), over 300 million youth live in countries affected by armed conflict and warfare (Integrated Regional Information Networks, 2007) - and are at severe risk of violence, abuse, and injury (United Nations, 2008).

Poverty

Young people constitute a major proportion of those living in poverty across the world – almost 209 million live on less than US\$ 1 a day, 515 million live on less than US\$ 2 a day (UN Department of Economic and Social Affairs [UN-DESA], 2005). Youth with disabilities face dual disadvantages as individuals with disabilities are more likely to live in poverty even in developed countries such as the United States (U.S. Census Bureau, 2008), thus multiplying their risk factors. Persons with disabilities across many developing countries experience multiple dimensions of poverty "at higher rates and in higher breadth, depth, and severity than persons without disabilities" (Mitra, Posarac & Vick, 2013, p. 11). Additionally, households with members with disabilities generally have lower incomes than other households and are at a significantly higher risk of living below the poverty line (Loeb & Eide, 2004; Hoogevan, 2005; Mitra et al.). As parents and family members take on care-giving roles, at least one parent or family member (mostly women) in many households may have to give up employment or sustainable livelihood activities due to limited Government supports, inaccessible community infrastructure, and financial limitations to pay for personal assistants.

Family Situation

The family is the central unit in the lives of most youth. For some families, having a child with a disability may bring them closer together, but for others it can pose significant challenges. In many places, there is considerable societal stigma imposed on families with young members with disabilities. Societal discrimination and negative attitudes arising from misconceptions, stereotypes, and myths, such as disability being a punishment for past sins or signs of a curse, are still predominant in many countries. Members of the community holding such negative attitudes may disassociate themselves from individuals of that family and greatly diminish the young individuals' chances for community participation and social inclusion. Feeling embarrassed and ashamed, families in these societies often do not acknowledge having a youth with a disability, keep them hidden and at home, and limit their interaction with the rest of society (Inclusion International, 2006).

Many families believe that their children need protection, thereby stifling their independence that can lead to lower self-esteem and a weaker sense of identity. This attitude prevents youth with disabilities from reaching their full potential. The proportion of youth with disabilities living independently is considerably less than for the general population (United States Department of Education, 1993). Some youth with disabilities may be in a vulnerable position within their family, as persons with disabilities are more likely to be subjected to physical or sexual abuse than the rest of society (Groce, 2003). Many may be institutionalized during their adolescence as their families find it too difficult to manage with limited resources or are too old to care for a grown individual (Groce,

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2004). A number of youth with disabilities will find themselves on the street, with one estimate suggesting that 30% of street youth have a disability (UNICEF, 1999).

Families, parents, and caregivers of youth with disabilities are also hindered by lack of information and knowledge on resources and services to support youth with disabilities. A shortage of resources and facilities such as Government assistance, inclusive education facilities, awareness about the rights of youth with disabilities, and public and private accessible facilities for social participation further isolate families who may not know the most effective ways to ensure equal participation in society. In some cases, there are limited avenues for continued medical support and rehabilitation beyond the immediate acquisition of a disability. For example, individuals with muscular dystrophy may need regular physical therapy to avoid secondary conditions and promote their capacity for socioeconomic participation. However, they may not be aware of this or have the required resources in their communities.

Cultural context is another key factor in the interplay between family and Government support for persons with disabilities. In cultures where disability is looked upon solely as an individual or family concern or is stigmatized, Governments may not fund adequate support programmes or initiate programs for educational and economic participation. In other cases, where persons with disabilities are looked upon with pity and presumed to be unable to be as productive as persons without disabilities, Governments may only offer financial support such as cash benefits and welfare programs. While financial support may be essential for some families, awareness and knowledge about effective practices for empowerment and services to support equal participation are crucial.

Education

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Education for all youth is critical for realizing their full potential. Yet, children with disabilities have lower probability of entering school as well as staying and advancing in school as children without disabilities (World Health Organization and the World Bank, 2011). By the time they enter adolescence, many youth with disabilities run a high risk of being illiterate, leading to restricted opportunities for further education, employment, and income generation (see for example Eide & Loeb, 2006; Eide & Kamaleri, 2009; Singal, Bhatti & Malik, 2011). Some families do not feel that youth with disabilities should receive an education, often believing that young people with disabilities are incapable of learning (Groce, 2004). In societies that favour males, young women with disabilities are further disadvantaged as families may be reluctant to allocate resources to them.

