Adolescents and Youth with Disability

Issues and Challenges

ABSTRACT

Globally, almost 180 million young people between the ages of 10-24 live with a physical, sensory, intellectual or mental health disability significant enough to make a difference in their daily lives. The vast majority of these young people, some 150 million (80%) live in the Developing world. Routinely excluded from most educational, economic, social and cultural opportunities, they are among the poorest and most marginalized of all the world's young people. Recent World Bank estimates suggest that individuals with disability may account for as many as one in five of the world's poorest. Because of this, disability is now increasingly recognized as a key development issue and its importance in relation to poverty, human rights and the achievement of internationally agreed upon development goals is receiving mounting recognition. This paper reviews issues that must be considered in assessing the needs of disabled young people and urges the inclusion of this all too frequently overlooked group in all international development policies and programming.

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**Introduction**

Globally, some 180 million young people between the ages of 10-24 live with a physical, sensory, intellectual or mental health disability significant enough to make a difference in their daily lives. The vast majority of these young people, some 150 million (80%) live in the Developing world. (UN: 1990) They are among the poorest and most marginalized of all the world's young people.

This paper provides an overview of the prominent challenges currently faced by disabled young people. It will be argued strongly that international development cannot move forward unless this subgroup is included throughout the process and as part of the overall solution.

Adolescents and young adults are grouped together and discussed jointly because they share common characteristics: they are often bypassed both by the programs and policies designed for disabled children and they are left out of advocacy initiatives and employment schemes designated for adults with disability. Nor are their unique social, psychological, education and economic needs addressed by programs designed to reach their non-disabled age-mates.

Of all groups with disability in the Developing world, the one group about which we know the least is disabled adolescents and young adults. This category encompasses both the age range labeled by UNICEF as "adolescents" (those between age of 10-18) and by the United Nations as "youth" (19-24). Subgroups within this category have distinct issues and concerns, (the needs of a disabled 12 year old are very different than for a disabled 21 year old), however, for the purposes of this paper, they have been brought together because of the large number of issues and concerns they share. All are making the transition between childhood and adulthood. These are the years when young people in all societies are expected to acquire skills, go through physical and psychological maturation and assume a social identify that will enable them to fully participate in their communities.
It is easier to list what is NOT known about disabled young people in the Developing world, than what is. With several notable exceptions, there has been virtually no research on disabled young people as a distinct group in any Developing country context and what exists on young people with disability in the Developed world focuses on them largely in the context of formal educational systems and transition to work programs. The call made by UNICEF (1999) in its global survey on adolescents for more research on the wide array of issues that influence the lives of disabled young people remains largely unanswered.

While research may be lacking, extrapolation from data that is already available on youth in general and disability in general can provide a starting point for assessing and addressing the current needs and untapped potential of disabled young people. This is because the needs of disabled young people are strikingly similar to that of their non-disabled peers - the need for education, job training and employment, and for fostering a successful transition from childhood to adulthood through participation in social, cultural, religious and economic affairs. What distinguishes this large group of youth is not their common needs, but the fact that these needs continue to go so largely unmet.

**Disability and Poverty**

Recent World Bank estimates suggest that individuals with disability may account for as many as one in five of the world's poorest. One family in every four has an immediate family member with a significant disabling condition. (Elwan: 2002) The costs to individuals, families and society are enormous. The cost of disability to the global Gross Domestic Product is between US $1.37 and US $1.94 trillion dollars. (Metts:2000) Because of this, disability is now increasingly recognized as a key development issue and its importance in relation to poverty, human rights and the achievement of internationally agreed upon development goals is receiving mounting recognition.

Disability is closely tied to poverty. Indeed, the United Nations Disability Statistics Compendium (1990) suggests that disability rates can be used as a socioeconomic indicator, to help assess poverty
and development. Not all disability is associated with poverty, of course, however, the poor are more likely to become disabled, and once disabled, individuals and families are more likely to begin a spiraling descent into deeper poverty. (UN:1990; Brock:1999) This feedback loop between disability and poverty places individuals with disability at a marked disadvantage at every stage of their lives. (Metts:2000) Those who are poor are likely to live and work in more physically dangerous environments, to have less to eat and to receive poorer quality medical care or no medical care at all. Whether poor to begin with or initially better off, there is a heightened chance that once a disability occurs, those who lived above the poverty line are more likely to be driven into poverty and those who were poor to begin with, are more likely to become destitute. (Acton:1983)

As World Bank President James Wolfensohn recently noted in a Washington Post editorial, "Unless disabled people are brought into the development mainstream, it will be impossible to cut poverty in half by 2015 or to give every girl and boy the chance to achieve a primary education by the same date -- goals agreed to by more than 180 world leaders at the United Nations Millennium Summit in September, 2002". (Wolfensohn:2002)

Despite the vast numbers involved, strikingly little is known about disabled populations. Outside of specific data sets collected largely from Developed countries where income maintenance schemes and general health care initiatives have prompted officials to keep statistics for specific rehabilitative or educational services provided to disabled groups, little information exists. This is particularly true for the Developing world. Elwan, referring to the current lack of knowledge, ably notes that "literature on poverty and disability in developing countries tends to be of a generalized nature, focusing on what is generally known about health, disabilities, poverty and vulnerable populations. Much of it relies on anecdotal evidence and case studies." (1999:2)

Moreover, the studies that do exist from Developing countries have concentrated almost exclusively on the epidemiology of specific causes of disability (i.e. polio, river blindness, traffic accidents) or on general discussions of the broad demographics of disability. Despite the fact that the most pressing
needs of most of the world's disabled population - poverty, social isolation, and denial of human rights, are non-medical in nature, only a small body of research, exists.

