

An Overview of Young People Living with Disabilities:

Their needs and their rights

Inter-Divisional Working Group on Young People
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Preface

UNICEF Programme Division is pleased to present this working paper summarizing the results of a study undertaken collaboratively by Yale University and the Child Protection and Health Sections of the Programme Division of UNICEF.

It focuses the social and economic issues that young people with disability face and serves as advocacy material in the promotion of behavioural change in communities. It also highlights results based on innovative programme approaches targeting adolescents and youth with disabilities.

Our goal is to ascertain the current status of adolescents and youth with physical, psychological and intellectual disabilities around the globe, with particular attention to their status in light of the United Nations Convention on the Rights of the Child.

We look forward to receiving suggestions and ideas on how to improve this paper to further contribute to the well-being of youth with disabilities.

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Over 200 organizations and advocacy groups representing disabled people as well as colleagues and adolescents with disabilities in 40 countries were asked to respond to a survey on current social, educational and recreational opportunities available to adolescents and youth with disabilities. In addition, medical, religious and social organizations were asked to provide information on programmes that include adolescents and youth with disabilities. We are indebted to all the organizations and individuals who took the time to respond to our questions.

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Executive Summary

Adolescents and youth with disabilities are among the neediest of all the world's children. Young people with disabilities face social isolations, poverty and discrimination. Despite the rights guaranteed to them by the United Nations Convention on the Rights of the Child and other documents, they are often prohibited from meaningfully participating in their families and communities. They often lack basic health care and are not allowed to attend school or to find work. Compared to their non-disabled peers, they are at greatly increased risk of physical and psychological abuse and sexual exploitation. In many countries, they are routinely institutionalized and are often the recipients of unnecessary and unwanted medical and surgical procedures, including forced sterilization. Young women with disabilities and young people with disabilities from ethnic and minority communities continuously face double discrimination based on both their disability and their gender or heritage.

Their plight is not only desperate, it is all too often overlooked. One in every ten young people lives with a significant disabling condition. Adolescent and youth organizations that advocate for young people in general rarely acknowledge the presence of young people with disabilities or understand that many of their needs are identical to those of their non-disabled peers. Organizations representing people with disabilities frequently group adolescents and youth together with younger children or with adults, leaving the unique social, psychological and physiological concerns of the adolescent and youth unaddressed.

In this paper, findings from the global UNICEF survey on Young People with Disabilities, are discussed. The global demographic, social and economic issues encountered by young people with disabilities are presented, and some of the innovative programmes and approaches that have successfully reached these most needy children, are highlighted.

The finding of this survey, however, reveals that much more needs to be done. Policies and programmes that address the specific needs of young people with disabilities are rare and usually small in scope. Even though small, these policies and programmes clearly demonstrate that ensuring the health, well-being and right to self-determination of young people with disabilities successfully enables them to become contributing members of society. It is concluded here that inclusion of young people with disabilities in all social, educational and health programmes benefit all members of a society. It is further argued that addressing the needs of this large and underserved population will be seen as a problem only so long as it is not seen as an opportunity.

Résumé analytique

Les adolescents et les jeunes qui souffrent d'incapacités sont parmi les enfants de la planète dont les besoins à satisfaire sont les plus grands. Les jeunes handicapés sont confrontés à l'isolement social, à la pauvreté et à la discrimination. Bien que la Convention relative aux droits de l'enfant et d'autres documents garantissent le respect de leurs droits, il leur est souvent interdit de participer de manière profitable à la vie familiale et communautaire. Les soins de santé de base leur sont souvent refusés quand on ne leur interdit pas d'aller à l'école et de trouver du travail. Par rapport à leurs compagnons non handicapés, ils courent davantage de risques d'être victimes de sévices sexuels, de violence psychologique et d'exploitation sexuelle. Dans de nombreux pays, ils sont placés en institutions et soumis à des interventions médicales et chirurgicales inutiles et non voulues, comme, par exemple, la stérilisation forcée. Les jeunes femmes souffrant d'incapacités et les jeunes handicapés appartenant à des groupes ethniques et minoritaires sont souvent victimes d'une discrimination liée non seulement à leur handicap, mais également à leur sexe ou à leur héritage culturel.

Leur situation est non seulement désespérée, mais souvent méconnue aussi. Un jeune sur 10 souffre d'une incapacité grave. Les organisations d'adolescents et de jeunes qui œuvrent en faveur de la jeunesse ne reconnaissent souvent pas l'existence des jeunes handicapés ou ne comprennent pas que leurs besoins sont pour la plupart identiques à ceux de leurs compagnons qui ne sont pas handicapés. Les organisations représentant les handicapés regroupent fréquemment les adolescents et les jeunes avec des enfants plus jeunes et des adultes, ne tenant ainsi aucun compte des problèmes sociaux, psychologiques et physiologiques uniques de cette tranche d'âge.

Ce document présente les conclusions d'une étude mondiale réalisée par l'UNICEF sur les jeunes handicapés. Les problèmes démographiques, sociaux et économiques auxquels ils sont confrontés partout dans le monde y sont décrits, ainsi que les programmes et méthodes novateurs qui ont permis d'aider avec succès ces enfants qui ont d'énormes besoins.

Cette étude révèle toutefois qu'il faudrait faire beaucoup plus. Les politiques et programmes qui répondent spécifiquement aux besoins des jeunes souffrant d'incapacités sont rares et généralement d'une portée limitée. Même lorsque ces politiques et programmes ne sont pas de grande envergure, la preuve est faite que la garantie de la santé, du bien-être et du droit des jeunes handicapés à l'autodétermination est importante puisque cela ouvre la voie qui leur permet de contribuer à la société. Il ressort de l'étude que tous les membres de la société bénéficient de la participation des jeunes handicapés à tous les programmes sociaux, éducatifs et sanitaires. En outre, l'étude fait valoir que la satisfaction des besoins de cette population importante et mal desservie ne sera considérée comme un problème que tant qu'elle ne sera pas perçue comme une possibilité d'avenir.

Resumen ejecutivo

Los adolescentes y los jóvenes con discapacidades se encuentran entre los niños con mayores necesidades de todo el mundo. Los jóvenes con discapacidades confrontan el aislamiento social, la pobreza y la discriminación. A pesar de los derechos que les garantizan la Convención sobre los Derechos del Niño de las Naciones Unidas y otros documentos, a estos niños se les impide a menudo una participación significativa en las actividades de sus familias y sus comunidades. Con frecuencia carecen de atención básica de la salud y no se les permite acudir a la escuela o buscar trabajo. Estos menores corren un peligro mayor que los niños sin discapacidades de que les maltraten física y psicológicamente, y de que les exploten sexualmente. En numerosos países se les interna habitualmente en instituciones y se les somete a operaciones médicas y quirúrgicas innecesarias y obligatorias, que incluyen la esterilización por la fuerza. Las jóvenes con discapacidades y los jóvenes con discapacidades que pertenecen a comunidades minoritarias y de una etnia diferente, se enfrentan constantemente a una discriminación doble, basada en su discapacidad y en su género o su herencia cultural.

Su difícil situación no sólo es desesperada, sino que a menudo se suele pasar por alto. Uno de cada 10 jóvenes padece una discapacidad importante. Las organizaciones de adolescentes y de jóvenes que defienden a la juventud en general reconocen en muy raras ocasiones la presencia de jóvenes con discapacidades y pocas veces comprenden que muchas de sus necesidades son idénticas a las de otros jóvenes sin discapacidades. Las organizaciones que representan a las personas con discapacidades agrupan a menudo a los adolescentes y los jóvenes con otros niños de menor edad o con adultos, sin atender a las cuestiones sociales, psicológicas y fisiológicas exclusivas de los adolescentes y los jóvenes.