However, even with supportive and encouraging families, many youth with disabilities face severe challenges in obtaining an education. Educational establishments are often inaccessible, lack appropriate facilities, and do not provide students with disabilities with necessary accommodations or assistive devices. Inclusive and accessible schools are essential conditions to promote the social inclusion, acceptance, and equality and opportunities in schools and colleges for individuals with disabilities. Sensitization, awareness-raising, and capacity building programmes are important to prepare teachers and school and college personnel, the lack of which often result in the exclusion of youth with disabilities from certain activities (World Health Organization and the World Bank, 2011). This is even more poignant for students with hidden or invisible disabilities and staffs need to be appropriately trained to provide these students with the most appropriate teaching strategies and supports.

There are differing perspectives on providing quality education to students with disabilities such as segregated and separate systems, integrated systems, and inclusive systems. Inclusive education is







increasingly considered to be the preferred method as it offers the greatest opportunity to educate the majority of the children without exclusion or isolation in cost-effective ways (World Health Organization and the World Bank, 2011). Special and segregated education may be below par with mainstream education, isolates these students, and may not lead to holistic learning and skill development (UNESCO, 2003). Additionally, it deprives students with and without disabilities of interaction with each other which would be a rich learning experience that could advance greater acceptance, and the normalizing and mainstreaming of disability in society. These barriers cause many youth with disabilities to drop out of school before their peers (Levin et al. 1986; Hollar 2005), further limiting their opportunities in the future. Youth with disabilities remain under-represented in higher education institutions, although numbers are increasing in several countries (Organisation for Economic Co-operation and Development [OECD], 2003). Limited school education and continuing inaccessibility of higher education institutions curtails their ability to participate in vocational training courses.

The World Programme of Action for Youth (WPAY) adopted by the United Nations, in 1995, calls upon states to pay particular attention to the education of youth with disabilities. Article 24 of the Convention on the Rights of Persons with Disabilities (CRPD) has provisions to ensure that persons with disabilities receive an education within the general education system that provides them with the necessary supports to facilitate educational activities as well as life and social development skills, and allows them to develop their full potential.

Transition into working life and financial independence

Many young individuals with disabilities face a difficult period of upheaval and uncertainty as they transition from childhood into adulthood, primarily in the area of achieving successful employment and independent living. For youth with disabilities excluded from community participation and interaction in their formal years, transition into adult independence in the real world can be particularly challenging as they face discrimination and attitudinal barriers. In developed countries with established services to support youth under the age of 18 through school, the sudden lack of individualized supports and services and the need to fight for appropriate accommodations can become a daunting barrier (National Council on Disability, 2000). The World Youth Report 2007, focusing on transition into adulthood, states that the lack of an enabling environment that supports youth development in all aspects including education and health care, is a critical constraint to successful transition into adulthood (UN-DESA, 2007). Inequities in, and inaccessibility of these systems for youth with disabilities. Youth generally face greater employment uncertainties and hiring disparities during economic downturns and shrinking labour markets (UN-DESA). In such scenarios, youth with disabilities face greater discrimination in hiring practices.

Employment

Not receiving the skills and qualifications to function in the wider society limits the employment opportunities for youth with disabilities. Unemployment rates for persons with disabilities are higher than persons without disabilities in every society across age groups. The unemployment rate of persons with disabilities is over 80% in some countries across continents (ILO, 2002; Mitra, 2007). A study across 15 developing countries showed that unemployment rates for persons with disabilities were significantly higher than persons without disabilities in most countries (Mitra, Posarac & Vick, 2013). Many persons with disabilities are offered low paying jobs, or may be employed in the





