

DEVELOPMENTAL ARTICLES

**ADOLESCENTS AND YOUTH WITH DISABILITY :
ISSUES AND CHALLENGES**

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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 marginalised of all the world's young people. 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.

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 (1). They are among the poorest and most marginalised of all the world's young people.

This paper provides an overview of the prominent challenges currently faced by disabled young people. Adolescents and young adults are grouped together and discussed jointly because they share common characteristics: they are often bypassed both by the programmes and policies designed for disabled children and left out of advocacy initiatives and employment schemes targeted for adults with disability. Nor are their unique social, psychological, education and economic needs addressed by programmes designed to reach their non-disabled age-mates.

Of all groups with disability, the groups about which we know the least are disabled adolescents and young adults. This category encompasses both individuals in the age range labelled 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. In transition between childhood and adulthood, these are the years when young people are expected to acquire skills, go through physical and psychological maturation and assume a social identity that will enable them to fully participate in their communities.

It is easier to list what is not known about disabled young people, than what is. With several notable exceptions, there has been virtually no research on disabled young people as a distinct group in developing countries 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 programmes. The call made by UNICEF in 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 (2).

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

DEMOGRAPHICS

World-wide, estimates of the number of adolescents and young adults who live with a disability vary widely. Estimating the number of disabled young people is 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 is that definitions of disability vary widely. In some nations, only individuals with significant disabilities are identified; in others, even those with mild disabilities are included. Issues of accuracy and reliability of statistics have been raised for individuals with intellectual disabilities and individuals with mental health concerns, as well as those with physical and sensory disabilities (3). Indeed Suris and Blum (4) note that the lack of homogeneity in definition, survey procedures and data collections “makes international comparisons almost impossible.” They report that disability rates are higher in wealthier countries. This seems to be because screening programmes are more available, allowing identification of more adolescents with moderate and mild disabilities (5). While high infant and child mortality rates in poorer countries may contribute to this discrepancy, under-reporting of disability also cannot be ignored. Suris and Blum (4) analysing the United Nations International Statistics Database for 42 countries, report wide disparity of rates. In the 10-14 year old

group, rates range from 108 per 100,000 in Myanmar to 6726 per 100,000 in Canada. Among 15 to 19 year olds, rates range 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. 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 recommendations are still several years away (6).

Here is what is currently known. By 2005, the UN estimates that there will be roughly 1 billion adolescents in the developing world (1). If one uses the UNICEF (1) and WHO estimates that one in every ten of these adolescents is disabled, then by 2005, the developing world will have 100 million 10-19 year olds. If a more conservative estimated rate of 5% is used, this still means 50 million disabled adolescents by 2005.

To this number must be added the number of disabled youth between the ages of 19 and 24. Again, specific global figures must be extrapolated on the basis of general population estimates. It is estimated that there are 500 million youth between the ages of 19 and 24 living in the developing world. Assuming 10% of this population is disabled, there would be 50 million individuals between the ages of 19-24.

Combining the statistics on adolescents and young adults from the developing world yields as many as 150 million young people who live with a significant disability. Using the lower calculation of only 5%, still yields a global population of 75 million young people.

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, assuming a 10% prevalence rate. Using the lower estimate of 5% yields 15 million individuals in developed nations.

The overall total globally for this age range, assuming a 10% prevalence, is 180 million, (assuming a 5% prevalence rate, the number still remains a very significant 90 million young people). Moreover, 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 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, who previously would not have survived childhood, to grow into adolescence. Young people are also at increased risk due to work-related injuries, risk-taking behaviour (including motor vehicle accidents, experimentation with drugs, and risk of violence). Many chronic disabling illnesses and mental health conditions appear only during adolescence.

The sensory, physical and mental health impairments associated with the HIV/AIDS virus will add millions of young people to the growing ranks of those who are disabled (7). Of equal concern, is the increased risk for young people with disability of becoming infected by the HIV/AIDS virus. 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 (8).

Nor are disabled young people evenly distributed within the general population. Experts generally agree that disability disproportionately affects the poor (9,10). 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 (1). However, such data may also reflect 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 young women with disability, open to question.

