

**EARLY CHILDHOOD DEVELOPMENT AND  
CHILDREN WITH DISABILITIES IN  
DEVELOPING COUNTRIES**

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# **Early Childhood Development and Children with Disabilities in Developing Countries**

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*One person in 20 has a disability. More than three out of four of these live in a developing country. An integrated approach is required, linking prevention and rehabilitation with empowerment strategies and changes in attitudes (Anonymous, 2002).*

## **Introduction**

The growth of early childhood development programs in countries around the world attest to the increasing recognition of the importance of promoting the physical, social, and psychological development of infants and young children at developmental risk due to the direct and indirect effects of poverty. Building on the experience and support of industrialized nations, comprehensive programs have been implemented in developing countries integrating healthcare, nutrition, and education have demonstrated positive impacts on childhood as well as fostering favorable outcomes for later development (Wegman, 1999; Young, 2002). A similar recognition of the need for early childhood development interventions for children with disabilities or developmental delays has emerged in recent years (Committee on Nervous System Disorders in Developing Countries, 2001). Factors contributing to this recognition include economic and social advances in developing countries, improvement in infant and child survival, and changing attitudes and knowledge about disability.

Although economic and social advances are often slow to occur in developing countries, the importance of acting on this recognition takes on particular significance in that these countries account for three-fourths of the individuals with disabilities in the world (Anonymous, 2002). In many developing countries, the declining rate of neonatal and postnatal mortality of children under 5 years of age in the last decade (UNICEF, 2000) has shifted the focus to look “beyond survival” to the prevention or reduction of disablement and the promotion of children’s health and development in the early years of life (Ebrahim, 1990). Universally, there is an increased awareness of the early years as a crucial period for promoting physical, mental, and psychological growth of children and preparing them for lives as productive adults (Zinkin and McConachie, 1995, UNICEF, 2001). It also constitutes a unique phase for capitalizing on developmental forces to prevent or minimize disabilities and potential secondary conditions.

This growing awareness of the need for early childhood intervention for young children with disabilities is reinforced by international declarations on children’s needs and rights and national advancement of legislation and programs to promote their physical and mental health and development. Although poverty is often a major factor associated with disability, early childhood development programs directed toward reducing the direct and indirect effects of

poverty are not likely to constitute a sufficient approach to the complexity of needs of young children with disabilities. Given the synergistic effects of poverty and chronic conditions or impairments, different levels of efforts will be needed to promote development and reduce or prevent disability as a function of the nature and severity of such conditions. To this end, differentiated efforts for infants and young children with disabilities can be productively approached within the framework of universal, selected, or indicated levels of prevention in order to effect a reduction of manifestations of delay or disability, their intensity and life-time impact (Simeonsson, 1994). In this framework, universal efforts are those designed to promote health and development and to prevent disability in all children at a certain stage in their development.

Selected efforts are targeted for children at increased risk based on a shared identity with a group, such as children living under slum conditions or children exposed to environmental hazards. The children do not have to be characterized by individual risk factors, however, as members of a group they have a higher probability of manifesting a disability than children not sharing the group characteristic. Indicated efforts are interventions designed for children manifesting disability or risk factors for disability. The goal of indicated prevention is to reduce the impact of the disability and prevent further complications. In the context of addressing disability in the developing world, universal, selected, and indicated levels of prevention also can provide a framework for prioritizing the focus and scope of efforts to address the problem of childhood disability from broad based initiatives directed at all children to services for children with severe physical, sensory, or cognitive impairments (Simeonsson, 1991; Simeonsson and McDevitt, 1999). This framework is used to describe model interventions and to summarize priorities and recommendations for early childhood intervention for children with disabilities.

The aim of this paper is to review and synthesize literature on the nature, distribution, and associated aspects of disability among young children in developing countries under eight years of age, examine existing services and practices to provide care and education for them and identify approaches with promise to address their developmental needs. Such a review and synthesis can assist social sector task managers of the World Bank in the identification and development of efforts on behalf of children with disabilities as well as provide information and suggestions for the Children and Youth Strategy. It also may serve as a resource for governmental and nongovernmental entities involved in the development of policies and implementation of services for children with disabilities and their families in developing countries. Finally, it may be of interest to foundations and funding organizations seeking to make investments in early childhood intervention programs in those countries.

To this end, the paper will define the rationale and context for early childhood intervention of children with delays and disabilities in developing countries. Issues in the provision of programs and services to meet their developmental needs will be examined through these additional questions: Who are young children with delays and disabilities and what is the scope of disability in developing countries? What defines the context of childhood delay and disability in developing countries? What programs and services currently exist to serve their

needs and may represent promising practices? What are the priorities and recommendations to address the needs of young children with delays and disabilities in developing countries?

Studies of disease and mortality among infants and young children in the developing world have been the focus of medical and social science literature for many decades. Literature on manifestations of morbidity in early childhood and associated social and economic factors of importance in preventing or reducing disability has been relatively limited and more recent in appearance. The scope of this literature review covers contributions from 1970 to the present and incorporates information from the periodical literature, earlier reviews, reports, and website repositories. Although an effort was made to insure the comprehensiveness of the review, it is not exhaustive of interventions, particularly those pertaining to health and nutrition. As little systematic research has been done on the effectiveness, cost, and impact of interventions for young children with disabilities, such coverage in this review is limited.

### **The Case for Early Childhood Intervention for Children with Disabilities in Developing Countries**

The case for early childhood intervention to promote development and prevent disability is supported by ethical principles as well as practical considerations. From an ethical standpoint, a fundamental responsibility of parents and caregivers in every society is to nurture its youngest for full membership in that society. From a practical standpoint, promoting the health and development of children with disabilities increases the likelihood that they will be prepared to participate as adults in the economic life of their communities. The rationale for early childhood intervention of children with disabilities builds on the same underpinnings as those that support the rationale for early childhood development initiatives in industrialized countries (Shonkoff and Phillips, 2000) and in developing countries (Balachander, Colletta, and Lyiang, 1996; Young, 2002). Issues of rights and equity form the framework for the health and nutrition of children in the developing world (Victora, Wagstaff, Schellenberg, Gwatkin, Claeson, and Habicht, 2003; Shrimpton, 2003). Those issues are equally applicable as principles to support the growth and development of young children (Myers, 1992; 1995) and to encourage the promotion of social and economic development of society in such a way as to include those with disabilities. However, for children with delays and disabilities, an expanded rationale includes goals of treating physical conditions, reducing the impact of impairments, preventing secondary problems, and supporting families with added physical and emotional demands in their caregiving roles. To this end, three key considerations form the basis for advancing early childhood intervention for children with disabilities in developing countries. Those considerations include the acknowledgement and formalization of the rights of children with disabilities; changing paradigms of development and disability; and evidence supporting the benefits of early intervention for young children with developmental delays or disabilities.

### *UN Convention on the Rights of the Child*

Children are vulnerable members of every society, and valuation of their personhood and recognition of their rights have been historically abridged in many countries around the world (Corker and Davis, 2000). Children with disabilities are likely to be the most vulnerable members of developing countries where their rights are most likely to be overlooked. In the past four decades, several documents have converged to make children with disabilities more visible and their rights made clearer. The United Nations Declaration of the Right of the Child was published in 1959, followed 30 years later with the United Nations Convention on the Rights of the Child. With reference to the 1989 Convention, Corker and Davis (2000) have stated that "...the 'globalisation' of children's rights through the medium of the United Nations Convention on the Rights of the Child ... has effectively transformed children's rights into international law" (p. 217). In their entirety, the 23 chapters of the Convention on the Rights of the Child define the rights of all children encompassing the rights to a name, a family, health care, education, and full membership in community life. Chapter 23 is devoted to defining the rights of children with disabilities. The first paragraph asserts that "...a mentally or physically disabled child should enjoy a full and decent life in conditions which ensure dignity, promotes self reliance and facilitates the child's active participation in the community." The second paragraph assigns countries the responsibility of recognizing the "...right of the disabled child to special care and shall encourage the extensions subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child." The United Nations Standard Rules for the Equalization of Opportunity (UN, 1994) has declared that education should be extended to young children with disabilities with particular reference to those in the preschool years. In addition to endorsing the rights advanced by these international documents, many developed countries have defined specific responsibilities to insure the rights of all children, including those with disabilities, to have access to fundamental societal supports.

### *Changing Paradigms of Development and Disability*

Recent decades have witnessed an improvement of life expectancy of persons with disabilities with an increase in the prevalence of disabilities (Ayyangar, 2002). It was not too many years ago that disability was viewed from a biomedical perspective as a static personal characteristic, attributed to adults and children. Societal response to disability was framed within a medical model of clinical diagnosis, treatment, and rehabilitation. Accompanying these demographic trends have been changes in the way in which disability is viewed from a medical perspective to a public health perspective and from a static condition of limitations to dynamic aspects of functioning.

Advancement of a public health perspective of disability with implications for prevention (Lollar and Crews, 2003) has been supported by population based studies of the distribution and impact of disability among adults and children. The Global Burden of Disease Study was conducted to identify the major causes of disease and disability and their contribution to the



burden they imposed on the populations of countries around the world (Murray and Lopez, 1997). To this end, a standard index, the Disability Adjusted Life Year (DALY), was used to make comparisons across countries. The DALY term has been criticized because of its negative connotation (Chaudhury, Menon-Sen, and Zinkin, 1995) and for technical inadequacies to document developmental disabilities in children (Institute of Medicine, 2001). The use of DALYs revealed that communicable and perinatal disorders among children accounted for three leading factors of global burden of disease and disability. Although DALYs are available for specific conditions or disease entities, they are not available for developmental disabilities more broadly defined. However, indicators associated with disability, such as malnutrition, provide a proxy perspective. In the Global Burden of Disease Study, comparative data across countries revealed that 15.9 percent of the world burden of disease and disability was attributable to childhood malnutrition (Murray and Lopez, 1997). This level of burden obtained in spite of the fact that for stunting as a consequence of malnutrition, an overall decrease in prevalence has been found over the last decade from 47 percent in 1980 to 33 percent in 2000 (deOnis, Frongillo, and Blossner, 2000). As deOnis and colleagues point out, this decrease has been uneven, with a decline in South East and South Central Asia, and South America, but an increase in Eastern Africa. A small positive change was found for the Caribbean and North Africa, whereas minimal change was observed in Western Africa and Central America. The significance of malnutrition as an indicator of compromised development is evident in its association with developmental disabilities. In a comprehensive study of 961 children in two age groups (0–2 years; 3–10 years), Oberhelman, Guerrero, Fernandez, Silio, Mercado, Comiskey, Ihenacho, and Mera (1998) concluded that malnutrition and parasitic infection were contributory factors for developmental disabilities. In this context, it is important to view malnutrition as a public health indicator requiring population based interventions (deOnis, et al., 2000) to reduce consequences for developmental delays or disabilities.

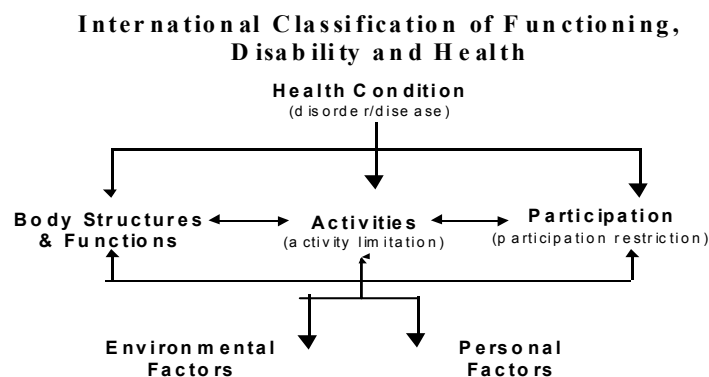
Within this perspective of population health and well being, there has been a shift away from viewing disability as a medical problem with a primary focus on treatment and rehabilitation of the individual. Instead, disability is viewed in the context of functional limitations characterizing a significant part of the population. This view shifts the focus from rehabilitation to a public health approach framed in terms of the reduction of risk factors and the removal of barriers to functioning. Reinforcing this population based perspective on disability have been complementary contributions to the concept of disability from developmental psychology and social science. Within a developmental outcome model, development and disability reflects the product of the child's transactions with the environment (Sameroff and Fiese, 2000), rather than as attributes located within the individual.

The social model of disability has in a related way emphasized the fact that disability resides not in the individual but in social constructions about limitations. Within this sociocultural perspective of disability, Groce (1999) has noted, "...that the lives of individuals with disability around the world are usually far more limited by prevailing social, cultural, and economic constraints than by specific physical, sensory, psychological, or intellectual impairments" (p.756). The population based and social conceptions of disability have sought to separate disability from underlying disease conditions, consistent with a framework that was

formalized two decades ago in the World Health Organization’s publication of the International Classification of Impairments, Disabilities, and Handicaps-ICIDH (WHO, 1980). A more explicit endorsement of a dynamic perception of disability is evident in the revision of the ICIDH in the form of the International Classification of Functioning, Disability, and Health-ICF (WHO, 2001). Building on a biopsychosocial model, the ICF advances disability within a public health approach recognizing that “...disability and health are not mutually exclusive terms, that is, disability does not necessarily equate to poor health” (Lollar and Crews, 2003, p.200).

In the ICF, disability is conceptualized as the product of the interaction of the person with a health condition with the environment, manifested in the dimensions of body functions, performance of activities, and participation. The ICF provides a framework for documenting the interaction of a person with a health condition with elements of the physical, social, and psychological environment (Environmental Factors). That interaction is defined by the components of Body Structures, Body Functions, and Activities/Participation (Figure 1).