informal sector (Powers, 2008). While inequities in educational and skill development resources can impact their competitiveness in the labour market, negative attitudes about disability and discrimination on the basis of disability are the most prevalent and primary obstacles to the successful employment of young people with disabilities. Negative perceptions of youth with disabilities and misconceptions held by employers, for example, that they are less productive than their peers, require too much assistance, affect the employer's image, and/or concerns over initial hiring costs (e.g. building ramps, accessible IT), pose a formidable barrier to youth with disabilities looking for employment. In fact, studies have shown that most accommodations do not impose significant financial costs to the employer and even persons without disabilities use and benefit from the use of supportive workplace policies and practices (Schartz, Hendricks & Blanck, 2006; Schartz, Schartz, Hendricks & Blanck, 2006). Youth with disabilities are given little room for error, and are quickly labeled unemployable if they are unsuccessful at their first job. For young women with disabilities, the situation is even worse as they have to counter disability and gender based societal prejudices, and women with disabilities have lower employment rates than men with disabilities and women without disabilities (see for example Statistics Canada, 2006). Even with a good education, young women with disabilities take a longer time to find a job (Roggero et al. 2005). These negative perceptions do not correspond with studies that show that persons with disabilities are just as productive, dependable, and less absent from work than workers without disabilities (Du Pont 1993; Zadeck & Scott-Parker 2003), and it is important to educate and raise awareness of employers to not have low expectations of persons with disabilities.

It is also important to recognize that employment does not stop at hiring or entry into the labour market, but that youth with disabilities should also receive equal opportunities to successfully retain and advance in their employment and build networks and relationships in their workplace similar to individuals without disabilities. Youth with disabilities should receive accommodations, supports such as assistive technologies, as well as appropriate training and skills development to obtain the employment of their choice that they are qualified for without discrimination on the basis of their disability. Advances in assistive technology have significantly reduced barriers to participation across types of jobs and professions (de Jonge, Scherer & Rodger, 2007).

The WPAY urges countries to take measures to develop the possibilities for youth with disabilities. Article 27 of the CRPD addresses employment concerns by stipulating that persons with disabilities have the right to work as everyone else in an open, inclusive, and accessible labour market, without discrimination, and with access to reasonable accommodations in the workplace.

Sex and Relationships

Sexual relationships are difficult to manage and having a disability adds further dimensions to them. In most places, society incorrectly believes that youth with disabilities are asexual and/or cannot be abused (Milligan & Neufeldt 2001; Groce, 2003, 2004). Access to reproductive health information is often not available to youth with disabilities, or disseminated through such inappropriate means as inaccessible clinics, inaccessible print or electronic media, or by providers who cannot communicate with youth with disabilities. Few education programmes cater to the reproductive needs of youth with disabilities. For example, in several countries youth with disabilities often do not receive advice on HIV/AIDS, as the clinics are physically inaccessible, material is not available for those with visual impairments, and providers are unable to communicate in sign language. Moreover, most health care professionals have no disability awareness and consequently feel unwilling or unable to address their issues (Yousafzai, et al., 2005). This example is far from unique and highlights that youth with disabilities are highly vulnerable to sexual abuse and rape.









The lack of social acknowledgment of their sexuality has several negative consequences for youth with disabilities. Many youth with disabilities will absorb and accept these negative beliefs as facts and refrain from sexuality and intimacy altogether (Milligan and Neufeldt 2001). Well-meaning parents may not acknowledge their children as sexual beings and discourage them from expressing any form of sexuality (Di Giulio, 2003). Other youth with disabilities will have relationships, but without receiving appropriate education may undertake high risk activities. Some might go through several uncertain relationships, as the marriage of persons with disabilities is frowned upon in a number of places and in some cases even legally prohibited (Groce 2003; United Nations 1995). In polygamous societies, young women with disabilities are unlikely to become the primary wife (Groce 2004). The right of persons with disabilities to have children is also curtailed and denied by many societies, sometimes by law. Article 23 of the Convention recognises the rights of persons with disabilities to form relationships, marry, and start a family and adopt children. It also states that countries should provide persons with disabilities access to the same sexual and reproductive health care and family planning education available to individuals without disabilities.

Political and Civic Participation

Article 29 of the CRPD raises the importance of ensuring that persons with disabilities have political rights and can exercise those rights on an equal basis with others as well as have equal opportunities to participate in public affairs. Youth have been increasingly influential in recent years in crucial political movements and are a key constituency for political advocacy and civic change, especially with the increased usage of social media and other internet driven mechanisms for civic participate in social change and political movements, make informed choices about voting and political decisions, or be active citizens due to accessibility barriers in physical and virtual domains of participation including access to information and meeting venues (Lord & Stein, 2008; Parker Harris, 2011). Youth with disabilities may be disenfranchised if they are unable to vote either due to accessibility barriers at the polling stations and booths or due to laws and policies that prohibit them for having the right to vote because of their disability (Lord, Guernsey, Balfe, Karr & deFranco, 2012; Schur & Adya, 2012).