Demographics

Worldwide, estimates of the number of adolescents and young adults who live with a disability vary widely. Issues of accuracy and reliability of statistics have been raised for individuals with intellectual disabilities and individual with mental health concerns, as well as those with physical and sensory disabilities. (Neufeldt and Albright:1998) Indeed Suris and Blum conclude their important 1993 paper on the demographics of disabled adolescents, by noting that the lack of homogeneity in definition, survey procedures and data collections "makes international comparisons almost impossible." (1) In 2002, the United Nations established a new international consortium, the Washington City Group to more accurately determine national and international statistics on disability, including those for disabled adolescents and youth, however, its report and recommendations are still several years away. (UN: 2002a)

Here is what is currently known. By 2005, the UN estimates that there will be roughly 1 billion adolescents worldwide. (UN Statistics: 1990) If both the UNICEF and the World Health Organizations estimates that one in every ten of these adolescents is disabled are used, (WHO, 1983), then by 2005, the Developing world will have roughly 100 million adolescents with disability. (If a more conservative estimated rate of 5% is used, this still means 50 million disabled adolescents worldwide by 2005).

To this number must be added the number of disabled youth between the ages of 19 and 24. Again, specific global figures for this subgroup must be extrapolated on the basis of general population estimates. Few countries tract disabled youth as a distinct subcategory. However, it is estimated that there are 500 million youth between the ages of 19 and 24 living in the Developing world. Assuming that roughly 10% of this population are disabled, it yields the figure of 50 million between the ages of
Combining the statistics on disabled adolescents and disabled young adults, yields 150 million adolescents and young adults who live with a significant disability. (Using the lower calculation of only 5%, still yields a global population of 75 million young people in the Developing world).

To this number can be added an additional 30 million adolescents and young adults with disability representing the 20% of young people who live in Developed nations, if we use the UN estimate that 10% of all populations are disabled. (If the more conservative prevalence rate of 5% is used for the 20% of disabled young people who are assumed to live in Developed nations, this still yields the substantial figure of 15 million individuals in Developed countries).

The total overall globally, for this disabled adolescents and young adults, assuming a 10% prevalence, is 180 million. (Assuming a 5% prevalence rate, the number still remains a very significant 90 million young people).

Moreover, these numbers are growing. With half of the world's population below 15, the number of young people with disability can be expected to rise markedly over the next decade, particularly in the Developing world. This rise will not simply reflect a rising birth rate. Better medical interventions, both in Developing and developed countries, will allow growing numbers of disabled infants and children, often with significant disabilities who previously would not have survived childhood, to grow into adolescence. Young people also are at increased risk due to work-related injuries, risk-taking behavior (including motor vehicle accidents, experimentation with drugs, and risk of violence). Many chronic disabling illnesses and mental health conditions appear only during early adulthood.

An additional concern is the distinct and rising toll that the HIV/AIDS epidemic is taking as a component of the disability issue. The problem is two fold. The health problems associated with the HIV/AIDS virus can be disabling; sensory, physical and mental health impairments will add millions of
young people to the growing ranks of those who are disabled. (UNICEF: 2002) Of equal concern, although all too often overlooked, is the increased risk for young people with disability of becoming infected by the HIV/AIDS virus. This is compounded by the fact that too often, it is incorrectly assumed that these young people are not or will not become sexually active, use intravenous drugs or be victims of abuse or rape, and so they are not provided basic sex education and the resources protect themselves, even in comparison to their non disabled peers. (Groce: 2003)

Nor are disabled young people evenly distributed within the general population. Experts generally agree that disability disproportionately affects the poor. (Elwan, 1999; Brock, 1999; Wolfensohn, 2002) Moreover, those few national data sets that do exist suggest that throughout the Developing world, disability affects more males than females, and is found more commonly in rural than in urban areas. (UN Compendium:1990; Harriss-White and Subramama:1999) However, such data is complex and may reflect a host of issues - survival rates, access to diagnostic services, census collection techniques and definitional differences of what constitutes a disability. These issues make conclusions about the distribution of disability within populations, especially for the very poor and for women with disability, open to question.

**Disability, Stigma and Prejudice**

Globally, it is widely acknowledged that the greatest impediment to the lives of young people with disabilities is prejudice, social isolation and discrimination. (Despouy:1991; Ingstad:1995) Some cultures are more and others less tolerant of those with disabilities. (ESCAP:1995) In many, although not all cultures, there has historically been a great deal of stigma attached to having a disability. In various cultures, being born with or acquiring a disability has been interpreted as evidence of 'bad blood', incest, or divine displeasure. (Helander:1993)
Interestingly, different types of disabilities are considered more or less disabling, depending in part, on the nature of the society in which an individual lives. For example, to have a physical mobility impairment in a rural agricultural society is often far more disabling than to have the identical type of disability in an urban setting where accessible sidewalks and public transportation allows the individual far greater ability to integrate into the society. In nations where many jobs are dependent on mastering higher levels of literacy and new technologies, such as computers, individuals with intellectual disabilities may struggle more than in societies where there are traditionally more jobs that call for manual laborers.