*Figure 1 International Classification of Functioning, Disability, and Health (WHO, 2001)*



Each of the ICF components represents a different manifestation of disability defined in terms of the aspects of physical, personal, and social functioning affected. The Body Functions component provides coverage of “the physiological functions of body systems (including psychological functions)” (WHO, 2001, p.47). Problems in Body Functions and Body Structures are defined as impairments. The Body Functions component encompasses eight major body systems: Mental; Sensory; Voice/speech; Cardiovascular, Haematological, Immunological, and Respiratory; Digestive, Metabolic, and Endocrine; Genitourinary and Reproductive; Neuromusculoskeletal and Movement Related Functions; and Skin and Related Structures. The Body Structures component encompasses “anatomical parts of the body such as organs, limbs and their components” (p. 105), essentially mirroring Body Functions, providing codes for structures of the major body systems. In the Activities/Participation component, Activity is defined as “the execution of a task or action” and Participation as “involvement in a life situation” (p.123). Problems experienced in these areas are defined as activity limitations and participation restrictions. There are nine units in this component as follows: Learning and applying knowledge; General tasks and demands; Communication; Mobility; Self-care; Domestic skills; Interpersonal interactions and relationships; Major life areas; and Community,

social, and civic life. Environmental Factors are defined as “the physical, social, and attitudinal environment in which people live and conduct their lives” (p.171). This component provides for the coding of five dimensions of the environment: Products and technology; Natural environment; Support and relationships; Attitudes; and Services, systems, and policies.

As illustrated in the conceptual model and reflected in the taxonomical structure, the ICF presents disability as a universal characteristic of the human experience. Central to this framework is the premise that disability can be defined on the basis of function rather than etiology or medical diagnosis, classifying characteristics, not persons. This definition can thus provide documentation of the profile of functional needs of individuals as well as distribution in a population. A significant potential of the ICF is that it can provide a shared view of disability and a common language for assessment and intervention of children and adults with disabilities.

This is an important contribution in that comprehensive interventions for children with disabilities are not based on the premise of “curing” underlying impairments but on promoting health, functioning, and development. Within the framework of the ICF, the generation of a child’s profile of functional limitations can provide the basis for the development of individualized interventions. Such interventions recognize the child’s interaction with the environment as the unit for assessment and the design of programs of supports and treatments based on the child’s profile of functioning defined by Activities and Participation (Simeonsson, et al., 2003). Complementary use of the Environmental Factors codes can serve to document the manner in which needed access and accommodation are realized. This perspective emphasizes the importance of moving beyond a medically based model of clinical services to a broader approach of supports and accommodations needed by children to fully participate in their community as a developing member of the society (Groce, 1999).

### *Evidence Supporting the Benefits of Early Intervention for Children with Disabilities*

The importance of the early years for full development of a child’s potential has been a central message of theory, research, and policy and is reflected in the terms used to define the work of major child advocacy organizations. Thus, UNICEF and the World Bank use the term Early Childhood Development-ECD, UNESCO refers to Early Childhood Care and (Initial) Education-ECCE and the Organization for Economic Development defines its work with the term Early Childhood Education and Care-ECEC. Although these terms have described various initiatives encompassing an agenda for health promotion and development of young children in developing countries, they are consistent with the focus of early intervention programs for infants and young children with disabilities in the United States and Europe. As such, they can be extended readily to define initiatives to reduce or prevent disabilities and complications secondary to underlying impairments or chronic conditions of children. Contributions to a priority on interventions designed to promote development and reduce or prevent disability in early childhood come from changing paradigms of child development and disability. A major contribution has come from the field of child development, defined by the transactional model of developmental outcome (Sameroff and Chandler, 1975; Sameroff and Fiese, 2000). This model set aside assumptions about main effects of biological or environmental determinism with

recognition of developmental outcomes as products of ongoing interactions of the child with the environment. Further, the model has served as a pervasive rationale for early intervention initiatives in the last three decades. The contribution of the transactional model as a rationale for early intervention has been complemented by a changed paradigm of disability from static to dynamic. Representative of this shift is the paradigm of disablement as a process that can be exacerbated or minimized by environmental factors (Verbrugge and Jette, 1994).

For infants and young children, the first few years of life provide a unique opportunity to capitalize on developmental forces to significantly reduce, if not prevent, disablement through primary, secondary, and tertiary prevention (Simeonsson, 1991). Although the potential of early intervention to minimize disability has been recognized for many decades, formalization of programs to serve infants and young children with developmental problems in the United States has been a phenomenon of the last two decades following the passage of PL 99-457. A similar timetable has been followed in other industrialized countries (McConachie, Smyth, and Bax, 1997). The commitment to early childhood intervention in much of the developing world is of a very recent origin, and in many cases is only now being implemented (Odom, Hanson, Blackman, and Kaul, 2003).

Given the low prevalence of children with disabilities, significant variability in the nature and severity of their conditions, and the need to individualize interventions, studies documenting the benefits of early intervention for young children with delays and disabilities are limited. Further, as the provision of early intervention has been perceived as a right of the child and an ethical responsibility of society (McConachie, Smyth, and Bax, 1997), evaluation of its efficacy has not been seen as warranted. Evaluation studies have generally taken nonexperimental or quasi-experimental forms rather than experimental research designs, with random assignment and no treatment controls. The confounding role of development is a complicating factor as well, but available research studies provide qualified evidence that infants and young children with delays and disabilities do acquire skills and competencies and that parents value the services and support of early intervention (Guralnick, 1997). The qualification of the evidence pertains to the nature and severity of the child's condition, the nature and setting of the intervention (home based vs. center based), as well as the intensity of the intervention. Summarizing a review of studies in this regard, Blackman (2003) concluded that programs associated with favorable outcomes for children were those that involved parents in a substantive way and provided a broad based approach to intervention. An important consideration was that outcomes were more likely to be in the affective and social realm, a finding consistent with Zigler's (2000) admonition that evaluation of early intervention should move beyond cognitive indicators such as IQ to a greater focus on skills needed for functioning in society.

## Who Are Young Children with Delays and Disabilities in Developing Countries?

### *Methodological Issues*

In 1984, the World Health Organization declared that “No country needs to undertake censuses, surveys or registration to find out the needs of its disabled citizens. They are so well known that CBR (community-based rehabilitation) can go ahead without questions-marks. Every dollar spent on further investigation is a dollar miss-spent” (WHO, 1984; as cited by Zinkin, 1995). If this statement, issued two decades ago, was designed to emphasize that limited resources should be put into rehabilitation rather than documenting prevalence, its intent may be understood. However, its validity with reference to the prevalence of individuals with disabilities is certainly open to question at the present time, if not also at the time that it was written. An adequate epidemiology is needed for countries to define the scope of needs and prioritize prevention, intervention and rehabilitation efforts.

It is recognized that disability is more prevalent in developing than industrialized countries with the estimate that 85 percent of children with disabilities live in the developing world (Helander, 1993), with a disproportionate distribution among younger populations. The quality of those estimates, however, is limited by the lack of a substantive epidemiological database. Although children with severe disabilities may often be known to members of the community where they live, children with less severe forms of disability and those at risk for disability may be less likely to be recognized as having needs for intervention. The absence of prevalence data limits the ability of communities to define the extent of childhood disability in the population and in turn their responsibility to establish needed interventions and supports. Important challenges to the development of an epidemiology of disability have been issues related to the definition of disability and the level of disability at which screening should occur (Khan and McConachie, 1995).

Related concerns have been the method of identification of children with disabilities. The fact that some impairments in children may be associated with stigma or otherwise not constitute a concern for family members or caregivers may require surveillance methods different from those in developed countries. Reliance on informal community identification of children with disabilities is likely to yield substantial underestimates of prevalence in light of the fact that stigma attached to disability may keep families from letting others know of their child’s condition. Reliance on informal identification also is likely to miss children with less severe or hidden levels of disability. The insertion of items in censuses or surveys and the use of key informants in screening are found not to yield reliable estimates. The approach that appears to have been most productive in yielding estimates of childhood disability in developing countries is the household survey. Such surveys are conducted by persons trained to interview a family member, typically the mother, using simple questions related to functional characteristics of the child.

## *Prevalence of Childhood Disability in Developing Countries*

Methodological problems and limited financial and technical resources preclude comprehensive population based studies of disability in developing countries. There are studies that can contribute data pertaining to the nature and scope of disability, however, they are characterized by variable and inconsistent definitions of disability. Further, such studies need to include chronic conditions of stunting, wasting and parasitic infestation that may impair functioning and be disabling to children. Definitional issues are compounded for estimating the epidemiology of disability in children in that emerging manifestations of disability or indicators for the risk of disability are challenging to document in that some constitute “hidden handicaps” such as hearing impairment (Olysanya, 2001). This is true not only for documentation of disability as defined by impairments or limitations of cognitive, motor, or sensory functions, but also of manifestations of chronic conditions that are likely to significantly reduce an individuals ability to perform basic activities of daily living. A major chronic condition in this regard is epilepsy among persons in developing countries. Documentation of epilepsy and its socio-cultural context is complicated by limited and variable data. Management and medication practices are similarly likely to be limited with an earlier estimate that only 6 percent to 20 percent of individuals in developing countries are receiving anticonvulsant treatment (Shorvon and Farmer, 1988).

In the absence of a common conceptualization and definitions, the ICF may serve as a useful framework for examining the nature and scope of childhood disability in the available literature. Drawing on the dimensional framework, manifestations of childhood disability may be productively approached as impairments of body function or structure, activity limitations, or restrictions in participation. Further, recognizing that many health conditions contribute to, or are associated with, disability, it would be appropriate to include conditions such as epilepsy, malnutrition, and chronic infections. To that end, studies were included for review if they addressed one or more of the following questions derived from the ICF framework of health conditions, body function and structure, activities, and participation. Of course, in many cases studies did not restrict the focus to a specific domain by presented information on conditions overlapping one or more domains.

For the purpose of this review, studies were included if they examined a relevant dimension regarding some aspect of the child’s health and disability. Does the child have a health or medical condition associated with or contributing to disability? Are there significant impairments of how the body and mind function? Are there significant variations in the form or structure of a child’s body? Is the disability characterized by limitations in performing essential activities? Does the child experience restrictions in engagement in life roles? These five questions address the ICF components of Health Conditions, Body Functions, Body Structure, Activities, and Participation. Drawing on this approach, an overview of reviewed studies is summarized in Table 1.

*Table 1 Prevalence of Indicators of Disability Among Children in Developing Countries (Simeonsson, 2003)*

<b>Reference</b>	<b>Study design</b>	<b>Age of children</b>	<b>Condition(s)</b>	<b>Findings</b>	<b>Assignment to ICF domain(s)</b>
Ansari and Akhdar (1998)	Descriptive study of representative Saudi population	Children less than 15 years of age	Childhood disability	3.76/1,000 major impairment, 42.8/1,000 minor impairment	Activities
Biritwum RB, Devres JP, Ofosu-Amaah S, Marfo C, Essah ER (2001)	Cross-sectional survey, Central Region, Ghana (N=2556)	1–15 year olds	Various cognitive, physical, sensory disabilities	Overall 18.0/1,000; prevalence increased with age	Body Function
Tamrat, Kebede, Alemus, and Moore (2001)	Community based cross-sectional, Northern Ethiopia (N=4214)	5 years or older	Various disabilities, motoric, visual, and epilepsy	Overall 4.9%, walking 1.7%, vision in one or both eyes 1.5%, hand dysfunction 0.8%, and epilepsy 0.7%	Health Conditions Body Function
Christianson, Zwane, Manga, Rosen, Venter, and Kromberg (2000)	Two-phase design, interview and pediatric, neuro-developmental assessment South Africa N=(6692)	2–9 year olds	Epilepsy and associated developmental disability	Prevalence for lifetime, 7.3/1,000 and 6.7/1,000 for active prevalence of epilepsy	Health Conditions Body Function Activities
Christianson, Zwane, Manga Rosen, Venter, Downs, and Kromberg (2002)	Two-phase design, interview and pediatric, neuro-developmental assessment South Africa (N=6692)	2–9 year olds	Intellectual disability (ID) and associated disability	35.6/1,000 in population with ID (.64/1,000 severe and 29.1/1,000 mild) congenital etiology 20.6%, 6.3% acquired and 73.1% undetermined. 15.5% epilepsy 8.4% cerebral palsy	Health Conditions Body Function Activities
Chopra, Verma, and Seetharaman (1999)	House to house survey (n=3560 children) Delhi, India	0–6 years old	Impairment disability or “at risk”	6.88% identified with disability (68.8/1,000)	Body Function Activities
Bashir, Yaqoob, Ferngren, Gustavson, Rydelius, Ansari, and Zaman (2002)	Prospective study of cohort from 4 areas in Pakistan (N=132)	6–10 year olds	Mild mental retardation and associated impairment	Overall 6.2%, 1.2% from upper-middle class; 4.8% in village; 6.1% in urban slum; and 10.5% in poor periurban slum. 75% with MMR and speech impairment. Mild mental retardation higher in a developing country than in developed country.	Body Function

<b>Reference</b>	<b>Study design</b>	<b>Age of children</b>	<b>Condition(s)</b>	<b>Findings</b>	<b>Assignment to ICF domain(s)</b>
Paul, Desai, and Thorburn (1992)	Population based survey (N=5468) Jamaica	2–9 year olds	Childhood disability and related medical conditions	Overall, 93.9/1,000; 24.9/1,000 for serious disability; 81/1,000 for cognitive; 14/1,000 for speech; 11/1,000 for visual; 9/1,000 for hearing; 4/1,000 for motor; 2/1,000 for seizure	Health Conditions Body Function Activities
Beasley, Booker, Ndinaromtan, Madjiouroum, Baboguel, Djenguinabe, Bundy (2002)	Sample of 1,024 children in national survey in Chad	6–15 years of age	Health indicators	Stunting 18.7%, underweight 16.5%, anemia 25.1%, goiter 23.3%, 2 species of helminth infection 13.2% and 32.7%	Health Conditions
Natale, Joseph, Bergen, Thulasraj, and Rahmatullah (1992)	Descriptive study of mothers in 2 lowest social classes	Children 2–9 years	Childhood disability	Prevalence in lowest class (17.2%), two times greater than next lowest class (8.4%)	Activities
Newton, Liu, Ke, Xu, and Bamford 1999	Two stage protocol of 1,020 parents in China	6–8 month old infants	Hearing impairment	2.25% confirmed with hearing loss	Body Function
Couper (2002)	Descriptive 2 stage study in Kwazulu Natal; identification; 2-confirmation of disability(N=2036)	Children under the age of 10 years	Childhood disability	Overall, 83/1,000 reported. Overall confirmed prevalence rate 60/1,000; mild perceptual or learning disability 17/1,000; cerebral palsy 10/1,000; hearing loss 10/1,000; moderate to severe perceptual 6/1,000 and seizure disorder 4/1,000	Health Conditions Body Function Activities
Yaqaob, Ferngren, Jalil, Nazir, and karlberg (1995)	Follow up of 1476 children Pakistan	0–24 months of age	Delay in milestone achievement	Infants in lower social class average of 3months delay compared to upper middle class	Activities
Meremikwu, Asinidi, and Ezedinachi (1997)	Follow up study of 39/45 survivors of cerebral malaria		Neurological sequelae	28.2% with neurological sequelae	Health Conditions Body Function
Durkin, Davidson, Desai, Hasan, Khan, Shrout, Thorburn, Wang, and Zaman (1994)	Two-phase design survey of 22,000 children in Bangladesh, Jamaica and Pakistan	Children 2–9 years of age	Childhood disability	Proportion screening positive was 8.2% in Bangladesh, 14.7% in Pakistan and 15.2 % in Jamaica	Health Conditions Body Function Activities
Tamrat, Kebede, Alemus, and Moore (2001)	Community based cross sectional study of 4214 persons in Northern Ethiopia	5–65 years	Various disabilities	4.9% epilepsy, motor or sensory disability,	Health Conditions Body Function