With the evolution of information and communication technology (ICT), it has become easier for young people with disabilities to exercise their civil and political rights, and they have increased opportunities to interact with persons without disabilities to exchange opinions and have conversations and debates. Social media and ICT-enabled information exchange can help raise the awareness of youth with disabilities of their rights and duties. Similarly advocates and political candidates are increasingly using technology to reach out to voters, and the use of accessible ICT will promote their outreach to youth with disabilities.

Acceptance

Young people with disabilities often experience rejection and isolation due to peers' misconceptions. Feelings of loneliness and isolation are reinforced by an environment inaccessible to individuals with different disabilities (e.g. movies at cinema halls without closed captioning). This is especially important when social cultures are rooted in shared experiences at local gymnasiums, community clubs, sporting clubs, and other community activities.







As social creatures, humans desire a sense of identity and belonging - a desire to be part of a community that respects and appreciates every individual, regardless of their differences. Yet for youth with disabilities, societal prejudice, other youths' awkwardness and discomfort in their presence, and environmental barriers largely prevent them from being accepted. The greatest impediments continue to be discrimination, prejudice, and social isolation (Despouy, 1991). Inaccurate or negative portrayals of persons with disabilities in the media also impact the conceptualization of disability in the minds of individuals with and without disabilities.

Ignorance of disability results in the needs of youth with disabilities being unrealised, leading to a loss of self-esteem, self-worth, and the creation of social isolation. Youth programmes seldom address issues of youth with disabilities; much less include them into activities. Other initiatives directed at youth often overlook those with disabilities. However, these societal misapprehensions need not be the case. When youth with disabilities interact with their peers, and there is a sense of belonging, these barriers collapse (Green, 2003). This works in both directions. By promoting inclusion and accessibility in all public environments, youth without disabilities will also have opportunities to interact with and learn about their peers with disabilities helping to change stereotypes and misconceptions and breaking down stigma around disability.

Increasingly, youth are engaging in virtual social networking using various multi-media tools online. However if these interactive platforms are designed without comprehension of the need for accessible features in information and communication technologies (ICT) that facilitate the use of assistive technology (AT), youth with disabilities who needs AT to access ICT will again be left out of opportunities for social participation.

Greater awareness and understanding of disabilities is fundamental to improving this situation. Concerted efforts to raise awareness and disseminate accurate information about persons with disabilities that challenge misconceptions and stereotypes, design public use infrastructure (physical or virtual) to be accessible, and provide equal opportunities for youth with disabilities to participate in all aspects of youth development are important and necessary to promote the full participation and inclusion of youth with disabilities.

The Convention on the Rights of Persons with Disabilities (CRPD)

The CRPD entered into force on 3 May 2008, and to date 138 countries have ratified and 158 countries have signed the Convention. At its core, the Convention ensures that persons with disabilities enjoy the same human rights as everyone else, and are able to lead their lives as citizens who are given the same opportunities to grow and contribute to society as those without disabilities. It marks a paradigm shift from seeing persons with disabilities as objects of charity and pity to holders of rights.

The Convention notes that "persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments." The extent to which these impairments disable someone is dependent upon the level of attitudinal and environmental barriers encountered in society. Examples of these can be seen everywhere from stairs into buildings, reading materials in inaccessible formats, and prevailing negative attitudes towards persons with disabilities. The more the barriers the less likely persons with disabilities are able to participate in society.









Concluding Remarks

The experiences that people face in their youth shape the rest of their lives. Youth with disabilities face the same issues and concerns as their peers without disabilities, but societal prejudices, barriers, and ignorance exacerbate their concerns. To date, most societies have not fully integrated youth with disabilities, leading to segregation and the condemnation of a whole segment of the population. Clearly, more work is required. Providing opportunities for full and equal social, civic, economic, and political participation is beneficial not only to youth with disabilities, but also their societies and countries as the youth can contribute fully to the country's development and economic growth. The Convention offers hope for improving the current situation. In many places, it will offer youth with disabilities human rights for the very first time, facilitating the process that empowers them to address the multiple societal challenges they face. However, its implementation and realization requires a focused effort by all stakeholders, and especially Governments and policy makers, to ensure that a significant proportion of their population does not remain an isolated and invisible segment but one that can realize its full potential, have equal access to all opportunities, and exercise the same rights as the rest of the citizens.

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 $_{\text{Page}}12$

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