En este documento se debaten los resultados de la encuesta mundial del UNICEF sobre Jóvenes con Discapacidades. También se describen los problemas demográficos, sociales y económicos que confrontan los jóvenes con discapacidades en todo el mundo, y se subrayan asimismo algunos de los programas y planteamientos innovadores que han beneficiado a estos niños necesitados.

Sin embargo, los resultados de esta encuesta revelan que todavía quedan muchas tareas por realizar. Las políticas y programas que abordan las necesidades específicas de los jóvenes con discapacidades son escasos y su ámbito suele ser reducido. Pero incluso a pesar de sus limitaciones, estas políticas y programas demuestran claramente que asegurar la salud, el bienestar y el derecho a la libre determinación de los jóvenes con discapacidades les permite convertirse en miembros activos de sus sociedades. La conclusión del documento es que la incorporación de los jóvenes con discapacidades a todos los programas sociales, educacionales y de salud, puede beneficiar al conjunto de la sociedad. Por tanto, se asegura que la satisfacción de las necesidades de esta amplia población, que hasta el momento ha recibido muy pocos servicios, seguirá siendo considerada como un problema solamente hasta que no se considere como una oportunidad.

Introduction

Adolescents and youth with disabilities are among the neediest and most overlooked of all the world's children.¹ Organizations of adolescent and youth that advocate for young people in general rarely acknowledge the presence of young people with disabilities or understand that many of their needs are identical to those of their non-disabled peers even as their rights are more likely to go unmet. Organizations that advocate on behalf of people with disabilities frequently group adolescents and youth together with younger children or with adults. In both cases, the unique social, psychological and physiological concerns of adolescents and youth with disabilities tend to go unaddressed.

For people with disabilities, the transition from childhood to adulthood is complex, in part because they are often seen as being 'childlike'. Children, particularly those with more visible disabilities, are frequently assumed to be in frail health and likely to die young. Indeed, in many countries, a child with a disability is referred to as a 'little angel'. Sending such children to school, including them in social interactions or preparing them for participation in the adult world seems unnecessary to many. Families of adolescents and youth with disability often anticipate their early deaths, but not their possible survival.

It should not be this way. The rights of adolescents and youth with disabilities are clearly included throughout the Convention on the Rights of the Child, especially in article 2 and article 23. Article 2 calls on States Parties to "respect and ensure the rights set forth in the Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status." Special attention to the needs of children, adolescents and youth with disabilities is discussed in article 23. These children are guaranteed:

- ❑ the right to a full and decent life, to ensure dignity, self-reliance and active participation in the community;
- ❑ the right to education, training and preparation for life skills and employment;
- ❑ access to health services;
- ❑ access to rehabilitation services and recreation; and
- ❑ the right to special care and assistance, appropriate to the child's condition.

All this should be done in conditions that ensure dignity, promote self-reliance and facilitate the child's active participation in the community in a manner conducive to allowing the child to achieve the fullest possible social integration, including his or her cultural and spiritual development. Lack of attention to the unique needs of adolescents and youth with disabilities is particularly unfortunate. Currently, few groups worldwide suffer as regularly from the denial of their basic human rights as adolescents and young people with disabilities.

Disability has always been part of the human condition. Many individuals are born with a disability, while others acquire a disability later in life due to a variety of factors, including infectious disease, inherited conditions or accidents, as a consequence of malnutrition, lack of adequate preventive health care, exposure to environmental pollutants or as a result of warfare or landmines.

It is estimated that between 300 to 500 million people worldwide, live with a significant disabling condition. Of these, according to the World Health Organization between 120 to 150 million are children, adolescents and youth. Not included in these numbers are the millions of additional children, adolescents and youth affected by chronic infectious diseases including HIV/AIDS, and girls who face significant impairments as a result of the practice of female genital mutilation.² One family in every four has an immediate family member with a disability.

Estimating the global numbers and distribution of adolescents and youth with disabilities is difficult. According to the United Nations, 80 per cent of all individuals with a disability live in developing countries, but their actual distribution is the subject of debate. In some nations, only the most severely disabled individuals are identified; in others, even those with mild disabilities are included in surveys and census reports. Estimated rates of adolescents with disabilities range from 108 per 100,000 in Myanmar to 6,726 per 100,000 in Canada. (Among 15- to 19-year-olds, similar ranges occur, from 142.6 per 100,000 in Myanmar to 5,099.5 per 100,000 in Austria).³

More affluent countries may report higher rates of disability both because of increased survival rates after a disability occurs and because census reports include individuals with mild or moderate disabling conditions who may not be listed as disabled in another context. For example, a young person with dyslexia may be considered disabled in Canada, where the majority of young people complete high school. On the contrary, in a country such as Mali, dyslexia may not even be identified due to lower literacy rates and the much smaller proportion of adolescents and youth who are in school.

Countries often report higher rates of disability for males than for females, with ratios ranging from almost equal, 1.1 boys for every girl in Cape Verde, China, Mexico and Pakistan, to slightly more than two boys for every girl in Egypt, to almost three boys for every girl in Venezuela. Reasons for this gender disparity may include higher rates of work-related injuries and greater risk-taking behaviour among males. In many regions, however, the cultural preference for boys appears to result in disabled males receiving better care. In Nepal, for example, the long-term survival rate for boys who have had polio is twice that for girls, despite the fact that males and females have an equal chance of being disabled by the disease.⁴ A young woman in India said:

After I got polio my mother refused to feed me, but I managed to keep myself alive by scavenging for food and stealing from my brothers. I never went to school but taught myself, with a neighbour's help, to read and write.

-Vandanah, a young woman from India

Violence as a cause of disability

Adolescents are at increased risk of being disabled by violence. Adolescents are frequently participants in or victims of wars, civil unrest, and tribal warfare. Both males and females are often forced to serve as child soldiers or drafted into armies and resistance movements. Violence against civilian populations, including landmine violence, is also of concern.

Additionally, many societies have high levels of social violence, with adolescent males and females joining in gang warfare and armed fights with guns, knives and other weapons. Adolescents are at increased risk of participating in various forms of interpersonal and domestic violence. In some nations, increased use of drugs and alcohol among adolescents, as well as poorly regulated or unregulated access to firearms, increases the likelihood that such conflicts will result in disability to the individual.

Moreover, children and adolescents living in societies affected by organised violence and violent households, are at significantly increased risk of severe psychosocial traumas or disturbances and physical disabilities. Adolescents once they become disabled, are often at increased risk for being victims of further violence in violent societies where they are unable to effectively protect themselves or be protected by others.