<b>Reference</b>	<b>Study design</b>	<b>Age of children</b>	<b>Condition(s)</b>	<b>Findings</b>	<b>Assignment to ICF domain(s)</b>
Bashir, Yaqoob, Ferngren, Gustavson, Rydelius, Ansari, and Zaman 2002	Two step household survey of 649 families in Pakistan	6–10 year old children	Mild mental retardation	Overall prevalence of 6.2%	Body Function
Shawky, Abalkhail, and Soliman (2002)	Survey of cohorts of children with visual (178), auditory (421) and mental (666) disabilities in Saudi Arabia	6–20 years of age	Factors associated with disabilities	Older age child-bearing and multiparity associated with increased risk of all 3 disabilities, consanguineous marriage increased risk of auditory disability,	Body Function
Prasansuk (2000)	Two phase survey of 12,395 children in urban, rural schools	6–15 years of age	Sensorineural hearing loss	Rural schools 3.6% Urban schools 3.5%	Body Function
Ellis, Manndhar, Shrestha, Shrestha, Manandhar, Costello (1999)	Follow up of 102 infants with neonatal encephalopathy and 105 controls	0–1 year	Developmental complications	18% severe impairment (cerebral palsy, multiple impairments)	Health Conditions Body Function
Islam, Durkin, Zaman (1993)	Two phase household survey in Bangladesh	2–9 years of age	Mental retardation	5.91/1,000 -severe mental retardation 14.4/1,000 -mild/moderate mental retardation	Body Function
Costello 1989	Descriptive study of 441 Nepali children at 2 time points	0–6 years of age	Stunting	Time I: 54% stunted, 17% wasted, Time II: 51% stunted, 9% wasted	Body Function
Olysanya (2001)	Descriptive study of 359 children in Nigeria	Mean age 6.7 years	Hearing impairment	13.9 hearing loss overall, 3.3% sensorineural	Body Function
Eckstein, Foster, Gilbert (1995)	226 children in schools for blind in Sri Lanka	6–15 years of age	Visual impairment	71% blind, 26% visually impaired, 3% normal vision	Body Function
Yaqoob, Bashir, Tareen, Gustavson, Nazir, Jalil, vonDobeln, Ferngren (1995)	Descriptive study of 1303 child in 4 SES groups in Pakistan	2–24 months of age	Severe mental retardation	22/1,000 periurban slum, 9/1,000 urban slum, 7/1,000 village 4/1,000 middle class	Body Function
Lundgren-Lindquist, Nordholm (1993)	Household survey in Botswana	Children under 15 years of age	Childhood disability	2.31% of children under 15 years of age; 10.4% of population overall	
Palombi, Marazzi, Mancinelli, Sallabanda, Bunomo (1996)	Descriptive community study in Albania	Under 18 years of age	Childhood disability	5.86/1,000; ( most frequent impairments were cerebral palsy, developmental delay, deafness)	Health Conditions Body Function Activities
Ying, Fengying, Wenjun, Keyou, Daxun, deOnis	Nutrition monitoring study of 10000 preschool children in China	Under 6 years of age	Stunting and underweight	Stunting greater than 40%; severe stunting 14%; underweight 24%-28%	Body Function

Screening for hearing loss of infants in China from 6 to 8 months of age was carried out in an innovative study using questionnaires in a two-stage protocol (Newton, Liu, Ke, Xu, and Bamford, 1999). Parents of 1,020 infants attending two child health clinics in urban areas were asked to respond to a questionnaire with 5 straightforward questions. These questions were based on behaviors that a mother could observe such as responding to a loud noise, noticing a car horn or bell, and eye contact when being spoken to. The mother also was asked to make an overall judgment about the child's hearing. A negative response to any item resulted in a referral for a follow-up questionnaire and examination. There were 67 (6.6%) infants who were identified in this way and of these 23 had a confirmed diagnosis of hearing loss. The sensitivity of the questionnaire was found to be 70 percent and the specificity was 96 percent. Although the sensitivity was low, the authors concluded that the use of a questionnaire is a feasible approach with parents in urban areas, with the goal of improving the questionnaire.

The prevalence of sensorineural hearing loss (SNHL) was investigated in a series of population based studies in Thailand (Paransuk, 2000). The studies took the form of two-phase projects in which an initial screening survey was followed by an examination of individuals screening positive and 10 percent of those screening negative. Prevalence estimates ranged widely across the five studies from 3.5 percent to 22.7 percent. For four of the five projects the age range was not provided, the fifth study involved 6- to 15-year-old students from rural and urban schools. This study yielded prevalence estimates of 3.5 percent for urban and 3.6 percent for rural schools. The large variation found in prevalence estimates across the studies was attributed to methodological differences, and it was concluded that the prevalence for sensorineural hearing loss in Thailand was most likely in the range of 3.5 percent to 5 percent.

Also addressing the prevalence of hearing impairment a study by Olysanya (2001) compared three methods to identify children with hearing impairments in Nigeria. The utility of the three methods of a parental questionnaire, tympanometry, and otoscopy were examined at the time of school entry. A high prevalence rate of 13.0 percent was found leading to the description of hearing impairment as a "hidden handicap" in that it is less likely to be attended to by parents and caregivers compared to more grave health conditions. Although Universal Newborn Hearing Screening is a goal for all countries, the urgency of identification of this "hidden handicap" calls for screening at school entry and parent education to insure that when identification of children with hearing impairment in developing countries is made, their needs for intervention will be met.

Among sensory problems that are disproportionately high in the developing countries compared to developed countries is that of childhood blindness. In a recent report, Eckstein, Foster, and Gilbert (1995) conducted a survey of several schools for the blind in Sri Lanka involving children 6 to 15 years of age. The estimated prevalence was 0.5 percent of the child population. In regards to services, 10 percent of the children were provided service in some program, 90 percent were not. An important finding was that cataracts, a condition that could be prevented surgically, accounted for a significant proportion of the blindness among children.

Documentation of the attainment of developmental milestones of infants from four socioeconomic groups in Pakistan was the focus of a study by Yaqoob, Ferngren, Jalil, Nazir, and Karlberg (1993). The negative impact of poor socioeconomic conditions on children in village, periurban, and urban slums was compared to that of children from an upper middle class environment. The psychomotor development of the children was tracked longitudinally over the first 24 months using 10 selected milestones covering gross motor, fine motor, language, and personal domains. The psychomotor functioning of children from upper middle class families was found to be comparable to that of reference groups in industrialized countries. Using this group as the reference, children from the poor environments were characterized by significant delays in psychomotor development. Although there were no sex differences in the pattern of delays, there was variation in the extent of delay, with 30 percent or more of the children from the poor environments showing delays on walking and fine motor milestones.

In another study by some of the same investigators, an analysis was made of severe mental retardation in a cohort study of 1,303 children in Pakistan aged 2 to 24 months (Yaqoob, Bashir, Tareen, Gustavson, Nazir, Jalil, vonDobeln, and Ferngren, 1995). Severe mental retardation was defined by a developmental quotient less than 50, when the child was assessed at 24 months of age. Relating severe mental retardation to specific socioeconomic levels yielded incidence values of 22/1,000, 9/1,000, 7/1,000, and 4/1,000 for the periurban slum, the urban slum, the village, and an upper middle class group, respectively. In addition to severe cognitive deficits, 100 percent of the children were characterized by language and 89 percent by movement impairments. Further, 22 percent had either cerebral palsy or epilepsy. These children were characterized by a heightened vulnerability manifested by a mortality rate of 36 percent.

Given the significant barriers to healthy development of children in many of the developing countries of Africa, there is a strong likelihood that the consequences of infections, diseases, and injuries are manifested as childhood disabilities. Studies documenting their nature and prevalence are emerging, but they often are specific to a sample rather than population based. They do however provide estimates of the scope of problems presented by disabilities in a given country. A cross-sectional study of households in three rural and one suburban area of Northern Ethiopia was carried out to estimate the prevalence of epilepsy and specific functional limitations (Tamrat, Kebede, Alemus, and Moore, 2001). Based on a sample of more than 4,200 individuals 5 years of age or older, a prevalence rate of 4.9 percent of disability was found. Of importance was the fact that conditions were identified as having an early onset related to injuries and infections, supporting the need for primary prevention and health promotion initiatives with young children.

In a cross-sectional survey conducted in central Ghana, screening for disability was made with a sample of 2,556 children under the age of 15 (Biritwum, Devres, Ofosu-Amaah, Marfo, and Esseh, 2001). An overall prevalence rate of 18.4/1,000 was found for children with disabilities. Limited mobility was the most frequent disability (1/3), primarily being the consequence of poliomyelitis infection. Problems with speech and hearing were the next most frequent conditions reported for 25 percent. Higher rates of disability were associated with lack immunization, older age, female gender, and rural residence. An important finding in this study

was the fact that for about a third of the children with disabilities, particularly girls, discrimination compounded their experience of disability. The experience of discrimination constitutes a preventable secondary condition of disability with implications for initiatives to influence social attitudes in a larger program of community awareness.

A major factor restricting estimation of the prevalence of disability in young children in developing countries is the limited availability of simple and efficient screening tools. The Ten Questions Screen was developed to address this limitation, as it screens for disability in children between the ages of 2 through 9 years of age. It also appears to be the only tool available that has been used with any consistency across a number of different countries following a two-phase design approach (Durkin, Zaman, Thorburn, Hasan, and Davidson 1991). The Ten Questions Screen was designed to identify children with seizures as well as cognitive, motor, vision, and hearing disabilities and was administered to parents by community workers trained on the instrument. A study comparing its use in several countries involved two phases, and was carried out in Bangladesh as a whole, a parish in Jamaica and the city of Karachi in Pakistan (Durkin, Davidson, Desai, Hasan, Khan, Shrout, Thorburn, Wang, and Zaman, 1994). Out of a total of more than 22,000 children, the percentage of children screened positive was 8.2 percent, 15.6 percent and 14.7 percent in Bangladesh, Jamaica, and Pakistan respectively. All of the children who screened positive and a random sample of children who screened negative were evaluated in the second phase of the study.

The values for the specificity of the Ten Questions Screen were consistently high across all disability types in Bangladesh, Jamaica and Pakistan (0.92, 0.85 and 0.86), indicating that children without disabilities screened negative. Sensitivity of the instrument on the other hand was more variable as a function of disability, with values for cognitive disability being 0.82 and 0.84 for Bangladesh and Pakistan, but only 0.53 for Jamaica. Sensitivity for serious vision and hearing disability ranged from 0.46 and 0.57 to 1.0 and 1.0, respectively across the three sites. Overall, it was concluded that the Ten Questions Screen can be an efficient tool in identifying children with nonsensory disabilities in developing countries. The reliability of the overall scores and the individual items of the Ten Questions Screen were analyzed in another study using the same data (Durkin, Wang, Shrout, Zaman, Haqsan, Desai, and Davidson, 1995). Test and retest reliability values of .58 and .83 and internal consistency estimates of 0.60 and 0.66 were found for Bangladesh and Pakistan, respectively. A similar value of 0.60 was found for internal consistency of total scores from the Jamaica sample. The prevalence of mental retardation in Bangladesh was estimated in a survey using the Ten Questions Screen with parents of 2 to 9 years olds that included both rural and urban settings (Islam, et al., 1993). The prevalence rate for severe mental retardation was found to be 5.91/1,000 and 14.4/1,000 for mild to moderate mental retardation.

Although most studies with the Ten Questions Screen have used it as designed for 2- to 9-year-olds, Couper (2002) made modifications to allow its use with children under the age of 2. In a prevalence study in KwaZulu-Natal, community health workers carried out screening of 2,036 children using a two-stage process. Those identified in the screen were followed up, resulting in a prevalence rate of disability of 60/1,000 for children under 10 years of age. The

most frequent disabilities, in descending order, were mild learning or perceptual disability 17/1,000, cerebral palsy 10/1,000, hearing loss 10/1,000, moderate to severe perceptual disability 6/1,000, and epilepsy 4/1,000.

In two related studies, the prevalence of childhood disability in the form of epilepsy and intellectual disability, was described among rural South African children between 2 and 9 years of age (Christianson, Zwane, Manga, Rosen, Venter, and Kromberg, 2000; Christianson, Zwane, Manga, Rosen, Venter, Downs, and Kromberg, 2002). A two-phase design was used in which the Ten Question Screen was administered in a household survey to mothers or caregivers. Based on a total of 6,692 children screened, 722 children (10.8%) screened positive and were followed up with a pediatric examination to validate screening results. Of these children, 49 (0.73%) had epilepsy, with prevalence rates of 7.3/1,000 and 6.7/1,000, respectively for lifetime and active epilepsy (Christianson, Zwane, Manga, Rosen, Venter, and Kromberg, 2000). More than two-thirds of the children with epilepsy had associated disabilities and more than half were not receiving medication to control seizures. A second report based on this household survey focused on documenting the prevalence of intellectual disability (Christianson, Zwane, Manga, Rosen, Venter, Downs, and Kromberg, 2002). The follow-up examination identified 238 children with intellectual disability for an overall prevalence rate of 35.6/1,000. The prevalence rate for children with mild intellectual disability was 29.1/1,000 and 0.64/1,000 for those with severe intellectual disability. Acquired and congenital causes were identified for 6.3 percent and 20.6 percent of the children, whereas an etiological determination could not be made for most of the group (73.1%). In an initial study on the epidemiology of intellectual disability among rural children in South Africa, the findings have implications for the development of educational, health, and social services to meet their developmental needs.