Within every society, differences in socio-economic status, class, caste and educational levels also make a significant difference in the quality of life for the individual. (Ingstad and White:1995; ICIDH:2002)

While all individuals with disability may be affected by this lifelong cycle of stigma and poverty, females are at increased risk. (ESCAP: 1995). To be female and disabled is often referred to as being doubly disabled. In societies where girls are valued less than boys, the investment in education, health care or job training that families are willing to make in disabled girls are often substantially less than for disabled boys. (Boylan:1991) Some of this discrimination may be subtle, for example, should a disabled daughter fall ill, a poor family may wait a few days more to invest in an antibiotic than they would for a disabled son, hoping that the condition will clear on its own. An indication of the depth of this problem can be seen in the survival figures of post-polio individuals from Nepal where census data indicate that the survival rate is 12% for males compared to 5.9% for females. Polio affects males and females in equal numbers, so the gender imbalance reflects higher mortality rates in female survivors, not higher prevalence rates of polio in males (Helander, 1993). A study by the International Labor Organization in six Asian Pacific nations found that the incidence of disability was in fact higher for women than for men (ILO 1989), making the fact of a subsequent higher survival rate for men with disabilities in the Asian countries surveyed, more strikingly unequal. (ESCAP:1995)

Young people with disability who are members of ethnic and minority populations are also at increased risk. Coming from different cultural, linguistic and religious traditions, these young people are less likely
to be included in whatever services and programs do exist. An ethnic or minority status can also compound the discrimination already encountered by disabled young women, who find themselves contending with forces that would exclude them on the basis of their gender, their disability and their heritage.

The Invisible Population

Despite growing numbers and their striking needs, adolescents with disability have historically fallen through the cracks. General programs that are intended for adolescents and young adults rarely include those with disabilities. Programs for disabled populations where they do exist, are unfortunately usually no more inclusive. Particularly outside the Developed world, programs for those with disability generally are either intended to provide services and general advocacy for all disabled members of a society or fall decisively into one of two categories - programs for disabled children or for adults with disability. The programs and advocacy for disabled children usually focuses tightly on issues of family, education and socialization. The programs and advocacy for adults with disability is largely focused on issues of employment and to some degree, housing and community integration. (Wallace:1990; Broch:1995)

Adolescents and young adults are rarely excluded from these child-focused or adult-focused disability programs. In government programs, voluntary organizations, community based rehabilitation (CBR) initiatives and local social service agencies around the world, adolescents with disability are potential recipients of services or program participants and are nominally included. The needs of a disabled five-year-old however, are usually strikingly different from those of a 13 or 17 year old. Those who run child-focused services report a marked decrease in participation by children once they enter adolescence. (UNICEF:1999) On the other hand, adult oriented disability organizations tend to concentrate heavily on job training, often emphasizing re-entry to the work place after an accident or injury. Such programs are of little or no relevance to older adolescents or young adults who have no prior preparation to participate in the work place. The result is that in many countries, adolescents and
youth with disabilities are alienated from those few disability support organizations that do exist, something that is of particular concern because their social, education and economic needs are so great during this period of rapid physical and psychological development.

Even within the United Nations, acknowledgment of or protection for adolescents with disability, is frequently overlooked. For example, in the United Nations General Assembly's Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993), which sets global standards for inclusion, an opportunity for underscoring the needs of adolescents is missed when groups of disabled individuals at particular risk are enumerated. Children are mentioned, as are members of ethnic and minority communities and adult women. Adolescents with disability however, are not.

**The Cycle of Disability, Poverty and Isolation among Young People**

Young people with disabilities have needs very similar to the needs of all other young people, as clearly stated in Article 23 of the United Nations' Convention on the Rights of the Child. (UNICEF, 2000). They need to live in a safe and supportive environment; they need education, health services and access to sport and recreation. They also need to develop skills that will serve them well in the community and the workplace. In many cultures however, the traditional approach to a young person with a disability is to acknowledge that they are no longer children but to assume that they will never be accepted or able to function, as adults. This is often true no matter what the nature of their disability. The problem of where they should exist is often dealt with poorly,
While all adolescents and young adults face the challenge of acquiring the skills and experiences they will need in order to become successful adults, the transition to adulthood for disabled young people is particularly complex. A fundamental reason for this is that people with disabilities are often seen as being "childlike." Disabled children, particularly those with more visible disabilities, are frequently assumed to be in frail health and unlikely to survive into adulthood. Indeed, in many countries, a significantly disabled child is referred to as “an innocent” or a "little angel." (UNICEF:1999) Sending such children to school, including them in social interactions or preparing them for participation in the adult world seems unnecessary. Families with significantly disabled children have often anticipated their early deaths, but not their possible survival. Bjarnason (2002) discussing the transition to adulthood of young disabled people in Iceland describes this as “eternal youth” – a limbo in which young disabled people are not expected to reach adulthood, but remain enmeshed in segregated services. Where no services exist, such young people usually must either continue to live as "children" in their parents' households, or find themselves on the street. In many countries, particularly where extended family units are still the norm, it is considered appropriate for all young people to remain at home, including those with a disability. Personal assistance, if needed, is provided by immediate family members, (most commonly the mother), which means that these young people with disability often have little or no say over even the most basic aspects of their lives. Such arrangements can also preclude a young person’s ability to establish a sense of autonomy or gain experience in making independent decisions about immediate or long-term plans.

Elsewhere, rapid moves towards modernization have lead to the expectation that young non-disabled adults will eventually want a live independently of their parents.

Young disabled adults however, are often expected to continue living at home - making their lived experiences as young adults increasingly different from that of their non-disabled peers. Of even greater concern is the reality that in many cases, poverty and lack of viable options will force many young adults, particularly young males, to leave home for a life without family supports or a life on the streets.
Education

The links between poverty and disability are established early, often in early childhood and extend throughout the lifecycle. For the vast majority of young people who have been born with a disability, their initiation into their own cycle of poverty begins early when they are unable to access needed medical and rehabilitation services, and when they are denied admission to school. For those who acquire a disability later in childhood, this initiation often begins after they acquire a disability, when they find themselves dismissed from school.