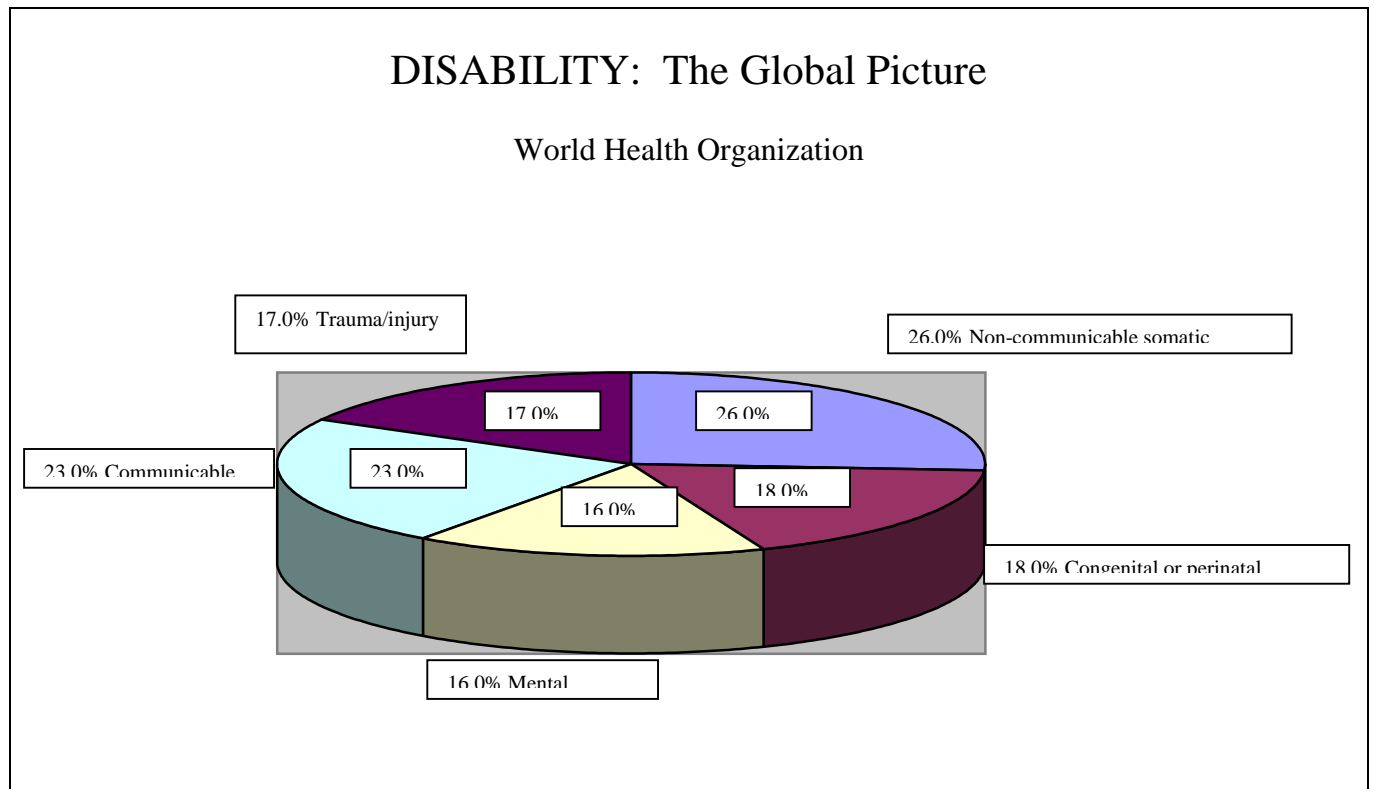


Table 1: Causes of disability and prevalence of people with moderate and severe disability in the world, estimates for 1990.

CAUSES OF DISABILITY	GLOBAL SUGGESTED RANGES OF ESTIMATES OF THE PREVALENCE OF MODERATELY & SEVERELY DISABLED PEOPLE (WORLD POPULATION 5,300 MILLION)
	MILLIONS
Congenital or perinatal disturbances	
Mental retardation	10 – 20
Somatic hereditary defects	10 – 25
Non-genetic disorders	15 – 20
Communicable diseases	
Poliomyelitis	5 – 10
Trachoma	8 – 10
Leprosy	3 - 4
Other communicable diseases	30 - 40
Non-communicable somatic disease	70 – 80
Functional psychiatric disturbances	15 – 20
Alcoholism and drug abuse	25 – 30
Trauma/Injury	
Traffic accidents	15 – 20
Occupational accidents	10 – 12
Home accidents	15 – 20
Other	7 – 10
Malnutrition	7 - 10
Other	2 - 3
ESTIMATED TOTAL	250 – 300

Sources: Einar Helander, Prejudice and Dignity – an introduction to community-based rehabilitation, UNDP, New York.

There also seems to be a consistently higher rate of disability among adolescents and youth in rural areas. Where census data distinguishes between rural and urban populations, the rural-to-urban ratio for adolescents and youth with disabilities ranges from a 1.3 to 1 rural-to-urban ratio in Pakistan to an almost 2 to 1 rural-to-urban ratio in Mali.⁵

Whether a lower or a higher estimate is used, it is clear that millions of adolescents and youth currently live with a physical, intellectual, sensory or psychological impairment significant enough to affect their daily lives. (It should also be noted that many have multiple disabilities.) Moreover, these numbers are growing. With half of the world's population under 15 years old, the number of adolescents and youth with disabilities can be expected to rise markedly over the next decade. This rise will not simply reflect an increasing birth rate. Adolescents and youth are at increased risk for acquiring a disability due to work-related injuries and risk-taking behaviour (including motor vehicle accidents, experimentation with drugs and unprotected sex.) Furthermore, many chronic disabling illnesses and mental health conditions first appear only during the second decade of life.

From a medical model to human rights

Disability has often been seen as a medical concern. Doctors, nurses and other health experts often are allowed to make decisions for those with disabilities and are given the right to control access to resources for them. While some individuals with disabilities do have health concerns, we have increasingly come to realize that the greatest problems faced by individuals with disabilities are social, economic and cultural - not medical - in nature.

Indeed, the World Health Organization now clearly states that one can be both disabled **and** healthy. There is no inherent reason why an individual's disability should keep him or her from attending school, finding a job, getting married, voting or participating in religious ceremonies or recreation and sports activities. What limits most individuals with disabilities from participating as fully as possible in the lives of their families, communities and societies are the limitations and stigmas placed upon them by others, not their specific physical, psychological or intellectual impairments.

Increasing numbers of individuals with disabilities around the world have come forward to organize and advocate on their own behalf. This social advocacy movement is known as the Disability Rights Movement. These individuals with disabilities have successfully reframed the issue of disability as a human rights issue, rather than a medical issue. In doing so, they have changed the nature of the discourse from an older 'charity' model, in which providing services to individuals with disabilities was considered an act of kindness, to a 'human rights' model, in which individuals with disabilities can now argue that they are entitled to the same rights, privileges and resources as all other members of society.

The world community agrees. The legal framework currently in place to protect human rights in general firmly affords protection to the rights of persons with disabilities. The framework includes the United Nations Charter together with the International Bill of Rights, comprising the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Right, the International Covenant on Civil and Political Rights and the Convention on the Elimination of All Forms of Discrimination against Women. In addition, the United Nations has adopted a series of declarations and resolutions aimed specifically at protecting the rights of persons with disabilities. The International Year of Disabled Persons in 1981 was followed by the United Nations Decade of Disabled Persons (1983 - 1992), which has prompted a series of national and international legislative initiatives to identify and articulate more firmly the rights of individuals with disabilities. Within the past few years, the Convention on the Rights of the Child, now ratified by 191 countries, and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities have firmly anchored disability issues into the broader human rights movement.⁶ Recently the United Nations General Assembly adopted Resolution 47/88, which asks the United Nations Development Programme to include an evaluation of the way a society treats its disabled citizens as one measure of the quality of life within that society as followed in the UNDP *Human Development Report*. The United Nations Human Rights Committee also requires assessment of how individuals with disabilities fare in countries, and the Committee on the Rights of the Child is considering similar monitoring efforts.

While the Disability Rights Movement around the world has grown and taken on increased relevance and power over the past 10 years, and significant strides have been made nationally and internationally on behalf of disabled children and adults, there is still one significant voice missing from the ongoing dialogue: the voice of young people with disabilities.