A recent study sought to determine the prevalence of mild mental retardation in 6- to 10-year-old children in Pakistan (Bashir, Yaqoob, Ferngren, Gustavson, Rydelius, Ansari, and Zaman, 2002). A two-phase process was used with the initial phase involving screening in the household followed by clinical assessment of those children who failed the screening. The findings revealed variable prevalence as a function of household social class. Although the overall prevalence of 6- to 10-year-old children was 6.2 percent, a relatively low rate was found for children of upper middle class families (1.2%). Rates of 4.8 percent, 6.1 percent and 10.5 percent were found for children of families as a function of decreasing socioeconomic status. Of interest was the fact that although the frequency of congenital conditions was low (10%), three-fourths of the children were found to have additional problems, the three most common being speech impairments, hearing impairments, and behavior disorders. The authors point to the high rate of co-occurring impairments as an important consideration for multidisciplinary services.

A preliminary step for establishing community based rehabilitation programs is to determine the nature and extent of disability in a given community. This procedure was followed in order to set up a CBR program in a rural setting in Albania (Palombi, 1996). A prevalence rate of 5.86/1,000 was found for disability in children and youth under 18 years of age. Cerebral palsy, developmental disability, and deafness were the most frequently identified conditions. In a different study, the prevalence of childhood disability was of interest in a representative Saudi

Arabian population of children under 15 years of age. Based on data from children less than 5 years of age and those 6 to 15 years of age, overall prevalence rates were recorded as 3.76/1,000 for those with major impairments and 42.8/1,000 for those with mild or minor impairments.

A door-to-door survey was carried out in a village in Botswana to determine the rate of childhood disabilities (Lundgren-Lindquist and Nordholm, 1993). The findings revealed a prevalence of 10.4 percent of the population with disabilities, of which 22 percent were children under 15 years of age. An interesting finding in this survey is the high percentage (30%) of consanguinity of those identified with disabilities, a finding similar to the etiology of mental retardation found in Bangladesh.

The relationship of social class with childhood disability was examined in a study of childhood disability in a southern Indian city (Natale, Joseph, Begen, Thulasiraj, and Rahmathullah, 1992). A random sample of mothers from the two lowest social classes in the city was interviewed using the Ten Questions Screen. The prevalence rate for children from the lowest social class (17.2%) was twice as high as that of children from the next lowest class (8.4%), reinforcing the significant role of poverty on disability in childhood.

Challenges related to screening for childhood disability in developing countries includes concerns about knowledgeable respondents and the sensitivity of tools. The Ten Questions Screen and other measures are typically administered in household surveys using mothers as respondents. In a novel study, in Pakistan school aged children were found to be effective in the identification of children with disabilities, (Saaed, Wirz, Gater, Mubbashar, Tomkins, and Sullivan, 1999). Validation of this approach in further studies, would provide a low-cost and efficient system for identifying young children with disabilities. Given concerns about the focus of existing tools to screen for developmental delay, Chopra, Verma, and Seetharaman (1999) identified the need to develop a simple tool to screen for the major disabilities of vision, hearing, and motor, physical, and cognitive functions. Following several phases of pilot-testing, the Disability Screening Schedule was administered to more than 3,500 Indian children (0–6 years) from urban slums in New Delhi. A total of 219 children were identified as having impairments, yielding an overall prevalence of 6.88 percent. Cross validation of the identified children with a sample of children not identified yielded values of 0.89 for sensitivity and 0.98 for specificity, supporting the use of this process as a simple and efficient tool to screen for disabilities of young children in India.

The above review indicates that there is an emerging epidemiology of childhood disability in developing countries. Findings with the Ten Questions Screen indicate that it is an efficient and reliable measure for identifying the prevalence of functional aspects of childhood disability in developing countries. The findings reveal that childhood disability constitutes a significant problem in developing countries, with values ranging from 8 percent to 14 percent, depending on the indicator investigated. Differences in prevalence were attributed to social and cultural factors often specific to certain countries. Comparison of findings across countries from studies not using the Ten Questions Screen, however, are difficult to make, given variability in the definitions used, the sampling technique, and the format of data gathering. The data,

however, do provide qualified evidence of the nature and distribution of disability among young children in developing countries of use for identifying priorities for intervention and further investigation.

## **What is the Context of Childhood Delay and Disability?**

### *Child and Family Factors*

Variability in the nature and distribution of disabilities among children in developing countries are attributable to child and family factors as well as characteristics of the physical, social, and cultural environment. Perhaps the most pervasive factor influencing disability is poverty, expressed in inadequate nutrition, lack of health care, and limited resources for growth. Micronutrient malnutrition is a global problem, associated with increased risk for death, reduced growth, cognitive impairment, and diminished ability to perform (Underwood, 1998). Although malnutrition disproportionately characterizes children in much of the developing world, the nutritional status of their peers with disabilities is even poorer. The greater level of nutritional deficit in children with disabilities has been documented in studies in Asia (Socrates, C., Grantham-McGregor, S.M., Harknell, S.G., and Seal, A.J., 2000), Africa (Tompsett, J., Yousafzai, A.K., and Filteau, S.M., 1999; Ojefetimi, O.E., 1983), the Middle East (Shaar, K., Baba, N., Shaar, M., and Merhi, J., 1994), and India (Pai, M., Alur, M., Wirz, S., Filteau, S., Pagedar, S., and Yousafzai, A.K., 2001).

Inadequate nutrition alone, or in combination with infections or disease, plays a significant role in the increased vulnerability of poor health and development of young children in developing countries. Variations in feeding beliefs and practices also are likely to be associated with poorer nutritional status of children with delays and disabilities. A recent qualitative study focused on beliefs of Indian families about nutrition and feeding practices for young children with disabilities (Yousafzai, Pagedar, Wirz, and Filteau, 2003). That study's findings revealed a lack of acceptance by families of the permanence of their child's disability and difficulties with providing adequate nutrition.

Inadequate nutrition may be determined by demographic changes related to infant nutrition status and economic development in developing countries, reflected by a decline in breastfeeding and an increase in artificial feeding. To examine the role of feeding practices on health and development, a comparative study was made of breastfeeding, artificial feeding, and a combination of the two with mothers of 6-month-old and 1-year-old Tunisian infants. The study was conducted with mothers across five levels of social class (Young, Buckley, Hamza, and Mandarano, 1982). The results of the study revealed that breastfeeding was associated with more favorable performance on motor and mental scales of development and protection from infection. These results were particularly evident for families from the lowest socioeconomic levels, reinforcing the differential protective factor of breastfeeding in the context of greater

poverty. The findings of both of these illustrative studies reinforce the pervasive effects of poverty on the development on children in general and on children with disabilities in particular.

Increased maternal employment in developing countries is another demographic trend with potential influence on the early development of children. To the extent that the mother is employed, her time with the child is curtailed. In a study of 18- to 30-month-old children in Egypt, the frequency of time involved in feeding and household activities were related to increased energy intake and reduced risk of diarrhea of the child (Ricci, Jerome, Sirageldin, Aly, Moussa, Galal, Harrison, and Kirksey, 1996). Another study conducted with Egyptian mothers also examined the changing demographic marker of maternal education. In an interview with 30 mothers of 5- to 8-year-old children from a low income neighborhood of Cairo, von der Lippe (1999) examined the relationship of maternal education on child rearing values and practices. Although all of the mothers represented families raising children under similar problems of crowding and poor housing conditions, differences existed in the level of schooling achieved by the mothers. Of the 30 mothers, 9 were educated and working, 6 were educated but were not working, and 15 had very limited schooling and were not working. The findings indicated that although all mothers endorsed traditional ideals for their child, educated mothers who worked were oriented to earlier timetables for development and more likely to provide stimulation and to interact with their children than the mothers with limited schooling. The author framed the findings in support of the importance of advancing female literacy.

Markers of socioeconomic status are clearly important in the search for risk factors predicting child health and morbidity in developing countries. However, the markers of education, occupation, and social class as used in industrialized countries may need to be supplemented in developing countries, as demonstrated by Durkin, Islam, Hasan, and Zaman (1994). Drawing on findings from surveys using the Ten Questions Screen, Durkin, et al., tested multiple indicators of socioeconomic status predictive of child health and death. In addition to items measuring education and occupation of the parent, a number of items measured dimensions of housing (e.g., electricity, floor material, water source, and so on) and of wealth (number of rooms and possessions). Factor analyses demonstrated the uniqueness of these two domains as markers of socioeconomic status with implications for use in documenting sources of demographic variability within and between developing countries.

Extending the survey work done in Bangladesh with the Ten Questions Screen for disability, an investigation was made to identify risk factors specific to severe versus mild to moderate mental retardation (Durkin, Khan, Davidson, Huq, Munir, Rasul, and Zaman, 2000). Risk factors for severe mental retardation were maternal goiter, postnatal brain infection, rural residence, and consanguinity. The risk factors for mild to moderate mental retardation, on the other hand, were maternal illiteracy, landlessness, history of pregnancy loss, and a baby who was small for gestational age. Documentation of different risk factors suggests that although prevention initiatives for mild and moderate mental retardation primarily reflect socioeconomic conditions, the risk factor of consanguinity may require unique educational initiatives to influence a longstanding cultural tradition contributing to severe mental retardation.



### *Environmental Risk Factors*

Many developing countries are characterized by significant environmental risk factors in the form of exposure of children to diseases, infections, and toxins in the environment. Many of these diseases are likely to be associated with physical complications and sequelae. Malaria is a condition endemic to a number of African countries with significant neurological consequences. Among a cohort of 39 children surviving cerebral malaria, 11 were characterized by severe short-term complications such as cortical blindness and speech and motor problems, and 1 experienced secondary conditions of dyslexia and other learning problems. The authors defined cerebral malaria and its consequences as a problem of childhood disability, amenable to primary prevention through malaria control and the early identification and treatment of those contracting the condition (Meremikwu, Asindi, and Ezedinachi, 1997).

Parasitic infections, malnutrition, and diseases may not only predispose children to developmental complications and disability, at any level, they may be factors limiting the child's ability to learn and achieve in school. Concerns about the role of health on the schooling of children served as the basis for an innovative nationwide survey in Chad. Using schools as sites for the survey, data were collected on the epidemiology of malnutrition, anemia, and parasitic infections (Beasley, Brooker, Ndinaromtan, Madjiouroum, Baboguel, Djenguinabe, and Bundy, 2002). This first nationwide survey was conducted with ecological zones as the frame for data gathering, rather than geographical zones. Regions of the country were defined by differences in land characteristics such as terrain and temperature. A prevalence rate of 18.75 percent was found for underweight, 16.5 percent for stunting, 25.1 percent for goiter, 23.3 percent for anemia and 13.2 percent and 32.7 percent for two forms of parasitic infection. Substantial variation was found as a function of specific ecological regions, reflecting differential risks for developmental problems associated with variability in land and climate characteristics. Such variation points to the need to design health education and associated health and nutrition programs that are fitted to specific regions. Building on comprehensive international support initiatives that integrate school health and nutrition, such as FRESH (Focusing Resources on Effective School Health), schools can and should play a significant role in addressing these health conditions.

### *Social and Cultural Factors*

Changing demographic patterns are factors contributing to problems of the health and development of young children in developing countries. In two companion studies, Cederblad and Rahim (1986) and Rahim and Cederblad (1986) examined the effects of changing urbanization patterns over time on health and behavior of 3- to 15-year-old children in Khartoum, Sudan. Comparing data on this cohort with data gathered on a cohort 15 years earlier, an increase in favorable health status was found for older (7–15 years), but not for younger (3–6 years) children (Cederblad and Rahim, 1986). This finding was attributed to the fact that more children were surviving, but were doing so with various complications. This was evident in an analysis of the distribution of somatic problems revealing an increase in preschool children with chronic conditions such as defective hearing, impaired vision, and epilepsy. The investigation of behavioral problems among children revealed an increase with urbanization. In contrast to

improvement in physical health with urbanization for older children, this finding suggests that the effects of urbanization are different as a function of developmental stage and illustrate child-environment interactions in the manifestation of mental health problems (Simeonsson, et al., 2003).

In a 1999 household survey in Guinea, access to education was analyzed with particular reference to factors related to school attendance (ORC Macro, 1999). As a developing country, Guinea is striving to increase the rate of primary school attendance that in 1999 was 61 percent for gross attendance ratio (children of any age) and 40 percent for net attendance ratio (children of primary school age). Of reasons given for nonattendance, the most frequent were monetary cost (18–36%), the need for the child's labor (20%–32%) and, in rural areas, the lack of a school or of a school nearby (26%–28%). Of interest in the context of this report related to disability was the fact that 6 percent of rural girls and 5 percent of rural boys and 10 percent of urban girls and 7 percent of urban boys were reported to not attend school because of illness or disability. Although details are not available in this regard, children with disabilities are probably the least likely to attend school. A related finding that is likely to be more of a barrier for children with disabilities is the difficulty of traveling to school, requiring an average of 47 minutes of travel time for children in rural areas. These concerns define the policy issue of equity for education of children with disabilities, and likely apply to many developing countries.