Lack of education is a key concern for most disabled young people in the Developing world. In many countries, children with disabilities are considered to be incapable of learning, no matter what their disability. Often a disabled child is considered a distraction to other students and simply sent home. Lack of schooling may reflect the belief that such children can not learn, that such children should not be put through the stress of learning or such children are an embarrassment (evidence of bad blood, incest or divine disfavor) and should not regularly be seen in public. School buildings are routinely built with stairs, or far from community centers, making them inaccessible to those with mobility impairments. Lack of trained teachers, appropriate teaching materials and an unwillingness to include disabled children in the regular classroom limits access to education for millions of blind and intellectually disabled children as well as those with mental health difficulties. Perhaps the primary reason these children are so rarely in school however, is because there is little perception by their families or their societies that they will have need of an education. (UNICEF:1999) This general lack of access to education is cumulative and by the time children with disability reach early adolescence, the vast majority find themselves far behind the educational levels and skills of their non-disabled peers.

Gender further compounds inequities found in education available to young people with disability. As Russo (2003) notes, cultural bias again women in general, makes many families and educational systems less willing to allocate resources and opportunities to all female students. Reduced expectations for
disabled females further limits what funds families and schools are willing to spend on academic and vocational training. Although, as is true of many other aspects of adolescents with disability globally, little information exits, it is clear that the educational resources and opportunities available to adolescent girls and young women is significantly less than even the already limited resources available to comparably disabled young males. Compounding this issue is the fact that in where school fees and barriers make universal education unavailable, anecdotal reports indicate that some parents choose to put all the family resources into educating non-disabled siblings, with the expectation that more education will guarantee a higher paying job, thus allowing the educated children to support their disabled sibling into adulthood and old age.  (Unfortunately, the option of educating the child with a disability to ensure his or her ability to be self-supporting is often not considered as an alternative).

A few studies have found some inclusion of disabled adolescents and youth in general classrooms without special consideration being given to their disabled status. Miles for example (1995) in a study in rural Pakistan, found 22% of all disabled children had received some schooling within the general classroom setting and reports similar observations from Sri Lanka. This "casual integration" is hard to track, but represents an important area for further study, not only for its implications for education, but also because it might provide functioning models of inclusion that have relevance to subsequent job training and economic development schemes.

Additionally, there has been growing interest in "inclusive schooling practices" with UNESCO and UNICEF promoting greater integration into the general classroom setting. However, most of these efforts have been directed towards younger children, not towards disabled adolescents. In fact, by adolescence worldwide, the vast majority of young people with disabilities are no longer in school.

The social isolation, poverty and discrimination faced by children with disabilities also sets up an interconnected pattern of problems. (Neueldt 1984; Helander:1995; Harriss-White:1996)  Many children with disabilities either do not attend school or leave school early. 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)

There are some exceptions. In Western Europe, North America, Japan, Australia and New Zealand there exists extensive educational systems for most children with disabilities from early childhood through late adolescence. Some nations integrate these adolescents into general classrooms. Others provide specialized classes and offer sophisticated training in social and job skills to help in the transition to adulthood. These programs have varying degrees of success. An extensive body of research has documented this process of transition in some detail, although there is still comparably little information on the effects of this process on the social integration of the individual and the implications for the family unit over the course of time. Comparable data from the Developing world is hard to come by.

However, presence in a classroom alone does not guarantee education. For example, the average reading level for deaf American high school graduates is at a third grade level. (Peinkoff:1994) Students with disability are often formally restricted in what course of study they are allowed to pursue. In a recent study from Ireland, Shevlin (2002) has found that disabled high school students were not allowed to enroll in the full range of academic courses that other students, of comparable abilities, were allowed to take. In China, disabled university students are not allowed to major in most sciences, as it is felt that the degree would be ‘wasted’ on an individual who would never be able to find a position in the field. This systematic lack of education comparable to that of non-disabled peers has immediate relevance to disabled young people as they begin to anticipate entering the workforce. 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.

**Job-Training and Employment**

Globally, employment is a problem for all adolescents and youth. Formal education for most of the world's young people ends by mid-adolescence after which most males and many females are expected
to work outside the home. The ILO has termed the pattern of present and growing global youth unemployment as "stark" (ILO:2002) Young people worldwide are at higher risk for unemployment, partial employment or full employment at lower wages than adult workers.

Adolescents with disabilities are at even greater risk. Coming on to the job market with little education and few or no skills, they have difficulty competing. (UNICEF:1995) For some, specific physical or intellectual impairments may further limit their job options. For most, social prejudice makes employers unwilling or hesitant to hire them. Yet, as the United Nation's report Disabled Youth and Employment states, "the aims of transition (into the work place) are the same for all ... the needs of those with disabilities are not different in kind, only in degree." (UN:1998)

Employment rates of disabled youth are rarely tracked in Developing countries. However, if the general pattern of unemployment and underemployment for the rest of the disabled population holds true, it can be anticipated that unemployment rates among disabled adolescents and youth will be the higher than for all other young people. Rates of unemployment among the general adult disabled population varies from country to country but on average, tends to be at some 40-60% higher than for the general non-disabled population. (Elwan:1999) This is true even in developed countries with sophisticated skills training programs to help in the transition from school to work and reserved employment schemes. (Elwan:1999; Metts:1999). Overall, the ILO estimates the unemployment rate among people with disabilities in the Developing world is an overwhelming problem - up to 80% in some countries. (ILO:2003) Furthermore, even when they enter the work place, adolescents with disabilities often find they have little margin for error. Unlike non-disabled adolescents who frequently fail at a first job or apprenticeship, adolescents with disabilities are rarely allowed to explore their options. 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.