Current lack of attention

Despite their growing numbers and their striking needs, adolescents and youth with disabilities have historically fallen through the cracks. World-wide, programmes that are intended for young people rarely include those with disabilities. Programmes intended for people with disabilities are targeted towards small children or adults, overlooking the specific needs of adolescents and youth.

Young people are not always excluded from disability programmes. In government programmes, voluntary organizations, community-based rehabilitation initiatives and local social- service agencies from Brazil to Malaysia to Tunisia, adolescents and youth with disabilities are considered to be covered by programmes for children with disabilities. The needs of a disabled five-year-old, however, are usually strikingly different from those of a 14 or 18 year-old.

Perhaps because of this, in many countries those who run services report a marked decrease in participation by young people once they enter adolescence. In Nepal, for example, programmes for children with disabilities include all children from ages 5 to 15. However, by the age of 11 or 12, most children have stopped attending. Adult-oriented disability organizations often have little relevance to adolescents and youth. The result is that adolescents and youth with disabilities are often alienated from those few disability-support organizations that do exist and are unable to join those youth-oriented general organizations that reach many of their non-disabled peers. This isolation is of particular concern because social, education and economic needs are so great during this period of rapid physical and psychological development.

Needs

Like all young people, those with disabilities need to live in safe and supportive environments; they need education, health services and access to sports and recreation. They also need to develop skills that will enable them to find work and that will serve them well in the work-place.

It is important to emphasize the similarities between disabled young people and their able-bodied peers because in many nations the needs of young people with disabilities have been considered similar, if not identical, to those of adults with disabilities. As the leading issue to confront adults with disabilities is usually poverty and unemployment, it is not surprising that many programmes targeting adolescents and youth also identify job training as their main focus. Although poverty and unemployment are very serious concerns for many of the world's disabled adolescents and youth, a survey of indigenous youth with disabilities in Mexico has recently found that young people report a greater desire for education, psychosocial support and rehabilitation than for job training.⁷

In the following section, problems that affect adolescents and youth with disabilities will be discussed in greater detail. It is important to emphasize, however, that these issues are not separate from one another but rather form an interconnected whole. It should also be remembered that a general discussion can be misleading; the needs and social expectations of young adolescents (at age 11 or 12), may be markedly different than for older adolescents (at age 18 or 19.)

Disability and prejudice

By far the greatest problems reported globally by experts and by individuals with disabilities are prejudice, social isolation and discrimination in society. To improve the lives of those with disabilities, education for the non-disabled majority must be undertaken and legal guarantees established and enforced.

Some cultures are more tolerant than others of people with disabilities. A society's attitude towards disability is shaped in part by what people believe to be the cause of disability (for example, bad blood, divine displeasure or punishment for actions in a previous life.) Such beliefs are not always negative. For example, in northern Mexico the belief that God often gives children with a disability to couples who are able to show them special compassion and care influences the way the surrounding community responds to these children. How people expect individuals with disabilities to contribute to society also shapes the manner in which families and communities respond to children and youth with disabilities. Within every society, differences in socio-economic status, class, caste and educational level also significantly affect the quality of life for the individual.⁸ It should be noted that many societies have very different attitudes towards disability, and some disabilities may be looked on more favourably than others, even within the same community. (For example, some societies are accommodating to people who are blind, but look negatively on people who have a mental illness.) It is also important to remember that in some societies traditional attitudes towards disability may be more favourable and more inclusive than the widely accepted 'modern' attitudes that are commonly based on Western medical models.

For all these reasons it is important to look beyond sweeping generalizations, in order to understand what life is like for adolescents and youth with disabilities. For example, a mildly retarded 16-year-old girl from a well-to-do family might live comfortably in her family home, escorted around town by a trusted family servant to ensure her safety. A girl from an impoverished family in the same city with a comparable degree of mental retardation might find herself working on the streets as a sex worker or beggar by the age of 16.

Young people with disabilities are no longer children but often will never be accepted as adults. The problem of where they 'fit' in a society is often dealt with poorly, if at all. The fate of an adolescent with a cleft lip/cleft palate recently recounted by a researcher in eastern Ecuador is all too common. The girl, who was about 17, was long out of school, teased about her looks and made aware that she would never marry. With no present or future, the girl apparently committed suicide. The researcher, meeting the girl's mother soon afterwards, said she was sorry to hear about the daughter's death. The mother looked away and replied, "I never had a daughter."⁹

Medical and rehabilitative care

For most adolescents and youth with disabilities, social, economic and educational issues are far more pressing than are medical issues. However, the availability of rehabilitative care, prosthetic devices, age appropriate and culturally sensitive trauma care need to be singled out because of significant problems world-wide.

The most prominent unmet medical need identified for adolescents and youth with disabilities is the continuing lack of rehabilitation services. The United Nations estimates that of those world-wide who need rehabilitation, only 5 per cent receive any sort of care. Moreover, rehabilitative services tend to be concentrated in urban areas and are often very expensive. Programmes that require long-term residency are also often unavailable to girls in societies where females are not allowed to travel unescorted or live on their own.

Prosthetic devices (artificial limbs, wheelchairs, hearing aids, eyeglasses and so forth) are often difficult and expensive to acquire, and a growing young person would need frequent replacements. The issue is not simply cosmetic. A poorly fitting artificial limb has profound psychological and social implications for an already - marginalized adolescent. A wheelchair that has become too small limits the ability of a young person to leave the house to attend school, do chores or establish any measure of autonomy.

Developmentally appropriate physical and psychological support services are often unavailable. Unlike their non-disabled peers, adolescents and youth who receive medical care are often served in clinics alongside infants and pre-school children.

In industrialized countries, where long-term rehabilitative care is available, there is often a lack of comprehensive rehabilitative programmes that deal with the psychological as well as the physical issues faced by youth. Many adolescents and youth, particularly those with a newly acquired disability, may spend months or years in rehabilitative care. In most cases, this means either a children's hospital or a nursing home. Newly disabled young people who receive care in children's hospitals often recall their experiences as distressing because many issues of particular concern to them, such as plans for the future, sexuality and peer support, are never addressed.

Even greater concern has been expressed by many adolescents and youth who have had to come to terms with their newly acquired disability while in an adult rehabilitation programme or nursing home. A young woman from Canada with a permanent spinal cord injury recalled:

I spent months lying between elderly patients [who were suffering] from dementia and broken hips in a nursing home, hundreds of miles from family and friends. I knew nothing about being disabled at the time. I saw the rest of my life, the next 50 years, stretch before me, with me lying on my back at the end of a darkened geriatrics ward, with TV soap operas humming in the background. Not once in all the months I was at the facility did anyone ever talk to me about a future outside the home. I thought I would never see my friends again, never go back to school and never have a job or a boyfriend.

Few of us look forward to spending our last years in such a situation - imagine such a prospect for a 14-year-old.

In addition, adolescents and youth with disabilities are sometimes made to undergo medical procedures that they neither need nor want. Disabled Peoples International and other organizations report continuing accounts from Europe, the United States, Latin America, Austria and Japan of disabled girls being pressured into sterilization -and even full hysterectomies- in order to prevent unwanted pregnancies or 'inconvenience' to their caretakers through menstruation. Many of these countries still have legislation allowing sterilization of disabled adolescents and youth at the request of their parent or guardian, with no input required or even requested from the youth undergoing the procedure.¹⁰ Although fewer accounts exist from Asia and Sub-Saharan Africa, the practice is believed also to be widespread in these areas, particularly among children of wealthier parents who can afford to have the procedure done.