### **What Programs and Services Currently Exist to Serve the Needs of Children with Delays and Disabilities and Represent Promising Practices?**

Although health and education programs to promote the development of young children in developing countries have been addressed in terms of policy, funded projects, and research studies for several decades, reports of comparable programs for young children with disabilities have been extremely limited and are only recently appearing. In the 1989 review of programs of how child care and education was provided in different countries (Olmsted and Weikart, 1989), description of services for children under 6 years of age in Kenya, Nigeria, and China did not include any reference to programs for children with disabilities. The only statement that acknowledged children with disabilities pertained to the fact that preschool teachers were expected to identify children with special needs, provide required assistance, be aware of available services, and communicate information to parents (Riak, Rono, Kiragu, and Nyukuri, 1989). In the section below are descriptions of representative programs and practices that currently exist to serve the needs of children with disabilities. This is followed by a description of representative programs with promise in regard to development of health based, community based, and school based services. Key features of these programs are summarized in Table 2, with reference to the focus on universal, selected, and indicated levels of prevention or intervention efforts.

*Table 2 Early Childhood Development Prevention Initiatives for Children with Disabilities in Developing Countries: Implications for Policy, Practice, and Research*

<b>Level of prevention</b>	<b>Policy</b>	<b>Practice</b>	<b>Research</b>
Universal	Female literacy Family Planning Birth registration Right to education	Implementation of proven child health and education programs; vaccination, nutrition	Surveillance and screening; Implementation of 2-stage screening Identification of effective interventions
Selected	Public health approach to highly preventable diseases; Community awareness of disability; Accessible schools	Increase number and expertise of personnel; Information based services; Internet capability Monitoring of birth defects	Development of efficient assessment and evaluation tools
Indicated	Primary health care as context for disability services	Multidisciplinary services; assistive technology Prevention of 2nd conditions	Evidence based practice Identification of risk factors for 2nd conditions

### *Current Health Programs and Services*

Programs addressing the nutritional needs of children in developing countries have been a major priority with a well-documented rationale for intervention (deOnis and Blosser, 2003; Gillespie and Allen, 2002). Although the relationship of nutritional deficiencies with physical growth is well established, the link to cognitive development is less firm and often specific to certain micronutrients (Black, 2003). The goal of nutritional interventions is to prevent stunting and promote physical and cognitive development. Representative programs in this regard are the Institute of Nutrition of Central America and Panama (INCAP) and the Nutrition Collaborative Research Support Program (CRSP), both designed to address the problems of stunted growth in early childhood and functional impairments (Allen, 1995). The impact of growth stunting in early development has implications for interventions and supports beginning in the perinatal period. The initial follow up of preschool children in the INCAP study revealed that dietary supplementation had beneficial effects for mothers and their children (Martorell, 1995). In the longitudinal follow up, the supplementation contributed to improved physical and cognitive functioning.

Reduced activity associated with under-nutrition has been assumed as a factor mediating poor development. This relationship was examined in a study comparing the effects of nutritional supplementation alone and in combination with psychosocial stimulation on the development of 9- to 24-month-old stunted children in Jamaica (Gardner, Grantham-McGregor, and Chang, 1995). Comparisons of activity levels and developmental status in these two groups and control groups of stunted and nonstunted children were made after 6 months of intervention. Results demonstrated that significant deficits in activity level of the stunted children were no longer present after 6 months of intervention. Both supplementation alone and the combination of supplementation and stimulation contributed to the prediction of improved developmental status after 12 months. A subsequent study involving a subset of the stunted and nonstunted children tested the hypothesis that stunting of growth in early childhood is associated with changes in the child's response to stress and may negatively affect cognitive and behavioral development

(Fernald and Grantham-McGregor, 1998). Behavioral and physiological measures were made of the responses of 8- to 10-year-old children to physical and psychological stress situations. The results provided support for the hypothesis, indicating that children with an experience of sustained growth retardation were characterized by significantly elevated physiological arousal compared to nonstunted peers living in comparable socioeconomic circumstances. Such altered levels of arousal are projected to have later negative effects on cognitive development.

Stunting also has been identified as a problem of young children in Nepal. A community based survey was made of children under 6 years of age at the time of harvest (N=546) and 6 months (N=479) later. The application of established criteria revealed that 54 percent of the children were stunted and 17 percent were wasted before the harvest, whereas 51 percent were stunted and 1.9 percent were identified as wasted 6 months later (Costello, 1989). Intervention for children under 2 years of age is particularly important, given that it is a crucial phase of growth.

Inadequate nutrition is clearly a basic factor limiting physical as well as mental development of children in developing countries, exacerbated by the limitations of poverty on experience. Programs to improve nutrition, health, and development recognize the need for specificity for micronutrients (Allen, 2003), and the need to improve the quality of diet as part of a comprehensive integrated program.

### *Promising Practices*

Access to health care and rehabilitation often is very limited for young children with disabilities in developing countries. A recent review of disability in the developing world (IOM, 2000) describes several programs that reflect innovative and responsive support for young children with disabilities and their families. A rehabilitation unit for children was established about 20 years ago in the context of a CBR program in Zimbabwe. Building on the provision of diagnostic and treatment services in the clinical setting by a multidisciplinary team, the unit made a primary investment in the training of health care and rehabilitation staff on disability and rehabilitation in the community setting. The commitment to CBR is evident in the fact that rehabilitation services are brought to the poor sections of the city to insure access for children with disabilities and their families. In the broader scope of its work, the unit organized a parent organization with many branches and a large membership despite limited external donor funds.

A second representative program is a hospital based unit encompassing child development and neurology services in Bangladesh. The rehabilitation focus is on children with motor impairments, developmental delays, and seizure conditions. In keeping with the experience of many programs in developing countries, the lack of trained personnel resulted in a commitment to prepare staff, in this case, an integrated specialty of developmental therapy. Responsiveness to the need for access to services by families in the community was evident in the establishment of a community based project. That project engages in community screening of childhood disability and activities to promote child development. As was true for the program in Zimbabwe, this unit is cost effective and is serving as a model for replication within Bangladesh.

A third example of an effective health-related program in the developing world (IOM, 2000) is the 3-D CBR program in Jamaica. This program also was based on the WHO initiative for CBR and was established about 20 years ago. The major element of the program is the delivery of supportive services to children with disabilities and their families by community workers. These workers often are parents of children with disabilities themselves and work in the context of clinics located in the community. Young children identified with a disability are provided developmental assessment and an individual program plan for intervention. The community worker visits the family on a weekly basis to provide training, with the child's progress monitored periodically by the clinic. The 3-D program also engages in related activities to support families and provides training on disability and rehabilitation to health and other community professionals. The effectiveness of the program is reflected by the fact that a quarter of the program budget was assumed by the Jamaican government.

A final example with implications as an intervention model is a program of stimulation provided to infants and toddlers in an Indian orphanage (Taneja, Sriram, Beri, Sreenivas, Aggarwal, Kaur, and Puliyeel, 2002). The children ranged in age from 6 to 30 months and were characterized by delays in motor, language, and psychological and social development. In light of the fact that social contact and stimulation were very limited, a daily intervention program of 90 minutes was planned consisting of structured play activities. At follow up, significant improvements were noted on measures of mental, motor, and social development and greater activity levels, independence, and responsivity characterized the children. The simplicity and structure of the program is seen as having potential for replication, providing important learning experiences for the children. It is important to note that all of the above programs were developed in the context of existing resources requiring limited external funding. Establishing programs and sustaining them with local resources is an essential consideration in building early childhood and educational programs. The programs described above have value not only in terms of the nature of services and supports they provide but also in terms of the way in which they are sustained.

### *Community and School Based Programs and Services*

Parent involvement has been recognized as an essential component of early childhood intervention programs in developed countries. With the growth of interest in early childhood intervention programs in developing countries, Shah (1991) advocates for an integrated service approach characterized by family and community involvement. As parent involvement evolved from industrialized countries, O'Toole (1989) raised the question of whether it was a concept that would be appropriate to apply in the culture of developing countries. To examine this question, a sample of 137 Guyanese mothers were administered a questionnaire on child development. The use of the questionnaire was designed to evaluate the extent to which mothers would be characterized by three skills seen as prerequisites for programs based on parent involvement. These skills encompassed an understanding of child development, belief in a teaching role, and recognition of opportunities for teaching the child. In broad terms, although responses of the mothers supported an understanding of child development and their role in

teaching the child, implementation of parent involvement programs required consideration of cultural and practical realities regarding the nature and level of child rearing practices in a developing country. O'Toole recommends that implementation of parent involvement programs in a developing country build on creative approaches that take into account the demands and responsibilities of care-giving unique to that culture.

In regard to community based programs for children with mental retardation, Shah, (1991) has proposed two strategies, corresponding to two levels of severity of mental retardation. In regard to mild to moderate mental retardation, efforts should be directed toward preventing common primary conditions and managing the development of those who do manifest mild and moderate mental retardation. An innovative example of a program integrating parental involvement and technology is the UPANAYAN early intervention program (Krishnaswamy, 1992). In this program, a manual or computer based software program is used to assess a child's skill level and prescribe intervention strategies for children under 2 years of age with mental retardation. The mother of the child assumes the primary role of the interventionist, implementing activities to help the child acquire skills. Implementation of the program thus far has been associated with favorable results for children and their parents. In regard to severe forms of mental retardation, focus should be placed on preventing the acquisition of secondary complications and the management of those who do manifest severe mental retardation (Shah, 1991).

The implementation of community based early intervention programs in several countries was reviewed by Serpell and Nabuzoka (1991). Although the specific nature of the program varied as a function of location, all were low cost and shared the principle of providing training or support to the immediate caregiver of the child. A program in Jamaica, for example, consisted of a community team of women who made weekly visits to the home of children with disabilities. Some members of the community team had children with disabilities themselves. The weekly visit consisted of demonstrations in the home so that the mother could carry out activities with her child later. In Mauritius, the community based program took the form of parent-to-parent training, focusing on the home visits to transmit simple techniques for parent trainees to use with their child. A somewhat different approach was used in a home based program in rural areas of Zambia to address the needs of children with intellectual disabilities. A nongovernmental agency provided coordination of support workers who made regular home visits to assist family caregivers in teaching activities for the child. In other programs in Botswana, Zambia and the Philippines, a three-step process was involved, with professionals training direct care workers who in turn would work with the child's caregivers. With recognition of the fact that programs have to adapt to unique community needs, Serpell and Nabuzoka (1991) describe the establishment of centers in the community for visits by children and families. Such centers can provide more specialized services while conserving professional resources.

In a comprehensive report of special education in China, Yang and Wang (1994) described the program for school-age children and the emergence of services for preschool children. At the time of the report, 2.66 percent of all children in China were children with

disabilities. A compulsory education law for 9 years of schooling is in place, with evidence that more than 97 percent of primary school-age students attended school in 1992. The level of schooling for children with disabilities is low, however, and varies as a function of the nature of disability and the region of the country. Yang and Wang reported that less than 20 percent of children with sensory impairments attended school and the rate for children with mental retardation was much lower. Attendance also is region specific with 7 or 8 of the 30 provinces accounting for most of the special education provided. These limitations reflect significant attitudinal barriers, funding, and shortages of qualified teachers. Although the focus of special education in China has primarily been on school-age children, there is a growing recognition of the need for early childhood special education. One of the official goals defined by the government for special education in 1989 was the development of early childhood special education. A related development in this regard was a declaration requiring that "ordinary institutions of preschool education shall admit disabled children who are able to adapt themselves to the life there" (Law on the Peoples Republic of China on the Protection of Disabled Persons, 1990, p.13; as cited in Yang and Wang, 1994). Local communities have assumed responsibility for conducting the majority of these preschool classes. A related area of emphasis is the provision of speech-language training for 3- to 7-year-old children with hearing impairments.

Recognition of the needs of preschool children with disabilities is emerging in other Asian countries as well. In Vietnam, an inclusion program was designed for preschoolers with disabilities (Ryan and Weills, 2000). An evaluation of the program revealed not only that the children benefited from the placement, but a side benefit was realized with increased community awareness of disability. Other related issues arising out of the inclusion program were increased intensity of training of teachers and implementation of the individualized educational service plan.

With reference to another part of the globe, Yousef (1993) described the emergence of educational services for children with mental retardation in the Arab world. In the absence of prevalence data, 2 million students were estimated to be in need of special education, using a 3 percent prevalence rate (2 standard deviation units below the mean). At the time of publication, early childhood special education was seen as just beginning with services for children 3- 6-year-old children, but not for those under 3 years of age. Lack of appropriate instructors as well as unfavorable attitudes were seen as limiting factors. It is likely that attitudes have changed in the ensuing years and that young children with disabilities are experiencing greater accessibility to early childhood special education.

### *Promising Practices*

A basic principle for the development of programs and services in developing countries is that interventions for children and adults with disabilities need to build on the community based rehabilitation approach (Chauhury, Meno-Sen and Zinkin, 1995). Institutional services settings such as residential programs, centers, and hospitals found in industrialized countries are not appropriate to address the needs of children in developing countries. This conclusion is

illustrated by the fact that only 5 percent of children with disabilities in India were served through institutional care. Although community based programs vary in terms of their focus and mode of service delivery, they share a common characteristic of involvement by parents and community members in the provision of services for children with disabilities.

The variability of CBR implementation is evident in a review of several programs illustrating their applications in different countries (Chaudhury, et al., 1995). Project Projimo (Werner, 1993), for example, is a program located in the mountains of Mexico focusing on the needs of children and adults with physical disabilities. The program is carried out by community health workers who themselves have disabilities. In addition to being responsible for their own condition, the community health workers are actively involved in designing and creating simple medical and rehabilitation devices. Consultation is provided to assist children in acquiring developmental skills. Another program in the Western Hemisphere is “Los Pepitos,” an organization formed by parents to meet the needs of their children with cerebral palsy. A significant component of the program involves the siblings of the children with cerebral palsy in expanding their experiences in the community through integration activities and raising awareness (Chaudhury, et al., 1995).

Two other examples of CBR programs have been developed in Uganda, the Ugandan Community Development Assistance Program and the Community Based Rehabilitation Alliance. The first of these two programs utilizes community development assistants trained to work with children and families in daily life activities. Training materials were developed by the program based on the experience of families and the book developed in conjunction with the Projimo Project, *Disabled Village Children*, by Werner (1987). As a community based project, children with disabilities are readily integrated into schools and the life of the community. The second CBR project in Uganda operates in an impoverished slum in Kampala, and is run by persons with disabilities, family members, professionals, and community members. The focus of the program is on the provision of advice to families of children with disabilities through home visits and discussion groups. In addition, it serves a valuable function in providing support and practical help with more general concerns of community members (Chaudhury, et al., 1995).