DISABILITY, STIGMA, GENDER AND MINORITY STATUS

Globally, it is widely acknowledged that the greatest impediment to the lives of young people with disabilities is prejudice, social isolation and discrimination (11). While all individuals with disability may be affected by this lifelong cycle of stigma and prejudice, females are at increased risk (12). 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 (13). Some discrimination may be subtle, for example, a poor family may wait a few days more to invest in an antibiotic for an ill daughter with a disability than they would for a son with a disability, hoping that the condition will clear on its own. A study by the International Labour Organisation in six Asian Pacific nations found that the incidence of disability was in fact higher for women than for men (14), making the higher survival rates for men with disabilities in the countries surveyed, more strikingly unequal (12).

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 programmes that 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 striking needs, adolescents with disability have historically fallen through the cracks. General programmes for adolescents and young adults rarely

include those with disabilities. Programmes for disabled populations where they do exist, are usually not more inclusive. Programmes 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 - programmes for disabled children or for adults with disability. Programmes and advocacy for disabled children usually focus on issues of family, education and socialisation. Programmes and advocacy for adults with disability are largely focused on issues of employment and to some degree, housing and community integration (15).

Adolescents and young adults are rarely excluded from these child-focused or adult-focused disability programmes. 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 (2). On the other hand, adult oriented disability organisations tend to concentrate on job training, often emphasising re-entry to the work place after an accident or injury. Such programmes are of little relevance to older adolescents or young adults who have never participated in the work place. The result is that in many countries, adolescents and youth with disabilities are alienated from those few disability support organisations that do exist.

Even within the United Nations, acknowledgement of or protection for adolescents with disability, is frequently overlooked. For example, in the United Nations General Assembly's Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (16), an opportunity for underscoring the needs of adolescents is missed when groups of individuals with disability 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 a safe and supportive environment, 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 work place. In many cultures however, the traditional approach is to acknowledge that they are no longer children, but to assume that they will never be accepted or able to function as adults. The problem of where they should exist is often dealt with poorly, if at all.

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" (17). 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 (18) discussing the transition to adulthood of young people with disability in Iceland describes this as “eternal youth” - a limbo in which these young people are not expected to reach adulthood, but remain enmeshed in segregated services. Where no services exist, such young people usually 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 often have little or no say over even the most basic aspects of their lives. This limits a disabled young person’s ability to establish a sense of autonomy or gain experience in making independent decisions. Elsewhere, rapid moves towards modernisation have led to the expectation that young non-disabled adults will eventually 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. 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

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 is. 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 cannot learn, that such children should not be put through the stress of learning or that such children are an embarrassment (evidence of bad blood, incest or divine disfavour) and should not regularly be seen in public. School buildings are routinely built with stairs, or far from community centres, 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 that their families and societies may not perceive that they need an education (2) This general lack of access to education is cumulative and by the time children with a disability reach early adolescence, the vast majority find themselves far behind the educational and skill levels of their non-disabled peers.

Gender further compounds inequities in education. As Russo (19) notes, cultural bias against women in general and reduced expectations for disabled females in particular, further limit

what funds families and schools are willing to spend on academic and vocational training. Compounding this, 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 these children will be better able to support their disabled sibling in adulthood. The option of educating the child with a disability to ensure he or she will 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, in a study in rural Pakistan (20), 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 may be of 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. However, most of these efforts have been directed towards younger children, not disabled adolescents. In fact, by the time they reach adolescence, the vast majority of young people with disabilities world-wide are no longer in school.

The social isolation, poverty and discrimination faced by children with disabilities also sets up an interconnected pattern of problems (21). Many children with disabilities 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 (2).

There are some exceptions. In developed nations there exist extensive educational systems for most children with disabilities through late adolescence. Some nations integrate these adolescents into general classrooms. Others provide specialised classes and training in social and job skills to help in the transition to adulthood. These programmes have varying degrees of success. An extensive body of research has documented this process of transition in some detail, although there is still relatively little information on the effects of this process on the social integration of the individual, and its implications for the family unit. Comparable data from the developing world are 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 (22).

Students with disability are often formally restricted in what course of study they are allowed to pursue. In a recent study from Ireland, Shevlin et al (23) report that disabled high school students are not allowed to enrol in the full range of academic courses. 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 has immediate relevance to disabled young people. 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 problem of growing global youth unemployment as "stark" (24). Young people world-wide 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 (25). For some, specific physical or intellectual impairments may further limit their job options. For most, social prejudice makes employers hesitant to hire them.