One more issue, generally classified as medical, is important to raise here. Around the world, hundreds of thousands of adolescents and youth live in institutions. Often, at the onset of puberty adolescents are sent to institutions for the mentally retarded, mentally ill or physically disabled. This is usually done because they have become too big to be attended to at home, because the family has expended as many resources as it feels it can on the child or because parents feel they must turn their attention to the non-disabled siblings. Adolescents and youth with mental illnesses are at particular risk of being institutionalized. In many countries, girls are more likely to be institutionalized than are boys with comparable disabilities because boys are valued more highly.

Once institutionalized, adolescents and youth with disabilities are at increased risk for physical and emotional neglect, social isolation and physical and sexual abuse (with the concurrent risk of pregnancy and sexually transmitted diseases, including HIV/AIDS.) To ensure compliance, many adolescents and youth in institutions are heavily sedated. Few have any legal right to appeal their family's decision to place them in an institution to begin with and even less ability or legal right to request that their cases be reviewed and they be allowed to leave. Furthermore, institutions in many countries have historically been built in remote areas, limiting the amount of contact patients are able to have with the outside world. Even if families of institutionalized adolescents and youth want to visit regularly, the remoteness of the facility often makes such contact impossible. It also frequently limits visits by professionals, advocates, government officials and others who are expected to oversee the conditions of the facility. Physical, psychological and sexual abuse is widely reported in such isolated institutional settings from Australia to Romania to Uruguay.

Social isolation

If adolescence is a period of transition that prepares young people for successful adulthood, for adolescents and youth with disabilities it is frequently a time of exclusion from many of the normal activities that build fundamental social, educational and economic skills. This exclusion is often formally sanctioned: young people with disabilities find themselves frequently barred from participating in formal cultural and religious ceremonies that help define an individual's changing status in the eyes of the community. They are also often left out of the less formal 'rites of passage' such as joining a sports team, dating or learning to drive the family car. This exclusion distinguishes young people with disabilities from all other groups of adolescents and youth in every society, and has a detrimental impact on many of these adolescents' sense of self-esteem and self-worth.

Education

World-wide, the vast majority of adolescents and youth with disabilities do not attend school. Many have never attend school or attended only once in a while, a fact reflected in UNESCO's estimate that the literacy rate for those with disabilities world-wide is only 3 per cent; the rate for girls and women with disabilities hovers closer to 1 per cent.¹¹

School buildings are routinely built with stairs, or far from community centres, making them inaccessible to many. In many countries, young people with disabilities are considered to be incapable of learning, no matter what their disability. Often a disabled student is considered a distraction to other students and simply sent home. Lack of access to schooling may reflect the belief that such young people cannot learn, that they should not be put through the stress of learning or that they are an embarrassment (evidence of bad blood, incest or divine disfavour) and should not be seen regularly in public. Poor parents often give priority to non-disabled children over their disabled siblings when money for school fees and uniforms is tight. Perhaps the primary reason why young people with disabilities are so often not in school, however, is because there is little perception by their families or their societies that they will need an education. This lack of education for young people with disabilities is found around the world. Even where educational systems exist, the services and attention provided for those with disabilities rarely allows them to obtain education equivalent to those of their non-disabled peers; for example, the average reading level for deaf Americans is third grade.

However, some adolescents and youth may also be in classrooms without being specifically identified as disabled. For example, in the rural North-West Frontier Province of Pakistan, 22 per cent of all those of school age with disabilities were in school, although officially there were no special education classes. This process has been termed "casual integration," and similar findings have been reported for Sri Lanka and elsewhere.¹²

In some regions, such as Western Europe, North America and Australia, extensive educational systems are in place for most individuals with disabilities, from early childhood to late adolescence. Some nations integrate these students into general classrooms. Others provide specialized classes and offer sophisticated training in social and job skills to help in their transition to adulthood. These programmes have varying degrees of success, but at their best, have much to offer.

Employment

Schooling for most of the world's young people ends by mid-adolescence, after which most boys and many girls are expected to work outside the home. As the United Nations report states, "the aims of transition (into the workplace) are the same for all ... the needs of those with disabilities are not different in kind, only in degree."¹³

Adolescents and youth world-wide are at higher risk for unemployment, partial employment or full employment at lower wages than adult workers. Young people with disabilities are at even greater risk. Entering the job market with little education and few or no skills, they have difficulty competing with their non-disabled peers. Specific physical or intellectual impairments

may limit their job options and social prejudice may further limit the number of employers willing to hire them.

In the workplace, adolescents and youth with disabilities also find they have little margin for error. Unlike non-disabled young people, who often fail at a first job or apprenticeship, adolescents and youth 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.

Citing employment figures however, may be misleading. Presumably, only those, whose disabilities are too severe or whose families are wealthy enough to provide for their needs do not contribute in some way. The vast majority of adolescents and youth with disabilities world-wide do in fact work, although usually they are officially listed as unemployed. Millions work outside the home, doing menial tasks or begging. 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. Many adolescents and youth with disabilities that work on the family farm or assemble piecework in the kitchen may have their work brought to the marketplace by others who receive the credit and collect the wages. While such work is often seen as a precursor to more independent, adult status for non-disabled youth, for those with disabilities identical work is frequently viewed as an end in itself or as a way of paying the family back for the trouble and expense of maintaining them. Their contributions, even when they are of great financial significance to the household, may go unnoticed by economists, local communities and even their own families.

Sexuality and marriage

A major issue in the lives of all adolescents is the growing physical maturation and changing social role that prepares them for marriage and families of their own. Social and family constraints make it unlikely that many young people with disabilities will marry. This is particularly true for girls. Without the prospect of marriage, in many societies these young people cannot hope to be accepted as full adult members of their communities.

Furthermore, when such adolescents and youth are viewed as 'childlike' or asexual, they usually receive little information about sex and sexuality in general and still less about specific concerns that are disability-related. This does not mean that they do not engage in sexual activities, only that there is no social acknowledgement or education provided them. This places girls with disabilities at increased risk for becoming pregnant and both girls and boys at increased risk for acquiring sexually transmitted diseases, including HIV/AIDS. Although there is a pressing need for further research on pregnancy and sexually transmitted diseases among adolescents and youth with disabilities, what does exist is cause for concern. For example, in the United States, the rate of AIDS within the deaf community is twice that of the general population.¹⁴

Avoiding pregnancy is not the only issue. The right of a young woman with a disability to choose to have and raise a child is often limited. In many countries, a young woman with a disability is not allowed to maintain a desired pregnancy, even if she is married. Young women with disabilities who do give birth often face the prospect of having their child given away for adoption, or taken away to be raised by relatives.

The failure to provide enough information on sexuality to young people with disabilities is very widespread. One young woman from the United States who uses a wheelchair recalled:

When I arrived at college my freshman year, I decided I wanted to set up a chatgroup of freshman women with disabilities. When we got together and began to compare notes, we realized that only one girl, who was disabled after puberty, knew any specific facts about sexual intercourse. No one - not our parents, our school teachers, not even our [able-bodied] friends - thought we would be interested in or need such information!

Lack of such basic information among educated young people with disabilities in a country as open about reproductive issues as the United States is particularly striking.

Youth with disability at risk

The social isolation, poverty and discrimination faced by adolescents and youth with disabilities means that many are at increased risk for physical, sexual and psychological abuse. In all countries, there is a pattern of interconnected problems. Many children with disabilities either do not attend school or leave school early. Millions of these young people end up on the street. Once on the street, these adolescents and youth are often soon involved in crime, sex work and drugs, frequently at the behest of others who see them as easy prey.