The Action on Disability and Development-India project is a CBR program involving an extensive network of rural villages coordinated by a nongovernmental organization. A unique feature of the Action on Disability and Development-India project is that it is based on the philosophy of advocacy for children and adults to secure the supports and services available for everyone, rather than specialized services for persons with disabilities (Chaudhury, et al., 1995). This emphasis on access to existing structures and resources involves facilitators, individuals trained to work with persons with disabilities, and their families to help solve the problems they encounter in their communities.

The feasibility of a community based project using the *Portage* manual of child development skills was tested in a rural Guyanese setting (O’Toole, 1988). The *Portage* approach is well established and builds on assessing the child’s status on checklists of major developmental domains. The child’s current status as measured by checklists forms the basis for



planned interventions. The intervention approach for preschool children involves visits to a child's home by trained community based workers to recommend skills that could be worked on with the child by the parent. The initial project began with 53 children and demonstrated significant improvements for the children and favorable reactions by the parents. The positive effects are reinforced with favorable cost figures and the success of the program is recognized in the form of national support (Chaudhury, et al., 1995). The *Portage* materials and approach are easy to use and have been adopted in projects in India, Bangladesh, and Jamaica (Sturmeay, Thorburn, Brown, Reed, Kaur, and King, 1992).

The increasing emphasis placed on evidence based practice found in industrialized countries is becoming expected in developing countries. For children without disabilities in developing countries, the effectiveness of early childhood interventions has been evaluated in Columbia, India, and Turkey, with appropriate research designs (Boocock, 1995). Comparable research on the effectiveness of interventions for young children with disabilities and their families in developing countries, however, are essentially lacking. An exception to the rule was a randomized controlled trial of different services to 85 children between 18 months and 5 years of age with cerebral palsy in Bangladesh (McConachie, Huq, Munir, Ferdous, Zaman, and Khan, 2000). The study involved the random assignment of 49 children living in an urban setting to either a center based group program available daily for mothers and their children or to a monthly distance training approach using demonstration and a pictorial manual. Forty-three children in rural settings were randomly assigned either to the monthly distance training or to a one-time health advice contact. Although follow up was complicated by the death of 8 children and difficulty tracking down or securing the cooperation of 20 families, the results provided qualified support for the distance training approach for mothers to support their children's development. The authors concluded that steps to increase the involvement of other family members would likely enhance the impact of the intervention.

In Costa Rica, the needs of children with learning disabilities are met through services overseen by aesoress, or curriculum specialists, who work in regions of the country (Stough and Aguirre-Roy, 1997). The aesoress provide consultation to classroom teachers on curriculum modification to meet the needs of the child in the regular classroom. Given overcrowding of schools, special education students are often served in recargo classes, which are classes taught by teachers on an overload basis at the end of the regular school day. This approach represents a creative use of existing physical and personnel resources to meet the special needs of students with disabilities.

Another example of innovative use of resources to provide schooling for children with disabilities in India is described in the work of the Karnataka Parent's Association for Mentally Retarded Citizens-KPAMRC (Mathias, 1995). This organization provides education for children with disabilities based on the "add-on principle," referring to the addition of facilities or resources to existing ones. An example would be placing what was described as "opportunity schools" for children with disabilities on the same campus as regular schools. In rural settings, resource rooms placed in regular schools would reflect the same principle. Over time, this model has come to be referred to as the "parallel education stream" in which students with and without

disabilities share most activities of schooling with the exception of subject matter. A related activity of this parent organization is that it has been committed to the preparation of teachers, reporting an average of 17 teachers trained a year and reflecting a productive community based program on behalf of schools. Although the programs in Costa Rica and India represent important achievements in assuring access to education for students with disabilities, educational services are not provided in fully integrated settings. However, the openness to change and the creativity of the KPAMRC program suggests that the educational model will continue to evolve in the direction of more inclusive opportunities. This also is likely for the educational program in Costa Rica.

An additional example of an effective school based program has been described in a comprehensive review of the status of children with disabilities in developing countries (IOM, 2000). The Protibondhi Foundation in Bangladesh was established in 1985, and is an organization committed to a range of activities to advance the education, development, and well being of children with disabilities and their families (McConkey and O'Toole, 2000). Two separate schools have been set up, one urban and one rural, to meet the needs of students with various disabilities. Each school provides integrated learning experiences for students with and without disabilities and both sites offer early childhood intervention programs to assist mothers and their young children. In addition to these direct provisions of education for children, the Foundation also engages in a distance training program offering informational packages to families who live too far away to access the center. The Foundation currently invests in the preparation of teachers with special education credentials in two university departments.

### **Priorities and Recommendations for Early Childhood Intervention for Children with Disabilities in Developing Countries**

Being born in most developing countries today significantly increases a child's risk for poor health, stunted physical and mental growth and development, inadequate preparation for adult life, and reduced longevity. The importance of preventing such outcomes and promoting growth and development has been recognized for several decades with recommendations made for the provision of comprehensive health care and education programs. Over time, while specific elements have changed, broad recommendations have been quite consistent, endorsing the importance of early intervention, the need for a comprehensive approach combining health and education, the central role of complementing family life, sensitivity to cultural norms, basing services in the community and planning for sustainability (Heron, 1979; Olmsted and Weikart, 1989; Myers, 1988; 1992). These recommendations, however, have focused on reducing risks and preventing compromised development of populations in a collective sense, not the increased developmental risks faced by the subpopulation of children with delays and disabilities. Recognition of the intervention needs of young children with disabilities in the developing world has been more recent and limited by comparison (Werner, 1988, Serpell, 1991). As noted in this review, the circumstances that compromise the early development of all children in developing countries also are associated with a disproportionate risk for developmental delays and disabilities. Addressing the needs of this group of children for comprehensive intervention is a

societal responsibility and indicated on the basis of cumulative evidence demonstrating the benefits of early intervention for later development.

Although broad recommendations for reducing risks and promoting development of all children in developing countries also are beneficial for children with delays and disabilities, the complexity and intensity of their unique needs will require additional and specialized interventions. Viewed in the well-known framework of the three levels of primary, secondary, and tertiary prevention (Simeonsson, 1991), broad recommendations for supports and services have been proposed. Activities implemented in primary prevention are designed to prevent new developmental conditions from emerging, that is, to reduce incidence of delays and disabilities at the population level. Activities defined as secondary prevention address prevalence through interventions to reduce the nature or severity of existing conditions. Tertiary prevention has been defined in terms of interventions designed to prevent complications and secondary conditions in children with existing disabilities. This framework of levels of prevention has been advanced as the basis for differentiating the nature of activities to prevent intellectual and other disabilities of children in Singapore, for example (Lyen, 1989).

In approaching intervention to promote the development of young children with disabilities in the developing world, the levels of prevention approach may be a useful framework in which to differentiate needed interventions. Such a perspective extends an approach focusing on the individual to a public health approach to disability in which "...people with disabilities are included as integral part of the public, a population group that needs attention in order to eliminate disparities" (Lollar and Crews, 2003, p.206). To this end, a modified prevention framework may be a productive way to define relative ways in which to prioritize interventions and supports in terms of their breadth versus intensity of effort. In response to the elevated level of risk for developmental problems experienced by most children in developing countries, including those with disabilities, such a framework posits prevention initiatives defined for universal, selected, and indicated populations, as noted earlier in this paper (Simeonsson, 1994).

Broad initiatives directed toward all children are defined as universal prevention, requiring no targeting of children on the basis of recipient characteristics. In this case all children are at a common level of risk for disability. Initiatives directed towards children having a group identity associated with increased risk are defined as selected prevention, that is, interventions are targeted to a group sharing a common identity. The child may not be characterized by individual risk factors, but is identified because of a shared identity such as social class, family characteristics, or location of residence. Indicated prevention defines initiatives directed toward children identified on the basis of individual risk factors such as an established medical condition, documented impairment, or disablement associated with disability. A recent synthesis of the scope of neurological, psychiatric, and developmental disorders in the developing world included a chapter addressing issues related to developmental disabilities (Committee on Nervous System Disorders in Developing Countries-CNSDDC, 2001). Although not solely focused on problems related to children, the chapter advanced a set of recommendations that

were consistent with the range of prevention activities covered by the three levels of prevention framework described above.

In the section to follow, initiatives for preventing disability and promoting health and development of children with disabilities in developing countries are reviewed within the framework of universal, selected, and indicated prevention. The recommendations related to developmental disabilities are incorporated as appropriate in this review and summarized in Table 3 as initiatives in a comprehensive approach relating to practice, policy, and research.

*Table 3 Representative Intervention Programs for Promoting Early Child Development of Children with Disabilities*

<b>Reference</b>	<b>Focus and level of prevention/ intervention</b>	<b>Target group</b>	<b>Context of intervention</b>	<b>Primary means / methods</b>	<b>Nature and evidence of intervention</b>
Cook and Rogers, 1996; IOM, 2000	CBR; Indicated level	Children with disabilities and their families	Central unit for services and coordination in Zimbabwe	Training of outreach teams for CBR; support groups for parents	Treatment and support in communities; national parent association established
McConkey and O'Toole, 1999; IOM,2000	Range of services; screening (Universal) to treatments (Indicated)	Children at risk and children with disabilities and their families	Foundation coordinating school, CBR, screening and training programs in Bangladesh	Early intervention and spec ed programs; CBR, distance training packages	Treatment and support in communities; teacher training
Taneja, et al., 2002	Early stimulation of development: Selected level	Infants and toddlers with dev delays/ disabilities	Orphanage in India	Provision of 90 minutes daily of play and stimulation activities	Improvement of motor, mental and social development; change in environment
Khan, et al., 1998; IOM, 2000	Acute and long term services at Indicated level	Children with CP, dev delay epilepsy/	Unit within hospital; community project in Bangladesh	Assessment and therapy; psychological /counseling services	Treatment; screening and counseling; higher educ training in dev therapy
Thorburn, 1999: IOM, 2000	CBR; screening (Universal) to intervention (Indicated)	Children with disabilities and families	Network of CBR in urban and rural areas of Jamaica	Trained community workers/ parents provide home based programming	Detection and intervention; formation of parent groups/ advocacy
Werner, 1993	CBR; support rehabilitation (Indicated)	Children and adults with physical disabilities	Community health workers carry out services in Mexico	Dev services and support; design of rehab devices	Provision of services in rural areas/ local resources
Chaudhury, et al., 1995	CBR; supportive services (indicated)	Children with disabilities and families	Community workers provide services in Uganda projects	Home visits providing support and services for daily life activities	Provision of information and support to children and families
Chaudhury, et al., 1995	CBR; secure general services and supports- not disability specific (universal)	Children and adults with disabilities and families	Nongovernmental network of rural villages in India	Advocacy to access existing resources available to all-	Facilitators work in communities to secure access

Reference	Focus and level of prevention/ intervention	Target group	Context of intervention	Primary means / methods	Nature and evidence of intervention
O'Toole, 1988; Chaudhury, et al., 1995	CBR; early childhood intervention (Indicated)	Young children with disabilities and families	Community based project in rural Guyana	<i>Portage</i> materials used by community workers in home visits	Promotion of children's development and education for families
McConachie, et al., 2000	CBR distance training of families for intervention (Indicated)	Young children with disabilities and families	Center and distance training project in Bangladesh	Monthly demonstration and training package	Support of children's development by families
Stough and Aguiree-Roy, 1997	Special education; Indicated level	Students of school age with disabilities	Use of public school facilities and resources at the end of regular school day	Consultation provided to classroom teachers; "Recargo" classes taught on overload basis	Educational program provided for students with disabilities
Mathias, 1995	Special education; Indicated level	Students of school age with mental disabilities	Special schools or resource rooms located on campus of regular school	Physical integration of students with disabilities on campus or in buildings of regular school	Educational program provided for students with disabilities; training of teachers

## Universal Prevention Initiatives

Within a dynamic view of the developing child, development and disability reflect the child's ongoing interactions with the environment. In this view, initiatives designed for all children, including children with disabilities, address fundamental needs of children for nutrition, access to health care, sanitation, and public education, as well as programs to screen for physical and developmental problems. As described below, universal prevention initiatives identified for young children with disabilities include maternal and child health services, screening for sensory problems, nutritional status, and access to education.

*Child health:* The lack of health care or substantial limitations of access to health care characterize the early years of the world's children, with particular reference to the developing world (UNICEF, 2001). Fundamental to the needs of all children, including those with disabilities, is access to basic resource elements supporting health (Consultative Group on Early Childhood Care and Development, 1993). These elements include protection from complications in the newborn period, diseases in the developing years, access to essential nutrients and sanitation and protection from environmental toxins such as lead (Khan and Khan, 1999). A comprehensive program to support the health of young children serves as a building block for their ability to benefit from education in developing countries. This relationship is illustrated in a study comparing the health perceptions of parents of 3 to 5 year old children from low income families provided preschool education in Nigeria, with the results of an examination. An investigation of children served in 43 preschools revealed malaria and catarrh to be the most

frequent health problems reported by parents and caregivers, whereas catarrh and ringworm were the most common based on examination (Goyea, 1988).

Changing demographic patterns, noted elsewhere, regarding maternal employment and increased reliance on artificial feeding has resulted in the fact that less than 40 percent of infants 4 months and under are breastfed. Access to adequate sanitation is available to less than 70 percent of children, less than 50 percent live in a household with access to the benefits of iodized salt. Less than 50 percent of children are registered at birth (UNICEF, 2001), significantly limiting the potential for follow up of newborns presenting with congenital conditions, perinatal, or neonatal complications. Immunization rates for 1-year-olds are varied, with levels less than 50 percent characterizing many of the developing countries in Africa, where children are likely to have increased exposure to diseases and infection. The devastating epidemic of AIDS among children (Lwin and Melvin, 2001) is particularly acute in Africa, with 35 percent to 59 percent of infected children not surviving beyond age 2 (Dabis and Ekpini, 2002). Of those who survive, there are direct effects of increasing developmental delay in HIV-infected children under 2 years of age (Msellati, Lepage, Hitimana, Goethm, VonDePerre, and Dabis, 1993). There also are significant indirect effects of the AIDS epidemic on children altering their caregiving environments and creating orphans of HIV-infected parents (Lwin and Melwin, 2001). The number of children orphaned around the world exceeded 15 million by the end of 2001, and more than 12 million of those children lived in Africa. Their orphan status requires them to manage not only their own development, but in many cases that of their siblings. Failure to meet these fundamental needs of children raises significant health problems exacerbating the risks for development caused by impairments and disabilities.