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 youth with disability will be the higher than for all other young people. Rates of unemployment among adults with disability vary from country to country, but on average, tend to be about 40-60% higher than for the non-disabled population (9). This is true even in developed countries with sophisticated school-to-work programmes and reserved employment schemes (9, 26). Overall, the ILO estimates that the unemployment rate among people with disabilities in the developing world is an overwhelming problem - up to 80% in some countries (27). 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, (which itself is double that of their non-disabled male peers). Disabled young people from ethnic and minority communities

also routinely have unemployment rates that are significantly higher than those of their non-minority disabled peers. For all these reasons, young people with disabilities are more likely to be unemployed, underemployed (working fewer hours, working at seasonal jobs) or 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.

Not only is their employment status in a continual state of flux, but young people with disability are also more likely to be hired for jobs that require little training and have few opportunities for advancement. Even when well educated, they take longer to find a position, have less job security and less prospect of advancement than do their non-disabled peers with comparable levels of education. This is true even for individuals with disability who have received a college education, and particularly true for college educated women with disability (28, 29).

Citing employment figures however, may be misleading. Presumably, only those whose disabilities are too severe or whose families are wealthy, do not contribute in some way. Most young people with disabilities world-wide do 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 (2).

For the non-disabled young adult, assuming an increasing number of chores within the family unit is often 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 justify the costs of their food and housing. Such work, even when it is 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.

Again, much more research is needed on young people living in these types of household arrangements. It is known that millions of adolescents and young adults with disabilities are 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

The period between 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' such as joining a sports team, courting, learning to drive the family vehicle. 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 (2).

A major issue in the lives of all non-disabled young people is the growing physical maturation and changing social role that prepares them for marriage and children. Yet 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. 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 certain types of disability are unable to legally obtain a marriage license. This is particularly true for disabled young women (12). Without the prospect of marriage, in many societies, these young people cannot hope to be accepted as full adult members of their communities.

This does not mean that young men and women with disability are not involved in relationships, or do not engage in sexual activities, only that there is often no social acknowledgement (and often no sex education) provided to them (15, 30). This places adolescent girls and young women with disabilities in particular, at increased risk for pregnancy, as well as sexually transmitted diseases. In one of the few studies of its kind, the United States National Longitudinal Study (31) found that three to five years after completion of high school, females with disability were significantly more likely to be mothers than 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. The majority of these pregnancies occurred outside of marriage. Already struggling to earn a living, 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 (14, 32).

In those societies where men take more than one wife or routinely keep mistresses, a teenaged girl or young woman with a disability is more likely to become a second or third wives or a mistress within a larger household, than to be 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. Finally, not only do expectations for what is an appropriate role for young men and women with disability vary from one country to the next, expectations often vary from one ethnic or minority community to the next. (33).

HEALTH AND MEDICAL ISSUES

Globally, social, economic and educational issues are far more pressing issues for many young people with disabilities than 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, social and economic discussions about disabled young people are side tracked by their presumed medical or rehabilitative needs (34). There are two areas of concern: unmet rehabilitative needs for some young people that may lessen their ability to fully participate in society; and lack of access to general health care and health promotion services that may lessen a young person's ability to maintain good health and productivity.

Rehabilitative services tend to be concentrated in urban areas and are prohibitively expensive. Programmes 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 (14). Globally women and children receive less than 20% of all rehabilitation services (12). 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. The issue is not simply cosmetic. A poorly fitting artificial limb has profound psychological and social implications for an already marginalised young person. A wheelchair that has become too small limits the ability of a young person to leave the house to attend school, work or establish any measure of autonomy. Community Based Rehabilitation (CBR) efforts, while offering significant benefits, too often concentrate either on younger children or on adults, again missing the opportunity to address the specific needs of young people with disability.

Lack of access to general medical care is also reported widely. 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 they do not need such information or should not utilise scarce resources (8).