Adolescents and youth with mild disabilities might be at particular risk. For example, in India, where national programmes provide services to severely disabled individuals, adolescents and youth with less severe disabilities (hard of hearing rather than profoundly deaf, mildly retarded not severely retarded) have considerable difficulties. Because their disabilities often go undiagnosed, their limitations in school and social interactions frequently go unrecognized or are poorly understood. They tend to leave school early, have difficulty finding jobs and often wind up on the streets.¹⁵

Girls with disabilities suffer discrimination based on both gender and disability. Even compared to boys with disabilities, they are less likely to receive an education or job training or to marry. Compared to their non-disabled sisters, they are at increased risk of physical and sexual abuse. If they are from extremely poor families, they are also at increased risk of being forced into prostitution and once there, for acquiring additional disabling or deadly diseases, including syphilis, tuberculosis and AIDS. For example, recently there have been reports from Thailand of poor families selling their deaf adolescent daughters to owners of prostitution rings. These girls are valued because their difficulty in communicating with the hearing world means that they can be held as virtual slaves.

Studies show that for both male and female children, those with disabilities are three times more likely to be physically or sexually abused as their non-disabled peers. Family members, caretakers, attendants and others often see children, adolescents and youth with disabilities as easy victims, not only because they often experience difficulties in defending themselves or in reporting the abuse, but also because even when they are able to report the abuse, their accounts are often dismissed or not believed. Even where intervention programmes exist for physically and sexually abused adolescents and youth, such programmes are unlikely to reach individuals with disabilities.

Substance abuse

Adolescents and youth with disabilities are rarely considered when issues of substance abuse (illicit drugs, alcohol and tobacco) are discussed. Yet, in fact, young people with disabilities are at risk and may be at increased risk of using and abusing substances. Although few statistics exist, enough is known to make us concerned about the risks they face.

Certainly, many of the factors that increase pressure on any young person to drink, smoke and take illicit drugs are frequently found among youth with disabilities. Adolescents and youth with disabilities are likely to be socially isolated, lonely and depressed, and to have a great deal of free time on their hands. Often adolescents and youth with disabilities are anxious to 'fit in' with their peers and eager to establish a sense of independence. In addition, many already take medications for chronic pain or other medical conditions that potentially can be misused.

There may be serious medical complications as a consequence of alcohol, tobacco or illicit drug use among adolescents and youth with certain types of disabilities. For example, use of stimulants can cause sudden increases in blood pressure, while tobacco-smoking can intensify existing lung problems. Consumption of alcohol can cause someone with an already unsteady gait to fall or can leave someone immobile and passed out in a wheelchair for enough time to allow pressure sores to develop. Taking alcohol or other drugs on top of routine medications for disability-related problems can cause death.

Over and above the unique medical concerns of some adolescents and youth with disabilities, the use of alcohol, tobacco and drugs by any young person with a disability involves all the well-known consequences of substance abuse. Substance abuse will make an adolescent or youth less likely to do well in school, on the job or in social interactions. It will increase the likelihood of accidental injury or death, and it may well damage one's long-term health and sense of well-being.

If adolescents and youth with disabilities share the risk of substance abuse found among youth overall, they are far less likely than their non-disabled peers to get help to overcome it. Family, friends, teachers, religious leaders and others often overlook prescription or illicit drug habits or alcohol problems that would immediately concern them in a non-disabled young person. Few health-care providers routinely ask about drug, tobacco or alcohol usage when they treat adolescents and youth with disabilities.

And as is the case with many other issues, young people with disabilities fall through cracks in the system when care is sought. Few organizations that address substance abuse problems for adolescents or youth in general include young people with disabilities in their outreach efforts or treatment facilities. Even efforts to teach young people about substance abuse routinely overlook adolescents and youth with disabilities in schools or in the community. For example, teenagers in high school special-education classes may be allowed to catch up on homework while their able-bodied peers attend an assembly on drug abuse. Some countries have placed most of their anti-drug campaigns on the radio - a format inaccessible to youth who have hearing impairments.

Those organizations that are specifically designed for adolescents and youth with disabilities rarely raise the issue of substance abuse. Moreover, disability-oriented organizations and

facilities almost never accept adolescents and youth with active substance abuse problems into their ongoing programmes.

Good practices, innovative programmes: Separate and Inclusive

There are an increasing number of programmes that address the specific needs of adolescents and youth with disabilities organized by government agencies, private voluntary organizations, religious associations, community groups and disability advocacy organizations. What makes many of these programmes noteworthy is that they emphasize the development of skills and abilities in adolescents and youth that will allow them a larger and more meaningful say in their own lives. Many also encourage adolescents and youth with disability to have a real voice in the programmes themselves. Most significantly, many of the following programmes help their participants establish a firm base upon which additional skills and experiences can be built. A successful programme is usually not an end in itself, but a vehicle which allows participants to gain new knowledge and self-confidences that will serve them well as they move into adulthood.

The number of such programmes world-wide however, remains limited. Many of the programmes that do exist are small or are only available to more affluent adolescents and youth. Such programmes fall into the two categories: separate programmes for those with disabilities and inclusive programmes where those with disabilities participate in activities designed for all adolescents and youth.

Separate programmes

In many industrialized nations, adolescents and youth with disabilities remain in school until their late teens, at which time they enter formal government-sponsored transition programmes that provide them with a number of practical skills, job training and, in some cases, supported employment. In some of these programmes, adolescents and youth are grouped together by diagnostic category (mental retardation, cerebral palsy) or by some other means (wheelchair user), while in others adolescents and youth with many types of disabilities are served.

Such programmes are not without problems. An Organisation of Economic Co-operation and Development study shows a consistent lack of co-ordination within many national programmes. For example, one government department may put resources into programmes that enable "disabled school leavers" to keep a job and live independently, while another agency uses resources to award pensions providing that the young person remain dependent and unemployed.¹⁶

There are also many programmes around the world that seek to foster growth and a sense of competency for adolescents and youth with disabilities. Many of these programmes are quite small, most are urban based and almost all are underfunded. Despite these limitations, many are very innovative. For example, Barbados has a small, successful programme that teaches social skills to adolescent girls with disabilities. Recognising that many young people with disabilities lack input from family and friends that helps them learn how to present themselves well in public, this programme provides such training. Initially, girls in the six-week course were taught how to dress, put on make-up and carry themselves in public. The course has proved so

successful that it now runs for three months and also teaches girls job skills and reproductive health issues.

A number of large, long-established disability organizations have recently begun to address the needs of adolescents and youth with disabilities as a distinct subgroup. Some, such as the World Blind Union, have established a committee on youth to improve outreach. Others have added programmes that are intended specifically for young people. For example, in South Africa, the popular Braille magazine *Blindaba* now carries some articles that specifically target adolescents.

In several cases, organizations have been formed to focus wholly on adolescents and youth with disabilities. In Russia, the new National Federation of Hard of Hearing Young People is bringing together adolescents and youth for mutual support and social interaction. In the United States, there is now a National Centre on Youth with Disabilities in Minnesota. In New York City, Oakland (California) and other communities around the United States, adolescents are paired with adults with similar disabling conditions, who serve as mentors.

Some programmes focus on the development of specific skills or provide unique experiences. For example, Mobility International and similar organizations offer adolescents and youth the opportunity to travel. The United States-based component of Mobility International (Mobility International, USA) has expanded its goal and now brings young people from around the world to leadership training programmes at its home base in Eugene, Oregon. In Seattle, Washington a new programme called Do-It encourages talented high school students with disabilities to consider a career in mathematics and science.