In the context of Shah's (1991) advocacy of primary health care as a context for promoting health of mothers and children, a comprehensive program of access to health care and supports are elements of universal prevention initiatives. This is consistent with the recommendation of the Committee on Nervous System Disorders in Developing Countries (2001) to implement established methods of primary prevention, including nutritional supplementation, vaccination, sickle cell screening and newborn screening. An important component of significance for all children is universal registration of all births. Such registration would have important implications for children with impairments or disabilities in that they would be less likely to be hidden by families due to stigma or shame and more likely to be identified and followed for early stimulation and support.

*Screening and disabilities:* Another step that is an essential building block to improve programs for early intervention and provision of services and supports is the development of tools to screen for etiological and developmental delay. Screening and identification of impairments and disabilities among young children represent significant challenges in developing countries, given limited resources for conducting the screening and qualified professionals to carry out the screening. However, valid identification of children with developmental delay or disability is important in deriving a base for planning effective early intervention programs. A major factor restricting valid documentation of the prevalence of disability in young children is limited availability of simple and efficient screening tools for use

in developing countries. In a clinical research study, Shevell, et al., (2000) developed a systematic framework with which they were able to make an etiologic diagnosis for 44 percent of children under 5 years of age with developmental delay. In their comment on this finding, Palfrey and Frazer (2000) describe the value of the approach derived by Shevell and his colleagues toward an international protocol for defining the basis for developmental delay. The availability of standard protocols, questionnaires, and screening tools such as the Ten Question Screen are important elements of a common language in the identification, assessment, and provision of intervention for young children at risk or with developmental disabilities. Using the 1980 WHO International Classification of Impairments, Disabilities, and Handicaps, Thorburn, Desai, and Davidson (1992) explored the utility of developing efficient means to measure different aspects of childhood disability in Jamaica. The approach was productive, with good psychometric evidence found for the measures.

As noted earlier in this review, the Ten Questions Screen appears to be the only measure that has acceptable psychometric properties and has been used in a variety of countries. Although the age range of 2 to 9 years does capture a critical developmental age range, the creation of measures with comparable qualities for children under 2 years of age would be an important research priority to improve screening for early intervention. A similar position has been advanced by the Committee on Nervous System Disorders in Developing Countries (Gell, et al., 1997).

To this end, alternative approaches that are low in cost but effective need to be developed and tested. Addressing the issue of developing surveys of disability suitable for use in different cultures, Bolton and Tang (2002) describe an alternative approach to translating western instruments. The goal of their work was to develop a measure to assess limitations of function in adults; and their approach consisted of developing a template for function assessment that took the form of a matrix with nine rows providing for listing of specific tasks or activities. Five columns defined the degree of difficulty from none to inability to do the task; a sixth column provided a place to identify the basis for the problem. To facilitate a respondents rating of task severity, culturally framed drawings provided the opportunity to rate the tasks nonverbally. The identification of tasks involved asking individuals from samples of convenience to generate free lists in response to three questions pertaining to what persons must do to take care of themselves, their family, and their community. The resultant measure was found to have good reliability and validity. This approach to document disability in a dimensional manner is similar to that of the ABILITIES Index (Simeonsson, et al., 1996) described previously. Such an approach would seem highly appropriate to investigate in the development of screening and assessment of childhood disability.

In the current context of evidence based decision making, rigorous surveillance efforts are needed to obtain reliable estimates of childhood disability. This is important not only in order to establish the scope of need but to monitor change in prevalence rates over time as a function of demographic changes as well as changes in the provision of services and programs. The publication of the International Classification of Functioning, Disability, and Health-ICF by WHO (2001), mentioned earlier in this review, can provide the conceptual model and taxonomy

within which such protocols and measures are framed. A current effort to prepare a version of the ICF for children and youth will make available a more detailed taxonomy for differentiating intervention priorities and the development of measures to assess and classify childhood disability (Simeonsson, et al., 2003a; Simeonsson, 2003b).

*Screening and nutrition:* Inadequate nutrition is a problem associated with disability for many children in developing countries, manifested in deficient growth or stunting. The scope of this problem is substantial, with at least 30 percent of children under 5 years of age reported to be moderately or severely stunted (UNICEF, 2001). Given the pervasive negative role of inadequate nutrition in the poor health and development of young children in the developing world, the establishment of nutritional programs and policies has been an important priority for many years (Popkin, et al., 2001). Implementation of policies related to nutrition at a country level requires a detailed projection of the extent to which a given policy will impact the problem of disease and disability. In this regard, it is important to consider effects that may vary as a function of developmental stage. As reported in the longitudinal study by Martorell (1995), nutrition intervention for mothers and children revealed different effects for children as a function of specific age groups. Effects for children between birth and 3 years of age were increased birth weights, lowered infant mortality, and increased growth rates. For long term effects, findings revealed increased stature, increased intellectual performance, and work capacity for the age range of 11 to 27 years. A data based approach, PROFILES, has been developed to assist countries in identifying the goals and impacts of a nutrition policy (Burkhalter, Abel, Aguayo, Diene, Parlato and Ross, 1999) and constitutes an important resource for countries planning universal prevention efforts to improve children's nutritional status.

*Screening and hearing:* The World Health Organization recommends screening for hearing problems in children at age 2 and just before school entry, using a checklist of behavioral indicators (McConkey, 1995). Olysanya (2001) recommends good questionnaires and parent education as tools for screening for hearing impairment at school entry. The value of using schools for screening is reinforced by the study by Prasansuk (2000), who reported prevalence rates of 3.5 percent and 3.6 percent for sensorineural hearing loss-SNHL among urban and rural children in Thailand, respectively. The fact that the prevalence rates for hearing disability were higher (3.9%–6.1%) than those for SNHL has important implications in that needed resources to support children with SNHL differ from those for children with hearing disability.

In the context of limited fiscal and technological resources of developing countries, behavioral methods have been recommended for assessing hearing impairment in young children (Gell, et al., 1992). Of particular importance is screening for hearing impairment among infants and young children in developing countries, as defined by recommendations of the 48th WHO World Assembly (WHO, 1995). Two key developmental points have been recommended for such screening, the first prior to the age of 2 and the second at the time of school entry (Gell, White, Newell, MacKenzie, Smith, Thompson, and Hatcher, 1992). Given that screening approaches based on high technology may be impractical and too expensive for developing countries, a priority exists for screening methods that are performance based, incorporating behavioral techniques. There are, however, several cautions in the implementation of such



screening approaches in developing countries. First, screening should not be implemented unless follow-up services are established. Second, the validity of screening based on behavioral methods requires sensitivity to the use of specific stimuli that are relevant in that country and culture. A third consideration is the importance of community based screening efforts, drawing on trained health workers to visit homes and to carry out screening using checklists for families and simple screening tests (Gell, et al., 1992).

*Education access:* Access to education is a right that children are deprived of in many developing countries (UNICEF, 2001). In sub-Saharan Africa, the net primary school attendance is 59 percent for boys and 51 percent for girls. In south Asia, the attendance figures are 78 percent and 64 percent respectively, and in the Middle East and North African countries 87 percent and 79 percent. In each instance, it is clear that girls are disproportionately deprived of education, often reflected by a disparity of 10 percent or more. The high rate of female illiteracy in sub-Saharan Africa (48%), Arab states (51%), and South Asia (59%) constitutes a vicious cycle for developmental disability. Lacking education and skills to improve their own situation, girls also have limited ability to fully contribute to the lives of their families as they become adults. This problem is particularly acute in those countries where one third of births are to women in their teens, compounding health risks of teen pregnancy with subsequent limited knowledge and child rearing skills by a mother who is not literate. The gender disparity is recognized by the Salamanca (UNESCO, 1994) statement, placing priority on education and the importance of guidance and the provision of role models for girls.

### **Selected Prevention Initiatives**

*Early childhood intervention and education:* Although no specific data were found comparing school or preschool attendance rates of children with and without disabilities in developing countries, it is likely that children with disabilities are among those who have been denied to access to schooling. As stipulated in the United Nations Convention on the Rights of the Child, the provision of education is a primary responsibility of societies for children with disabilities. This is further defined by the U.N. Standard Rules for the Equalization of Opportunities, in that priority is assigned to the provision of educational opportunities for preschool children with disabilities. The emphasis on early childhood education and school inclusion also is advocated for policy purposes in the Salamanca statement (1994). An example of how these priorities have been recognized and acted upon is described in the work of the Karnataka Parent's Association for Mentally Retarded Citizens-KPAMRC (Mathias, 1995). This organization provides education for children with disabilities based on the "add-on principle," referring to the addition of facilities or resources to existing ones. Examples would be placing special schools along regular schools or designating resource rooms in regular schools. The responsiveness of this organization to the need for teachers prepared to work with young children with disabilities is reflected by the fact that they train teachers yearly, with a new curriculum established in 1991, called "Early Intervention for Children with Developmental Disabilities."

The need for access to regular school settings by children with disabilities and the corresponding need for preparation of teachers for inclusive education are advanced in the Salamanca Statement (UNESCO, 1994). Implementation of the premise of inclusion in practice was described in an early childhood intervention program for 40 young children in Singapore (Quah, 1997). A successful pilot phase of this project demonstrated that children with disabilities were accepted by personnel and nondisabled peers in mainstream preschool centers, and families valued the intervention. Implementation of early intervention programs in developing countries may require adaptation both in terms of translating concepts across cultures and in terms of practical issues. With regard to translation of concepts, early childhood special education teachers in Korea reported infrequent assessments, inadequate resources, and confusion about the underlying concept and application of the Individualized Education Program (Paik and Healey, 1999). Practical constraints existed in the implementation of early intervention services for children with cerebral palsy in a rural area of Bangladesh (McConachie, Huq, Munir, Kamrunnahar, Akhter, Ferdous, and Khan, 2001). The form of the program was the use of pictorially based materials that mothers took the home following advisory sessions. The frequency of attendance was affected by practical, cultural, and medical considerations in the form of lack of transportation, prohibitions against independent travel by the mother, and by seizures of the child. These programs illustrate the importance of adopting an approach in the establishment of early childhood intervention programs in developing countries that build on a recognition of local needs and reflect the cultural and practical realities unique to each country (Hartley, 1998). In the translation of a needs based approach, a conceptual model encompassing dimensions of functioning can provide an integrating framework for service delivery (Hartley and Wirz, 2002).

*Community based rehabilitation:* An important selected prevention activity is to build upon the contribution of CBR as an intervention framework for developing countries. In light of the fact that CBR has not been the focus of extensive scientific inquiry, Mitchell (1999) has identified four issues that need to be addressed through evaluation and research. The first is the system for delivering service, that is determining how and by whom services may be provided in the community in the most efficient way. The role of parents as Community Rehabilitation Workers has been a very successful element of early intervention programs in Jamaica (Thorburn, 2003). Having received limited but highly targeted training, these workers, many of whom were parents of the children with disabilities, became an essential component of the program staff. The second issue pertains to the transfer of technical skills and information. At the heart of the CBR approach is the third issue of community involvement. The focus is on how the attitudes and resources of the community can be invested in the program for children and adults with disabilities. A final issue in need of investigation pertains to how CBR is organized and managed at local and broader levels. Key issues have to do with finding an organizational model best suited to a given setting and insuring that there is participatory involvement of persons with disabilities and their families in the management process (UNESCO, 2001). A good example is the low-cost and home based early intervention program in Jamaica carried out by Community Rehabilitation Workers (Thorburn, 2003).

Although these four issues are focused on CBR as a framework for services, they are sufficiently broad to be inclusive of concerns pertaining to early childhood intervention for children with disabilities. To that end, they can be used productively as frameworks for identifying priorities and recommendations to advance practice, policy, and research agendas for young children with disabilities in developing countries. It is important however, to reiterate Serpell's (1991) caution in regard to how implementation should occur: "If CBR is to fulfill its promises of promoting full participation, normalization and acceptance, genuine technical support must be provided to those entrusted with 'hand-on' responsibilities, in the form of training, regular visiting and back-up" (p. 107).

Documenting the effectiveness of early childhood intervention is an important priority in developing countries. However, implementing such evaluation efforts presents significant challenges. With the goal of evaluating the 3-D early intervention project in Jamaica, Thorburn (2003) drew on the Operations Monitoring and Analysis of Results-OMAR program (Jonsson, 1994) that encompasses the areas of effectiveness, impact, relevance, efficiency, and sustainability. Although it was thought that the evaluation provided useful feedback for the program, problems with questions, data collection, and analyses precluded drawing conclusions about the project.

*Information based intervention:* A universal need experienced by families with children who are disabled is the need for information about the child's condition, stimulation and treatment, and developmental prognosis. In a study of the needs of urban and rural Chinese families with children with disabilities, Chen and Simeonsson (1994) found that the highest area endorsed was the need for information. This need for information is similar to that found for parents of children with disabilities in industrialized countries (Bailey and Simeonsson, 1989; Roll-Petterson, 1994). As such, the need for information reflects a shared universal family priority to find out as much as they can about their child's condition and what resources are available to them in the care-giving role of their child. Miles sees information for persons with disabilities and their families as the central component of rehabilitation and special education efforts. In this context, he has advocated for information based rehabilitation as an integrated approach to disseminating and sustaining information about disability and intervention methods and procedures. To insure comprehensive coverage of needed information, Miles describes a matrix format to identify existing and needed information in forms that are culturally and linguistically appropriate. The matrix was set up to identify information resources corresponding to four groups of users (parents, siblings, lower professionals, and senior professionals) across eight types of disabilities.