Unemployment among disabled young women, in all societies, averages 50% higher than unemployment among comparably educated disabled young men, (itself double that of their non-disabled male peers).
Disabled young people who are members of ethnic and minority communities also are routinely found to have an unemployment rate significantly higher than that of their non-minority disabled peers.

For all these reasons, young people with disabilities are more likely to be unemployed, more likely to be underemployed (i.e.: working fewer hours, working at seasonal jobs) and more likely to be employed at a lower wage, than their non-disabled peers. Moreover they are often the last to be hired and the first to be laid off or fired should time become hard.

Not only is their employment status in a continual state of flux, but individuals with disability are also more likely to be hired for jobs that require little training and have few opportunities for advancement. Even when they have received a solid education, they take a longer time to find a position, have less job security and less prospect of advancement with that job than do their non-disabled peers with comparable levels of education. This is true even in industrialized countries for individuals with disability who have received a college education and particularly true for college educated women with disability. (Fine and Asch:1988; Ficke:1991)

Citing formal employment figures however, may be misleading. Presumably, only those whose disabilities are too severe or those whose families are wealthy enough to provide for their needs, do not contribute in some way. The vast majority of young people with disabilities worldwide do in fact work, although they usually are officially listed as unemployed. Millions work outside the home, doing menial tasks or working as street beggars. Millions more work long hours within the family home or on the family farm. They cook, clean, baby-sit, care for ailing and aged relatives, or tend gardens, fields and flocks. (UNICEF:1999)

For the non-disabled young adult, taking on an increasing number of chores within the family unit is often seen as a way of building skills that will eventually lead to more independent, adult status. Identical work is frequently viewed as an end in itself for those with disabilities or as a way of helping to cover the costs of their food and housing. Such types of work by disabled young adults, even when they are of
great financial significance to the household, may go unnoticed by economists, local communities and even by their own families. Moreover, many young people with disabilities working on the family farm or assembling piece work in the kitchen, may have their work brought to the marketplace by others who receive the credit and collect the wages for that work.

As is the case with so many other aspects of disabled youth, we simply know very little about young people living in these types of household arrangements. Overall however, the situation continues to be dire. Millions of adolescents and young adults with disabilities find themselves in the position of being unable to support themselves for the present or to plan for the future. Moreover, not only do they routinely earn far less than their peers, but in many cases, society and their families allow them little or no control of what income they do manage to bring in.

**Social Implications**

For non-disabled young people, the transition from childhood to adulthood is a period that prepares the individual for successful adulthood. Yet for young people with disability, there is an almost universal lack of inclusion in activities that build fundamental social, educational and economic skills. This exclusion is often formally sanctioned, with adolescents and youth with disabilities being barred from participating in formal cultural and religious ceremonies that help define an individual's changing status in the eyes of the community. Disabled young people are also often left out of the less formal 'rites of passage': joining a sports team, courting, learning to drive the family truck. This exclusion distinguishes young people with disability from ALL other groups of young people in every society and this exclusion has profound implications for their personal lives..(UNICEF:1999)

A major issue in the lives of all disabled young people is the growing physical maturation and changing social role that prepares them for marriage and children. In reality, young people with disability often have little or no say over where they will live, whom they will live with and what role they will play within their families or communities. Moreover disabled young people are often denied the right to build
families of their own. Social and family constraints make it unlikely that many young people with disabilities will marry. Indeed, in some countries, individuals with some types of disability are unable to legally obtain a marriage license. This is particularly true for disabled young women. (ESCAP:1995) Without the prospect of marriage, in many societies, these young people can not hope to be accepted as full adult members of their communities.

This does not mean that young men and women with disability do not become involved in relationships, or that they do not engage in sexual activities, only that there is often no social acknowledgement (and often no sex education) provided them. (Wallace:1990; Cheng and Udry:2002) This places adolescents girls and young women with disabilities in particular, at increased risk for pregnancy and sexually transmitted diseases. In one of the few studies of its kind, the United States National Longitudinal Study (1993) found that three to five years after completion of high school, females with disability were significantly more likely to be mothers than were either non-disabled females or disabled males. Although 23.7% of all youth in this demographic pool had had children, only 16.5% of disabled males had become fathers. In contrast, 40.6% of all disabled females in this age range had given birth to one or more children. For young women with emotional disturbances, learning disabilities or those with hearing impairments, almost 50% had become pregnant in the years immediately following high school. For disabled females who had dropped out of school, 54% had become mothers. (US Department of Education: 1993) The majority of these pregnancies occurred outside of marriage. Already struggling to earn a living comparable to that of their non-disabled peers, the necessity of providing for a child, particularly in those cases where they are not married, places yet an additional burden on these young disabled mothers. (ILO: 1989; Crawford et al:2002)

In those societies where men are allowed to take more than one wife or routinely take a mistress, a teenaged girl or young woman with a disability is more likely to become a second or third wives within a larger household or a mistress, than to become a first or primary wife. In these types of arrangements, the young women with disability, and their children, often will have less right to play a key role in family decision making and significantly less claim to both household resources and inheritance.
Not only do expectations for what is an appropriate role for young men and women with disability vary from one country to the next, within countries, expectations often vary from one ethnic or minority community to the next. (Groce and Zola: 1993)

**Health and Medical Issues**

Globally, social, economic and educational issues are far more pressing issues for many young people with disabilities than are medical issues. However, the availability of rehabilitative care, prosthetic devices and age appropriate health care need to be singled out both because of a significant lack of such services and because all too often, socio-economic discussions about disabled young people are side tracked by the presumed medical or rehabilitative needs of the population. (SIDA 1995)

There are two areas of medical concern that must be noted: unmet rehabilitative needs for some young people may lessen their ability to fully participate in society; and lack of access to general health and health promotion services may lessen a young person's ability to maintain good health and productivity.