Special sports programmes have long been in existence; however, the number and diversity of these programmes has increased dramatically in recent years. For years, the Special Olympics has specifically targeted young people with mental retardation. Over the past decade new disability-oriented sports teams, leagues and international games from Australia to Peru have stressed increased levels of serious athletic accomplishment. These have drawn a particularly strong response from young people. Many of these recreational efforts are innovative. For example, a small group in the Côte d'Ivoire is promoting a new disability-adapted game called Handy-Foot.

Inclusive programmes

While separate programmes continue to thrive, there has also been a rise in the number of programmes for adolescents and youth with disabilities as part of the larger community. Some of these programmes are fully inclusive, meaning that those with disabilities participate in all activities; others are only partially inclusive, meaning that those with disabilities are allowed to participate in some, but not all activities. A number of international organizations such as the Boy and Girl Scouts and Guides now have an increasing number of such programmes.

Many religious youth organizations have also changed from making young people with disabilities the recipients of charitable acts to having able-bodied and disabled young people work together on issues that affect their communities.

Attempts to link young people 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, adolescents and youth. Some of these are sophisticated, others are still rudimentary. While many could benefit, the computer might prove particularly helpful for those young people whose communication or mobility problems make regular contact outside the home difficult. The potential benefits of linking young people in a remote village or isolated farmstead with others facing similar medical and social concerns are great. Unfortunately, only a small number of young people with disabilities world-wide currently have access to a computer or have enough education to use one effectively.

Evaluation

Because there is such a diversity of programmes for young people with disabilities world-wide, it is difficult to establish universal criteria for judging the success of certain programmes. However, successful programmes seem to share the following attributes:

- ❑ they all are consistent with the Convention on the Rights of the Child;
- ❑ they all help to build skills needed for the future. Whether serving young people with disabilities separate from or alongside 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;
- ❑ they are culturally sensitive. Programmes that violate or ignore social mores are not as effective as those that take sociocultural issues into consideration;
- ❑ they have well-thought-out outcomes, sufficient organization structure and funding for ongoing support;
- ❑ they include an evaluative component to ensure that programmes and services provided meet the current needs of adolescents and youth. Such programmes are effective when adolescents and youth with disabilities *themselves* help design, oversee and evaluate them.

Ensuring input from youth with disabilities in the planning of both inclusive and separate programmes is important. The International Save the Children Alliance recommends the following steps to create a successful programme:

- ❑ Develop supportive methods that enable young people with disabilities to express their views;
- ❑ Be aware of particular barriers to participation by disabled young people (for example, hold meetings in places that do not have stairs, make available sign language interpreters and have information that is accessible in Braille, tape or other appropriate formats);
- ❑ Avoid other barriers to dialogue with young people with disability, such as use of jargon or inaccessible language;
- ❑ Encourage self advocacy and peer advocacy (the representation of a young person's interest by himself or herself or by another disabled young person or by a designated adult, not necessarily a parent or caregiver);

- Train and prepare staff and non-disabled peers to ensure that they view individuals with disabilities as equals, not as objects of charity, or as people whose opinions can be dismissed or ignored.¹⁷

A good rule of thumb for anyone involved with a youth-oriented group is that 1 in every 10 young people lives with some type of disability. If you can look out over a room full of young people gathered for any programme, training session or social event, and less than 10 per cent have a disability (or if there is no one in the room with a disability), then your organisation is obviously missing a significant portion of the community's young people.

Programmes for disabled young people must display a great deal of cultural sensitivity or they will not last. For example, a programme for adolescent girls with mental retardation in Pakistan found that discussion of sex and sexuality was not approved by the girls' parents. Yet to keep themselves safe, these girls needed not only specific instruction but needed to have this instruction repeated a number of times so they retained it. Those leading the programme hit upon the idea of having it called 'Modesty Class', which gained parental approval, for modesty is a traditionally important attribute. Training the girls in modest behaviour, they were also able to impart appropriate information on sex, sexuality and sexual abuse in a culturally sensitive manner.¹⁸

Into the future

The issue of disabled children in general, and disabled young people in particular, is coming into its own. The recognition that children with disabilities are among the most marginalized and neediest of all the world's children prompted the Committee on the Rights of the Child to designate 6 October 1997 as a Thematic Day specifically devoted to hearing testimony on the Rights of Children with Disability. Almost all of the testimony during this historic session speaks directly to issues of adolescents and youth with disabilities.

Dr Nafsiah Mboi, Rapporteur for the Committee on the Rights of the Child, opened the session with a call to action:

In the best interests of the disabled child and to overcome discrimination, social isolation, denial and abuse of their rights, we will call for action by all on the social-cultural and economic fronts to promote throughout society new values and activities supportive and inclusive of disabled children.¹⁹

In addition to the organisations and advocacy groups that spoke to the Committee on Thematic Day, two youth with disabilities also shared their stories and their ideas.

How disability shapes a life and a family

I am Chantal Rex. I am a 17-year-old disabled youth representing South Africa. I was born with Spina Bifida, a condition in which the spinal cord does not fuse completely during foetal development, but is split, thus exposing part of the nerves, which become damaged during birth. As a child I needed many operations to enable me to use my limbs effectively. I have since birth required constant medical attention, and living in a rural area far away from good medical facilities made this very stressful for my parents to cope with. As a family we suffered tremendous financial difficulties as a result of

travelling to and from hospitals which were far away from home and also accommodating the rising medical bills.

At the age of 10, a decision was taken to move home from Willomore in the Eastern Cape to Cape Town, where I enrolled at a special school, which provided all the necessary facilities. I live with my parents and two younger sisters who are all very supportive. I am currently a standard nine pupil at Astra School for the Physically Disabled in Montana, Cape Town. I am actively involved in club athletics and have achieved numerous medals.

I do, however, feel that physically challenged pupils should be integrated with able-bodied pupils throughout their school career to break down the barriers and misunderstandings put in place by society's ignorance regarding disabled people.

*I would like to appeal to people throughout the world: **disabled people throughout the world are standing up for their rights. Please do not stand in our way of leading a better life. We demand the recognition we deserve. Don't pity us, become actively involved and support us!!!***

Breaking down barriers to participation

My name is Pearl Makutaone. I am a deaf youth from Soweto in Johannesburg. I became deaf at the age of two years. I am currently studying at a mainstream institution to become a beauty therapist.

Even though I am happy, I do still feel frustrated and isolated as my colleagues are all able-bodied and they cannot adequately communicate with me. Communication is done through writing and this is very time-consuming. It is time we get sign language interpreters in our society, in hospitals, clinics, libraries, etc.

Disability in South Africa as a whole is perceived with superstition, and disabled children are voiceless. Disabled children are not given the opportunity to participate and play like normal hearing children. They are prevented from participating in social events. Let disabled children come out and fight for their rights. They have the right to survival, protection and love.

Recommendations

At the end of testimony by youth, individuals, advocacy groups and national and international organisations working on issues of children and youth with disabilities, the following recommendations were made:

- In its examination of States Parties reports, the Committee should commit itself to highlighting the situation of disabled children and the need for concrete measures to ensure recognition of their rights including in particular the right to life and maximum survival and development, the right to social inclusion and to participation. The report emphasized that adequate monitoring of the situation of children with disability in all States must be undertaken and encouraged moves to promote the collection of statistics and other information to enable constructive comparisons between regions and States.