Although print was the primary form of dissemination at the time that Miles described this approach, the underlying premise of information based rehabilitation can clearly be complemented in significant ways through increasingly available electronic forms, even in developing countries. At the level of service systems, the contribution of the Internet (Edejer, 2000) and telemedicine (Wright, 1998) constitute resources that need to be capitalized upon for sharing effective practice with programs in developing countries. Increasingly, clinical centers and programs providing comprehensive services in the United States and Europe maintain Web

sites that can be readily accessed for information on assessment, intervention, and evaluation issues. Investing in the technical support for ready access to the Internet would be an excellent way to share advances in care and management of children with disabilities for programs with limited resources. At the level of training and personnel development, the International Society on Early Intervention, a society devoted to the international exchange of ideas, clinical approaches, and research findings, maintains a Web site accessed by persons working with young children with disabilities around the world <http://weber.u.washington.edu/-isei/>. Expansions through the virtual environment support Miles' recommendation for information based rehabilitation as "...an approach accessible to countries at most stages of development for both government and non-government organizations...(and may be the only strategy, for millions of disabled people in the Third World, that has any realistic likelihood of benefiting them" (Miles, 1989, p.211).

*Integration of service programs:* In the continued drive to improve early childhood intervention, it is important to address risk factors for disability in the adoption of a public health approach. Such an approach integrates efforts in medicine and environmental health through known methods to prevent disease and disability. Efforts in this regard include meeting micronutrient deficiencies, immunization or treatment for certain infections, and genetic counseling regarding consanguineous marriages and removal of environmental toxins (CNSDDC, 2001, Durkin, 2002). As elevated blood levels have been found to contribute to neurological disorders in children (Kumar, Dey, Singla, Abasht, and Upadhyay, 1998), reducing children's exposure to lead (Durkin, 2002) reflects the changing nature of rehabilitation for young children. The shifts in practice that have been described earlier in this report are reflected in what Helder, Engelbert, Custer, Gorter, Takken and Van Der (2003) have called the changing "panorama of paediatric rehabilitation." One aspect of that changing paradigm is to identify and track infants at significant risk for developmental disability. In this context, Castilla, et al., (1991) have described monitoring of birth defects in Uruguay as a low-cost primary prevention component of a comprehensive program for developing countries. Another aspect of the changing paradigm has been characterized by a shift in focus on intervention directed toward the child alone to recognition of the importance of the role of family and community.

Because the needs of young children with disabilities cut across a variety of sectors, integrated programs are needed at the primary health care level (CNSDC, 2001), and support systems provided by health, education, and social services (Ayyangar, 2002) should be coordinated. A further reflection of the changing approach in rehabilitation is the emphasis on outcome based evidence to document intervention effectiveness of medical interventions for injuries related to disability (Bickler and Rode, 2002). Similar priorities have been identified for cost-benefit studies of newborn screening, nutritional supplementation, and prevention of infections (CNSDS, 2001).

*Personnel development:* The need for personnel prepared to work with young children with disabilities and their families has been a topic of limited attention in the literature on early childhood intervention. It is recognized that the model of training highly skilled, specialized members of multidisciplinary teams working in industrialized countries is not a model that is

affordable or practical in developing countries (CNSDS 2001, Durkin, 2002, McConkey, 1995). There is, however, a strong need to increase the number and the expertise of persons trained to work with children with disabilities and their families in a nonspecialist capacity (Wirz and Lichtig, 1998; Hartley, 1998).

A model described by McConkey (1995) involves a project coordinator who works with a number of field workers. In this approach, project coordinators with experience in disability provide training and supervision of field workers who relate directly to the family or caregiver. The field workers, on the other hand, may have little if any formal education, but are given highly practical skills to work with the families. McConkey (1995) has provided an outline of suggested training topics emphasizing that training must be placed in the practical context of the settings where they will work. Practical materials for field workers as well as family members on health, nutrition and development can be reviewed in publications such as *Disabled Village Children: A Guide for Community Health Workers, Rehabilitation Workers and Families* (Healthright, 1987), *Helping Health Workers Learn* (Werner and Bower, 1982) and *Training in the Community for People with Disabilities* (WHO, 1989). Practical materials that can be used in community based work in developing countries also may be secured at Teaching Aids at Low Cost, P.O. Box 49, St Albans, Herts., AL14AX, United Kingdom.

### **Indicated Prevention Initiatives**

The Salamanca statement issued in 1994 (UNESCO, 1994) advanced a broad framework for promoting early childhood intervention and education for children with disabilities. Specifically, one of four priority areas was assigned to early childhood education, to support the child's development, and to prepare the child for school. To achieve this goal, investments should be expanded in early childhood intervention efforts with a commitment to documenting positive outcomes for young children with disabilities and their families in inclusive settings.

*Participation:* Limitations in personal and social development are frequent characteristics of children with disabilities in developed as well as developing countries. With reference to the International Classification of Functioning and Health, participation is defined as involvement in life roles. For young children, this implies engagement with peers in play settings and involvement as an active family member. Access to peers and the opportunity to participate in social activities often are limited by the nature of the child's impairment. A sensory impairment of blindness or deafness is likely to limit the child's ability to interact with other children. Difficulties with mobility are likely to limit physical access to settings where peers may be playing. Of further concern is the fact that families may restrict the child's participation in community life because of the stigma attached to the child's condition. The child also may experience discrimination from children and adults in the community, as noted in the study by Biritwum, et al., (2000) on the experience of girls with disabilities in Ghana.

Recommendations for a Convention on the Rights of Persons With Disabilities (2003) have been defined in a regional seminar in Quito, Ecuador, calling for an end to discrimination,

the creation of accessible environments, and the full integration of persons with disabilities into society. Such international conventions provide a standard for establishing policy for early childhood intervention, however, to be effective, they must become part of regulations and laws that can be implemented in practice.

*Secondary conditions:* Although achievement of personal and social competence is an essential goal for children with disabilities in developing countries, research on this aspect of children's development is limited. With a broader commitment to promote the health and development of children, interventions to support social integration and participation of children with disabilities are important to prevent secondary conditions and to promote quality of life (Simeonsson and McDevitt, 1999). Secondary conditions can be defined as complications that are the unintended results of interactions of living with a primary impairment under conditions of inadequate environments or supports. The primary condition is a necessary but not sufficient condition for the manifestation of secondary conditions. For young children in developing countries, complications may be manifested in structural, neurological, or behavioral forms secondary to inadequate or dangerous environments. The lack of positioning for a child with cerebral palsy may result in scoliosis; isolation may contribute to stereotyped behavior; and inhalation or ingestion of lead in the environment may result in neurotoxic effects (Kumar, Dey, Singla, Ambasht, and Upadhyay, 1998). The implications for intervention are that secondary conditions can be prevented through the provision of appropriate stimulation, treatment, and access to physical and social environments.

A recent study examining the nature of social integration of Indian children with epilepsy (Pal, Chaudhury, Sengupta, and Das, 2002) can be seen to illustrate a preventable secondary condition. A cross-sectional approach was used to compare the social activities of 88 children with epilepsy (2-18 years of age), with 250 randomly selected children without epilepsy. All comparisons revealed social deficits of children with epilepsy. The parent's response to the epilepsy was to overprotect their children who were of preschool age and to assign fewer responsibilities to older children and adolescents. Of concern was the fact that the nature and extent of social deficits were not attributable to the underlying condition of epilepsy, indicating they were the manifestation of preventable, secondary complications. The findings emphasize the importance of social integration in the context of community based rehabilitation for children with disabilities.

*Family life:* Coping with the demands of raising a child with disabilities is challenging for families in industrialized and developing countries (Thorburn, 1999). Given the limited material and financial resources characterizing family life in developing countries, meeting the additional physical and caregiving demands of a young child with disabilities often may be extremely difficult. Health resources are likely to be extremely limited, if available at all. Added to these challenges are cultural beliefs and values assigning stigma to the child's condition and the experience of living with negative attitudes of the community (Ingstad, 1988).

Identifying efficient and culturally appropriate ways to support families in their care-giving role for a child with disabilities within the restricted context of developing countries is an

important priority. This issue is illustrated in a study by Pal, Chaudhury, Das, and Sengupta (2002) on the adjustment of Indian parents in raising a child with epilepsy. In light of the fact that formal systems of support are limited or lacking in many developing countries, the interest in this study was to identify the nature and extent of informal sources of support for the families and their relationship to their sense of adjustment. To this end, 46 families of children with epilepsy (6–18 years of age) were administered a measure of social support followed by a measure of adjustment 12 months later. Although the severity of epilepsy was negatively related to adjustment, satisfaction with informal social support was a positive predictor of adjustment. The finding of a relationship between positive support of family and friends and family adjustment was seen as a favorable element of community based rehabilitation. Opportunities for parents to interact with other families of children with disabilities and build networks are feasible and important support mechanisms for families in developing countries. Illustrative of the significant role of parents in early childhood intervention programs is the success of parents as Community Rehabilitation Workers in Jamaica (Thorburn, 2003).

## **Conclusion**

This review has confirmed the disproportionate distribution of early childhood disability in the developing world. The higher prevalence of childhood disability is a reflection of synergistic effects of nutritional deficiencies, increased exposure to illnesses, lack of immunization and access to health care, inadequate housing and sanitation, and barriers to education. Addressing any one of these factors to promote development and to prevent disability would be a significant challenge, as recognizing their synergistic action implies a formidable task. In keeping with the parallel challenge of improving child health in developing countries (Tulloch, 1999; Anonymous, 2003), an approach paralleling the Integrated Management of Childhood Illness is needed, defined perhaps in terms of an integrated management of child health and development. Although their numbers are low, this review has identified selected programs in several countries that embody aspects of an integrated approach. In the development of further programs, the unique situation and needs of each country will define the universal, selected, or indicated focus of prevention and intervention needed. Key issues that need to be considered in the development of needed programs are integration, sustainability, and quality assurance as summarized in Table 4.

*Table 4 Key Elements in Developing and Sustaining Early Childhood Development Programs for Children with Disabilities in Developing Countries*

<b>Element</b>	<b>Description</b>
<b>Integration</b>	
System integration	A coordinated approach to early child development involving health, education and social service sectors
Community integration	Integration of programs into structure and life of local community
<b>Sustainability</b>	
Financial	Clearly defined program components; building on existing resources; maintenance of local control
Human capital	Provision of information and skills for family members and caregivers; training of community workers; and key professionals in health and education
<b>Quality assurance</b>	
Evidence based documentation	Accountability to families and funding sources through objective evidence of valued and reliable outcomes
Quality control assurance	Accountability to families through establishment of standards defining ethical and scientific validity of programs

Sustaining the prevention, intervention, and rehabilitation programs beyond their initial establishment is an essential requirement for early childhood intervention initiatives in any developing country. Consideration needs to be made of two aspects of sustainability, one focusing on financing and the second on human resources. In light of the fact that programs in the developing world are often established with external funding and are nongovernmental in nature, strong parent advocacy and support are essential for sustainability. A set of conditions that can be used as a checklist for sustaining early intervention programs has been identified by Ager (1990). Conditions that need to exist at the outset include clarity and consistency of program components and direct control over resources. Conditions following implementation are defined in terms of evidence showing that expected outcomes have been achieved that are valued, reliable, prompt, and natural, rather than contrived.

Another element essential to the sustainability of early childhood intervention is human capital. As has been evident in this review, a wide variety of programs in developing countries rely on significant family and community involvement. As early childhood intervention programs continue to grow, there is a need for the establishment of formal programs to systematically prepare community health workers and other personnel to implement services. A number of the exemplary programs reviewed in this report have demonstrated responsiveness to the need for personnel with innovative training, for community workers, and for persons with various levels of professional training. Formalization of training may contribute to sustainability by providing visibility for early childhood intervention programs.

Incorporation into community health services and education in appropriate government ministries should be the goal for early childhood intervention programs. As Thorburn (2003) noted in the work to incorporate early intervention programs in Jamaica, such efforts may take time and repeated attempts.



Quality assurance in the form of evidence based practice is increasingly becoming the expectation, if not the requirement, of human service programs. This applies to programs for children with disabilities in early intervention, as well as in special education. The United Nation's developed Operations Monitoring and Analysis of Results-OMAR (Jonsson, 1994) as a comprehensive system to evaluate programs in terms of the dimensions of effectiveness, impact, relevance, efficiency, and sustainability. Although the form of quality assurance activities will likely differ in developing countries from those in place in industrialized countries, the rationale for quality assurance remains the same (Simeonsson, 1999). First, programs need to be accountable to families, providing services that are responsive to their concerns and the needs of their young children with disabilities. Second, generating evidence of program quality is important from a scientific standpoint. Careful documentation of what is effective in a program is necessary in order to generalize findings about successful programs and avoid investment in those that are not effective. Such evidence also is important to external funding sources, including governments.

An issue related to quality assurance is that of evidence to distinguish between acceptable and controversial treatments (Harris, Atwater, and Crowe, 1988). Such evidence is important for families and providers everywhere, but particularly important for families in developing countries who may have limited education and lack of access to information on which to make informed decisions about interventions appropriate for their children. Providing information on this topic to parents is an ethical as well as scientific issue, reflecting a responsibility to assure families that interventions and treatments do no harm.

As countries enter the new century, there is a continual move toward the internationalization of business, industry, science, media, and many other spheres of life. Advocacy and action agendas are being advanced for the awareness of the rights and needs for adults and children with disabilities. It is timely that internationalization is reflected in early intervention initiatives for infants and young children with delays and disabilities and support for their families. The disparity in prevalence of disability in the developing world and its concentration among children calls for heightened efforts directed toward the prevention of disablement and promotion of health and development. The electronic revolution is bringing together people from every corner of the world and in one way or another can provide a link for health information and support for every household with a member who is disabled. The ease and rapidity of information exchange provide developed and developing countries with valuable opportunities to exchange what they have in common and share knowledge and skills to advance the important endeavor of early childhood intervention. Drawing on that shared knowledge, programs can be established and sustained to prevent disablement and promote the health, development, and well-being of all children with disabilities.

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