The United Nations estimates that worldwide only 3% of all individuals with disability who need rehabilitation receive any sort of care. (Helander:1999) Moreover, rehabilitative services tend to be concentrated in urban areas and are prohibitively expensive. Programs that require long-term care are unavailable to many. This is particularly true for young women in societies where females not allowed to travel or live away from home unescorted once they enter puberty. (ILO:1989) Globally women and children receive less than 20% of all rehabilitation services. (ESCAP:1995:10) Prosthetic devices, (artificial limbs, wheelchairs, hearing aids, eyeglasses, etc.) are often difficult and expensive to acquire, and a rapidly growing adolescent will need a replacement every year or two. (Werner:1987) The issue is not simply cosmetic. A poorly fitting artificial limb has profound psychological and social implications for an already marginalized 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. Community Based Rehabilitation efforts (CBR), while often offering significant interventions and programs, usually concentrates either on younger children or on adults, again missing the opportunity to reach out specifically to address the specific needs of young people with disability.

Decreased productivity for disabled young people is not attributable solely to lack of access to rehabilitative care and technologies. Lack of access to general medical care is also reported widely. (Altman:1999) In many cases, health care facilities are simply inaccessible - stairs block access for wheelchair users or there is a lack of Sign Language interpreters, making medical consultation virtually meaningless for deaf individuals. Additionally, health care workers often refuse to provide basic vaccinations or reproductive health information to disabled young people because it is felt that these people do not have the need for such information or do not have the right to utilize scarce resources. (Groce:2003) All of this has significant implications for potential productivity of individuals with disability and can lessen their ability to contribute to their communities.

An additional issue that is often overlooked, but a key concern to the health and well being of young people with disability is their increased risk of being victims of violence. Many young people are initially disabled as a result of violence, either through interpersonal violence within the household or community, or as a result of warfare, child soldiering, through landmines or other forms of civic strife. Once disabled, these individuals are at increased risk of being victims of physical and psychological abuse, domestic and sexual violence and rape. Again, few statistics are available, but what statistics do exist indicate that individuals with disability are at up to three times as likely to be the victims of domestic violence, violence in the community and rape as their non-disabled peers. (Sobsey:1991, 1996; Chenoweth:1996; Nosek et al:2001) These young people are at risk in the home and in the community. They also face a profound lack of legal protection. In many countries, police and prosecutors will not even take complaints from disabled individuals or will not allow them to give testimony in courts - which means that such violence can continue unchecked. Indeed, in both Developing and industrialized countries, there has been a growing number of accounts of disabled young
people being targeted by sexual predators specifically because they either cannot report the abuse or will not be believed when such abuse is reported. (Groce:2003)

Violence and sexual abuse is also of great concern for the significant number of young people who continue to be institutionalized in schools, hospitals and asylums. Some young people have been consigned to such institutions as young children, however, many are sent to institutions and asylums during adolescents by families who feel they have grown to big or are now too old, to be able too live at home. Reports of violence in such institutions, as well as a number of other significant human rights violations, are of particular concern. (Crossmaker:1991; MDRI:2002)

Programs for Young People with Disability

There are an increasing number of programs that address the specific needs of young people with disabilities organized by government agencies, private voluntary organizations, religious organizations and community groups. However, globally the number of such programs remains small. In an international survey on the status of disabled adolescents (UNICEF:1999) only 12% of all the disability experts and organizations contacted were able to identify specific programs that targeted disabled young people as a distinct group. Almost all the programs identified were very small, serving fewer than 100 young people in nations where millions are disabled. Such programs furthermore, are more likely to be urban based and only available to more affluent young people. These small programs can provide models, but have not yet been taken to scale or systematically evaluated.

Also in recent years, a number of disability organizations have begun to address the needs of young
people with disabilities as a distinct subgroup. Some, such as the World Blind Union have established a Committee on Youth to improve outreach. In several cases, organization have been formed to focus wholly on adolescents or young adults with disabilities. For example, in Russia, the new National Federation of Hard of Hearing Young People, is bringing together adolescents for mutual support and social interactions. In the United States, there is now a National Center on Youth with Disabilities in Minnesota. In several communities in both the United States and Canada, adolescents are paired with older adults with similar disabling conditions, who serve as mentors.

Because there is such a diversity of the types of programs for young people with disabilities worldwide, it is difficult to establish universal criteria for why certain programs are judged to be successful. However, programs identified as successful in the UNICEF study (1999) seem to share the following attributes: whether serving young people with disabilities separately from or alongside of their non-disabled peers, such programs encourage them to engage in activities that build the skills and confidence they will need to function effectively in society. These programs have well thought out outcomes, sufficient organization structure and funding for on-going support. They include an evaluative component to ensure that programs and services provided meet the actual needs of young people as well as their long-term goals. Finally, and of great importance, such programs were felt to be particularly effective when young people with disabilities themselves help design, oversee and evaluate them. Such programs also appear to be more successful when they help to foster leadership, advocacy and self-sufficiency skills in young people with disability through the mentorship of older disability advocates. (Crawford, et al 2002)

The need for more gender sensitive programs that ensure that the unique programmatic needs of girls and young women are considered and addressed, has also been reported. Russo (2003) notes that adolescent girls and young women are less likely to participate in programs than are their disabled male peers and are more likely to leave such programs if their specific needs are not meet. Of additional concern is the fact that in a number of countries and regions, the leadership of disability advocacy groups remains predominantly male. Where females are included, they are often assigned to oversee
and advocate in arenas traditionally defined as ‘female’ - for example, the welfare of disabled children or
of education. A similar pattern has been noted for individuals with disability who come from ethnic or
minority communities: they are often asked to oversee disability advocacy efforts or outreach programs
targeted to their particular ethnic or minority populations. Broader leadership and policy roles in
organizations are often denied these women and members of minority populations – no matter what their
specific individual interests and aspirations might be.