- There is a need for States to review and amend laws affecting children with disability that are not compatible with the principles and provisions of the Convention. In many States, the Committee found that these include:
 - legislation that denies children with disability an equal right to life, survival and development;
 - legislation that denies children with disabilities the right to education; and
 - legislation that requires children with disabilities to use separate institutions for care, treatment or education.

The Committee on the Rights of the Child strongly recommended that States actively challenge practices and attitudes that historically have denied children with disabilities equality (for example, infanticide and traditional practices, beliefs and attitudes prejudicial to health and development.)

The Committee also found that promotion of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities provided relevant standards for implementation of the Convention and strongly urged cooperation with the United Nations Special Rapporteur on Disabilities and with UNESCO, UNICEF other relevant agencies to ensure inclusive education. The rights and interests of disabled children should be included in the agenda of multilateral and bilateral agencies, development and donor agencies, and funding organizations such as the World Bank and regional banks as well as technical co-operation agencies.

The Committee recognized the importance of adequate research. Empirical evidence should be promoted with a view to:

- a. promote awareness of the extent to which the right to life of disabled children is denied;
- b. challenge the widespread existence of superstition, prejudice, social stigma and denial of access to education in relation to disabled children;
- c. challenge the argument of “cost effectiveness” used to marginalize disabled children and evaluate the costs of exclusion and lost opportunities.

Finally, the Committee firmly stated that the inclusion of children with disabilities is a right and not a privilege and that, like all other children, they have a right to participate in decisions that affect them. The Committee closed by noting that while marginalization and exclusion of children with disabilities is often defended on the grounds of cost-effectiveness, the losses incurred in human potential and productivity when children with disabilities are not educated or included in their societies far outweigh the expense of inclusion.

Based on the discussions begun during Thematic Day, the Committee recommended the organization of a working group on the rights of children with disabilities to ensure follow-up to the general discussion begun on 6 October. This working group has now been established. The potential for such a group to bring issues concerning children with disabilities to the fore and to keep attention on their needs and concerns is great. It is hoped that the specific concerns of adolescents youth with disabilities will figure prominently in this promising effort.

What should and must be done for adolescents and youth with disability needs to be addressed not only at the level of the state, but also at the level of the community. Around the world, community leaders, civic organizations, schools and training facilities, religious and secular youth groups, associations and clubs have begun to realize the benefit to all of including adolescents and youth with disability.

Much of this change is begun by a more open discussion about what disability means and what life for those with a disability is like. In some countries, the media has been instrumental in bringing a more realistic view of disability before the public. In others, a religious or political leader has taken a strong and principled stand on inclusion. In many more, those with disability and their families have been key in raising long unexamined issues and bringing them to public attention. Often the most effective change has come about when advocates, politicians, civil society, families and individuals with disability work together to reformulate community attitude and policy. As young people at the recent Workshop on Discrimination in Braga, Portugal have noted, governments and the United Nations agencies must hear the voice of young people and actively develop partnerships with young people's organizations. Moreover, substantial progress can be made if adolescents and youth are allowed to join in partnership with adults to address issues of significance in their lives. (22)

Ways in which such change can be brought about include:

- Inclusions of adolescents and youth with disability in the life of their families and of their communities. This participation must allow these young people as full and as equal a role as possible as their non-disabled peers in cultural, social, religious and recreational activities.
- Adolescents and youth with disability must have the right to education and training. This includes formal education, apprenticeships and opportunities to learn that will allow these young people to gain the knowledge and skills they will need to assume meaningful roles as adults in their communities. Often, this education must begin long before adolescence and young children with disability benefit from a strong, early foundation in the skills they will need within and beyond the classroom. For example, a child with hearing disability must be taught sign language early in life if she is to learn at the same rate as her hearing peers.
- Employment for adolescents and youth with disability is important. While poverty and unemployment or underemployment is a problem many adolescents and youth face, too often, the opportunities available to those with disability are particularly limited. Adolescents and youth with disability must no longer be denied work or restricted to a small group of jobs that are considered "appropriate" for those with disability. It is now clear that with proper support – including a solid education or a good apprenticeship, an established social network of friends and acquaintances, a supportive family and a welcoming community, many with disability can hold a wide variety of jobs and enter a number of career paths.

Furthermore, it is important to recognize not only the right of adolescents and youth with disability to find a job, but also for some, the right to fail and to try again. Many non-disabled adolescents and youth will try several jobs or career paths before finding

something that is right for them. Those with disability must have the same right to explore where their talents and interests lie.

- Adolescents and youth with disability must have equal access to all resources within a community, including equal access to good health care and where needed, adequate rehabilitative care and prosthetic devices. Efforts that promote health and prevent disease for all members of society must be made available to those with disability. Included in this are counselling and guidance in matters of sexuality and family planning, mental health services, HIV/AIDS, alcohol and drug prevention and treatment. Adolescents and youth with disability are often at increased risk for many of the significant risks to health and well being that adolescents and youth around the world face; they deserve services and interventions as much as do their non-disabled peers.
- Programmes, services and educational resources for those adolescents and youth with disability must be equally available to both girls and boys.
- Programmes, services and education resources for those adolescents and youth with disability must be equally available to members of all ethnic and minority populations within a country. Such programmes and services must be designed to reach those living in rural as well as in urban communities.

Finally, freedom from discrimination and prejudice must be ensured. Discrimination and prejudice towards those with disability comes in many forms. It can be obvious – teasing, turning an adolescent away from a celebration because they are ‘spoiling’ the fun for others, being physically violent or emotionally abusive. It can also be subtle – not allowing a youth with a disability to make decisions independently or to try something new. Prejudice can be shown by strangers, by neighbours, even by immediate family members. Elders can discriminate against young people with disability, but so can non-disabled adolescents and youth. Discrimination, prejudice and ignorance underline many of the problems discussed throughout this paper and unless they are addressed, many of the significant problems faced by those with disability can not be adequately addressed or permanently solved. The Workshop on Discrimination at Braga - Portugal, emphasized the importance of respect and valuing each other – it is a simple, but a fundamentally important place to start. (22)

Some conclusions

Although a growing number of programmes for adolescents and youth with disabilities exist world-wide, this group as a whole remains largely overlooked and underserved. Millions of youth between the ages of 10 and 24 are disabled, and few currently have lives or will have futures as rich as those of their non-disabled peers. These individuals’ physical, intellectual, sensory or psychological impairments are not, for the most part, what will hold them back. It is the common social, economic and cultural attitudes towards disability that will limit their choices.

Adolescents and youth with disabilities are placed at double disadvantage. Many non-disabled people are uncomfortable dealing with disability or allowing those with disability a say in deciding what their lives will be like. Many adults do not know how to deal with young people

in general. Young people with disabilities may encounter opposition by those who are uncomfortable with both their disability and their age group. Yet young women and men with disabilities must be allowed to play active parts in their own lives; they have the right to have a meaningful say in their future.

In too many countries, disability is seen as a transient state. The expectation that an individual with a disability will either recover or die, and hence is not worth investing in, does not fit the realities of those adolescents and youths with disabilities who will survive, often for decades to come. They 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. But their existence - and all of society's - will be much richer if they are allowed to develop to their full potential. Addressing their needs will only be seen as a problem so long as it is not seen as an opportunity.

End Notes

1. 'Adolescents' here are defined in accordance with the Convention on the Rights of the Child as all children between the ages of 10 and 18; the term 'youth', as used by the United Nations, covers individuals from age 15 to 24 and 'young people' covers ages 10 to 24.
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