An additional concern related 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 through violence, either through violence within the household or community, or as a result of warfare, child soldiering, landmines or other forms of civic strife. Once disabled, these individuals as well as all other disabled young people, are at increased risk of being victims of physical and psychological abuse, domestic violence and rape. Again, few statistics are available, but what exists, indicate that individuals with disability are three times as likely to be the victims of domestic violence, violence in the community and rape as their non-disabled peers (35, 36, 37). These young people also face a profound lack of legal protection. In many countries, police and prosecutors will not even take complaints from disabled individuals or allow them to give testimony in courts - which means that such violence can continue unchecked. Indeed, in both developing and industrialised 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 (8).

Violence and sexual abuse are also of great concern for the significant number of young people who continue to be institutionalised in schools, hospitals and asylums. Some young people have been consigned to such institutions as young children; however, many are institutionalised during adolescence by families who feel their disabled child has grown too big or too old to be able to live at home. Reports of violence in such institutions, as well as other significant human rights violations, are of particular concern (38, 39).

PROGRAMMES FOR YOUNG PEOPLE WITH DISABILITY

There are an increasing number of programmes that address the specific needs of young people with disabilities, organised by government agencies, private voluntary organisations, religious organisations and community groups. However, globally the number of such programmes remains small. In an international survey on the status of disabled adolescents (2), only 12% of all experts and organisations surveyed were able to identify programmes that targeted disabled young people as a distinct group. Almost all the programmes identified were very small, serving fewer than 100 young people in nations where millions are disabled. Such programmes furthermore, are more likely to be urban based and only available to more affluent young people. These small programmes can provide models, but have not yet been scaled up or systematically evaluated.

In recent years, some disability organisations have begun to address the needs of young people with disabilities as a distinct subgroup. For example, the World Blind Union has established a Committee on Youth to improve outreach. In several cases, organisations 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 Centre on Youth with Disabilities in Minnesota.

With such a diversity of programmes for young people with disabilities, it is difficult to establish universal criteria for why certain programmes are judged to be successful. However, programmes identified as successful in the UNICEF study (2), seem to share a common attribute. Whether serving young people with disabilities separately from or alongside of their non-disabled peers, such programmes encourage them to engage in activities that build the skills and confidence they will need to function effectively in society. These programmes have well thought out outcomes, sufficient organisation structure and funding for on-going support. They include an evaluative component to ensure that programmes and services provided meet the actual needs of young people as well as their long-term goals. Finally, such programmes were felt to be particularly effective when young people with disabilities themselves help design, oversee and evaluate them. Such programmes 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 (32).

The need for more gender sensitive programmes that ensure that the specific needs of girls and young women are addressed, has also been reported. Russo (19) notes that adolescent girls and young women are less likely to participate in programmes than their disabled male peers and are more likely to leave such programmes if their specific needs are not met. 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 education. A similar pattern has been noted for individuals with disability who come from ethnic or minority communities: they are often asked to concentrate on disability advocacy efforts or outreach programmes targeted to their particular ethnic or minority populations. While such advocacy initiatives are often very important, broader leadership and policy roles in organisations are often denied to women and members of minority populations - no matter what their own interests and aspirations might be.

TRANSITIONAL PROGRAMMES: SCHOOL TO WORK

Where transitional programmes exist, research is needed to better assess their effectiveness. In many industrialised nations, adolescents with disabilities remain in school until their late teens after which, they enter formal government sponsored transition programmes. Such programmes are not without problems. A study by the UN Office of Economic Co-operation and Development shows a consistent lack of co-ordination within many national programmes (40). It is not unusual to find that one government department puts resources into programmes

that enable “disabled school leavers” to keep a job and live independently, while another agency uses even more resources to award pensions provided the adolescent remains dependent and unemployed (41).