**Transitional Programs: School and Home to Work**

Where transitional programs do exist, research is needed to better assess their effectiveness. In many
industrialized nations, adolescents with disabilities remain in school until their late teens after which time,
they enter formal government sponsored transition programs that provide them with a number of
practical skills, job training, and in some cases, supported employment. Such programs are not without
problems. A study by the UN Office of Economic Cooperation and Development shows a consistent
lack of coordination within many national programs. It is not unusual to find that one government
department puts resources into programs that enable "disabled school leavers" to keep a job and live
independently, while another agency uses even more resources to award pensions providing that the
adolescent remain dependent and unemployed. (Gerry:1992)

While a body of research on various types of income maintenance schemes and reserved employment
programs can be found primarily from North America and western Europe, such programs are often
very closely tied to specific national social security programs and national health care systems. These
programs also reflect specific national ideologies about the rights of citizens and the responsibility of the
community as well as being the product of idiosyncratic historical factors. The support system available
to disabled youth in Sweden or Canada looks quite different from those in the United States or
Germany. While a number of valuable lessons and approaches can be gleaned from reviewing such
transitional mechanisms for use in Developing countries, it is also important to note that overall, such
systems have not eliminated the substantial differences that continue to exist in employment rates and
income levels between comparable groups of disabled and non-disabled young people. Of even greater significant, as Elwan notes “income maintenance schemes and even reserved employment schemes have limited applicability where there is no effective labor market.” (1999:11) Moreover, there remain many issues for these young people in transition, (family, home, social lives), about which relatively little is known.

Models for transition to the workplace have begun to appear in the Developing countries as well. (Crawford:2002) For example, the Barbados has had a successful small program for adolescent girls with disabilities, which teaches job skills. Recognizing that many adolescents with disabilities lack input from family and friends that helps them learn how to present themselves well in public, this program provides such training. (UNICEF:1999) In Cambodia for the past four years, the ILO with funding from the Japanese Ministry of Labor and human resources from Cambodia’s Ministry of Social Affair, Labor and Youth Rehabilitation (MOSALVY) have field-tested the Disability Resource Team concept. It assists young people with disabilities with training and support to enter mainstream vocational training programs and find a job or use their skills to start a business. So far, it has helped 180 people, 67% of whom completed the course and have been employed. (ILO:2003) The possibility of linking adolescents with disability through the internet to allow them to share experiences and resources, including those about transition to adulthood, has also received growing attention (Filgueiras, 2001) – although poverty and illiteracy will continue to pose formidable barriers to internet access for the majority of young people with disability. (2)

Programs that have provided solid grounding for disabled young people particularly as they enter the workplace, fall roughly into one of two categories – those programs that are separate from and exclusively for (or primarily directed towards) individuals with disability and those programs which are inclusive, allowing disabled young people to participate in programs alongside of, and as equals to their non-disabled peers. Ideally both types of programs should be made available to disabled young people in a community.
Disability Led Programs – Programs Run by People with Disability

Separate income producing programs have existed for many years, often in the form of sheltered workshops in both the developed and Developing world. In a sheltered workshop the initiative for the program and decision making for the program are generally not under control of individuals with disability. (They function as employees of the workshop). Increasingly, however disability-led cooperatives, using micro-credit models, have been successfully introduced. For example, small loans of capital have allowed women with disability to invest in small-scale income generating endeavors (e.g., a sewing machine or chickens that can produce eggs) which have resulted in real social and financial independence. Comparable cooperatives for young people with disabilities, and the inclusion of young people in on-going disability cooperatives, where they can be mentored by older disabled adults, are much needed. Such cooperatives, where young people with disability learn production and marketing skills in addition to earning extra money by selling their crafts and produce, hold particular promise (D'Aubin 1991; Brock:1999; Crawford:2002) Ideally, disability-led economic enterprises could have a mechanism in place to regularly bring in and train disabled younger people, thus allowing them both to assume a measure of economic independence and to receive guidance and mentoring from older, more experiences adults with disability.

Ideally, disability-led cooperatives could not only allow disabled young people to learn to produce and market items and services of immediate use (agricultural, services), but also to develop and market skills that will be needed in the coming decades, such as computer training. It should be noted that historically, many cooperatives have tended to be in areas such as needlework, handicraft, dressmaking and carpet weaving, skills that are time consuming, low paying and that offer little opportunity for advancement. Many of these skills are also oriented to the production of non-essential items or items that are for the tourist trade, the first markets to slump when economic times become hard. (Drieger:1991). Also, it must be noted that even in Developing countries, those intervention programs that do exist are much more likely to reach young people with disability in urban areas rather than in rural areas.
Inclusive Programs

Separate programs for disabled young people are not alone the answer. All too often, young people with disabilities are not included in broader international development programs; for example, village-wide, regional, and national programs that targeted to all young people in the general community. Given the prevalence of disability in the community, some 10% of any group of young people in any community should be young people with disability. If young people with disability are missing from a skills building initiative or local development project, then the question for whomever is organizing the program is: where are they?, why are they missing from a program designed to benefit the general population? Innovative examples are beginning to appear, such as the World Bank's recently initiated Velugu project which is intended to systematically integrate disabled people into the mainstream of rural poverty alleviation programs.