While research on various types of income maintenance schemes and reserved employment programmes can be found primarily from North America and western Europe, such programmes are often very closely tied to specific national social security programmes and health care systems. These programmes reflect specific national ideologies about the rights of citizens and the responsibility of the community. They are also a 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 developing countries can draw a number of valuable lessons by reviewing such transitional mechanisms, it is important to note that 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 significance, as Elwan notes, “income maintenance schemes and even reserved employment schemes have limited applicability where there is no effective labour market” (9). 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 also begun to appear in developing countries (32). For example, the Barbados has had a successful small programme for adolescent girls with disabilities, to teach them job skills. Recognising that many adolescents with disabilities lack inputs from family and friends to help them learn how to present themselves well in public, this programme provides such training (2). In Cambodia, the ILO with funding from the Japanese Ministry of Labour, and human resources from Cambodia’s Ministry of Social Affairs, Labour and Youth Rehabilitation have field-tested the Disability Resource Team concept. The programme assists young people with disabilities with training and support to enter mainstream vocational training programmes, and helps them find a job or use their skills to start a business. So far, it has helped 180 people, 67% of whom are now employed (27). The possibility of linking adolescents with disability through the internet to allow them to share experiences and resources including those of transition to adulthood has also received growing attention since 1995 (42). Organisations 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. Many sites target specific subgroups, such as blind adolescents or deaf young adults. 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 health and social concerns are great. Unfortunately,

only a small number of adolescents with disability world-wide currently have access to the computer or have enough education to be able to use it effectively.

Programmes that provide a solid grounding for disabled young people, particularly as they enter the workplace, fall roughly into one of two categories - those that are separate from and primarily or exclusively for individuals with disability, and those that are inclusive, allowing disabled young people to participate alongside their non-disabled peers. Ideally both types of programmes should be available.

Separate income producing programmes have existed for years, often in the form of sheltered workshops in both the developed and developing world. In a sheltered workshop the initiative for the programme and decision making for the programme are generally not under the control of individuals with disability, who function as workshop employees. Increasingly however, disability-led co-operatives, 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 endeavours (e.g., a sewing machine or chickens) which have resulted in real social and financial independence. Comparable co-operatives for young people with disabilities, and the inclusion of young people in on-going disability co-operatives, where they can be mentored by adults with disability, are much needed. Such co-operatives, 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 (10, 32). Ideally, disability-led economic enterprises could have a mechanism in place to regularly bring in and train disabled adolescents and youth, thus allowing them both to assume a measure of economic independence and to receive guidance and mentoring from older, more experienced adults with disability.

Historically, many co-operatives have concentrated on areas such as handicraft, dressmaking and carpet weaving, skills that are time consuming, low paying and offer little opportunity for advancement. Many of these skills are also oriented to the production of non-essential items or items for the tourist trade, the first markets to slump when economic times become hard (43). However, such co-operatives could also allow disabled young people to develop and market skills that will be needed in the coming decades, such as computer training.

INCLUSIVE PROGRAMMES

Separate programmes for disabled young people are not the only answer. All too often, young people with disabilities are not included in broader village-wide, regional, and national development schemes targeted to all young people in the general community. Given the prevalence of disability, some 10% of any group of young people receiving skills or job training should be young people with disability. If these young people with disability are missing from a skills building initiative or local development project, then the question for

whomever is organising the programme is: where are they and why are they missing from a programme 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 programmes, but more is needed.

DEVELOPMENT OF AN ADVOCACY BASE

While the past decade has seen a blossoming of disability-directed advocacy groups worldwide, in fact, only in a small percentage of these groups do young people with disability play a significant role. However, there are some examples of programmes 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 programmes at its home base in Eugene, Oregon; specifically targeting young women with disability for leadership training (32). The Japanese Society for Rehabilitation of Persons with Disability has an international Fellows Programme 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 levels, must be fostered as part of overall advocacy, both to strengthen the present and to guarantee the future.

Of particular note are Centres for Independent Living, both in industrialised countries and increasingly in developing nations. In countries where the norm is for young people to establish independent households, develop job skills, enter the workforce and establish social networks separate from those of their families, such centres have been instrumental in reaching out to 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 centres often put young people with disability in touch - sometimes for the first time - with other disabled young people and adults with disability who can provide them with crucial support networks and mentoring relationships. Currently, such centres 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 only a small percentage of these currently have lives or will have futures as 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 youth.

While specific policy, programmes and initiatives for disabled young people will vary from one culture to the next and the expectations of young people in general must be assessed in light of social and cultural expectations, the basic question of whether young people with disability have the same right to education, employment, social participation and self-determination as their non-disabled peers, offers a starting point for assessing the economic and social inclusion of adolescents and young adults in a broader cross-cultural framework.

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 the well-being of society as a whole however, will be much richer if these young people are allowed to develop to their full potential. Young people with a disability will continue to be seen as a problem only so long as their potential goes unrecognised.

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