It has been suggested that the fundamental measure of inclusion cross-culturally is, 'does a disabled young person have the same rights to participate and to make decisions on their own behalf as do their non-disabled peers'. Answering this question offers a starting point for assessing economic and social inclusion in a broader cross-cultural framework.

Development of an Advocacy Base

While the past decade has seen a blossoming of disability-directed advocacy groups throughout much of the Developing world, in fact, only in a small percentage of these groups do young people with disability play a significant role. However, there are examples of such programs that already focus on the development of specific skills or provide unique experiences for young people with disability. For example, Mobility International USA, (MIUSA) brings disabled adolescents from around the world to leadership training programs at its home base in Eugene, Oregon; specifically targeting young disabled women for leadership training. (Crawford et al, 2002) The Japanese Society for Rehabilitation has an
international Fellows Program that identifies and brings to Japan a select group of disabled young people from Developing countries who have shown great promise as future leaders. Such leadership among disabled young people at the local, national and international level, must be fostered as part of overall advocacy, both to strengthen the present and to guarantee the future.

Of particular note are Centers for Independent Living, both in industrialized countries and increasingly in the Developing world, where in addition to broader advocacy issues, increasing attention has been paid to issues of mentoring young people by older individuals with disability. In countries where the norm is for young people to establish households independent of those of their parents, develop job skills, enter the workforce and establish social networks separate from those of their families, such centers have been instrumental in reaching out to many young people in transition. They provide young people with disability access to information, choices and supports that allow them new options and ideas. Most importantly, such Centers often put young people with disability in touch - (sometimes for the first time in their lives) with other disabled young people and with disabled adults, who can provide them with crucial support networks and mentoring relationships. Currently, such Centers tend to be poorly funded and urban based. How they can be better adapted to reach young people with disability in rural areas, those living within more traditional family and traditional community structures, still needs to be more systematically examined.

Conclusion

Millions of young people between the ages of 10 and 24 are disabled and few currently have lives or will have futures a rich as those of their non-disabled peers. These individuals' physical, intellectual or mental health impairments are not what will hold them back. At issue are common social, economic and cultural prejudices against disability that are particularly pronounced when viewed in conjunction with the widely held social discomfort with the needs of adolescents and young adults.

In too many countries, disability is seen as a transient state. The expectation that a child with a disability
will either recover or die does not fit the realities of those young people who will survive, often for decades to come. These young people will survive whether or not they receive an education, are provided medical and rehabilitative care or are included in the social, religious and economic life of their communities. Their existence and our own however, will be much richer if they are allowed to develop to their full potential.
Endnotes

1. Estimating the number of disabled young people can be complex, for two reasons. The first is that frequently, disabled young people are grouped together with children or adults, blocking attempts to estimate their numbers as a distinct group. The second, as noted in the text, is because definitions of disability vary widely. In some nations, only individuals with significant disabilities are identified; in others, even those with mild disabilities are included in surveys and census reports. As Suris and Blum (1993) suggest, in countries with higher standards of living, disability rates are likely to be higher because disability is more broadly defined. Indeed, they report a positive correlation between disability rates in adolescents and GNP. This seems to be because screening programs are more widely available, allowing identification of more adolescents with moderate and mild disabilities. (Newacheck 1994; Suris 1999) While high infant and child mortality rates in poorer countries can also contribute to this discrepancy, under-reporting of disability also cannot be ignored. Suris and Blum (1993) analyzing the United Nations International Statistics Database for 42 countries, report a wide disparity of rates: in the 10-14 year old group, rates ranging from 108 per 100,000 in Myanmar to 6726 per 100,000 in Canada. Among 15 to 19 year olds, similar rates occur, ranging from 142.6 per 100,000 in Myanmar to 5099.5 per 100,000 in Austria. There is sometimes a lack of consensus on what constitutes a disability even within countries. (United Nations:2002)

Calculations cited in the text are based upon the estimate that 1 in every 10 individuals lives with a disabling condition and that 80% of the world's disabled population lives in the Developing world. If these numbers are extrapolated to include the Developed countries as well, then the total number of individuals living with a disability between the ages of 10 and 24, is 180 million. This number has been rounded off in the introduction and the figure of 180 million disabled young people globally, with 150 million of these living in the Developing world, cited. It is underscored here again, that these calculations are based on only the roughest of figures. There is a need for far better demographic data on this population.

2. Attempts to link adolescents with disabilities together in cyberspace have grown exponentially since 1995. Organizations such as the World Deaf Congress, the American National Spinal Cord Injury Association and others have established web pages, chat groups and bulletin boards for children and adolescents. Some of these are sophisticated, others are still rudimentary. Many target specific subgroups, such as blind adolescents or deaf young adults. (Filgueiras:2001) Studies of these networks indicate that they provide a social support and resource network that allow adolescents with similar types of handicaps to compare experiences and help each other make the transition into the
adult world. The potential benefits of linking an adolescent in a remote village or isolated farmstead with others facing similar economic, health and social concerns, are great. Unfortunately, only a small number of adolescents with disability worldwide currently have access to the computer or have enough education to be able to use it effectively.

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