



# Early Childhood Development and Disability:

A discussion paper





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WHO Library Cataloguing-in-Publication Data

Early childhood development and disability: discussion paper.

1.Child development. 2.Disabled children 3.Child welfare. 4.Child health services. I.World Health Organization. II.UNICEF.

ISBN 978 92 4 150406 5

NLM classification: WS 368)

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Editing: Donna Phillips

Cover photo: CBM/argum/Einberger (taken in Tanzania)

Design and layout: Inis Communication – [www.iniscommunication.com](http://www.iniscommunication.com)

Printed in: Malta

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Centre for Disability in Development/ Shumon Ahmed (taken in Bangladesh)

# 1. Introduction

Early childhood is the period from prenatal development to eight years of age. It is a crucial phase of growth and development because experiences during early childhood can influence outcomes across the entire course of an individual's life (1,2). For all children, early childhood provides an important window of opportunity to prepare the foundation for life-long learning and participation, while preventing potential delays in development and disabilities. For children who experience disability, it is a vital time to ensure access to interventions which can help them reach their full potential (1,3).

Despite being more vulnerable to developmental risks, young children with disabilities are often overlooked in mainstream programmes and services designed to ensure child development (4). They also do not receive the specific supports required to meet their rights and needs. Children with disabilities and their families are confronted by barriers including inadequate legislation and policies, negative attitudes, inadequate services, and lack of accessible environments (5). If children with developmental delays or disabilities and their families are not provided with timely and appropriate early intervention, support and protection, their difficulties can become more severe—often leading to lifetime consequences, increased poverty and profound exclusion.

The *Convention on the Rights of the Child* (CRC) (6) and the *Convention on the Rights of Persons with Disabilities* (CRPD) (7) highlight how children with disabilities have the same rights as other children—for example to health care, nutrition, education, social inclusion and protection from violence, abuse and neglect. Ensuring access to appropriate support, such as early childhood intervention (ECI) and education, can fulfil the rights of children with disabilities, promoting rich and fulfilling childhoods and preparing them for full and meaningful participation in adulthood (4).

This discussion paper provides a brief overview of issues pertaining to early childhood development (ECD) and disability. It lays the foundation for a long-term strategic and collaborative process aimed at improving the developmental outcomes, participation and protection of young children with disabilities. Essential to this effort is dialogue between United Nations agencies and relevant stakeholders to identify sustainable strategies which build on existing efforts, and expand on multisectoral approaches to guarantee the rights of young children with disabilities and their families.





UNICEF/NYHQ2010-0417/Holt (taken in Chad)



# 2. Children with disabilities

## What is disability and who are children with disabilities?

Our understanding of disability and who people with disabilities are has evolved considerably over time.

The *International Classification of Functioning, Disability and Health: Children and Youth Version* (ICF-CY) regards **disability** as neither purely biological nor social but instead the interaction between health conditions and environmental and personal factors (8). Disability can occur at three levels:

- an impairment in body function or structure, such as a cataract which prevents the passage of light and sensing of form, shape, and size of visual stimuli;
- a limitation in activity, such as the inability to read or move around;
- a restriction in participation, such as exclusion from school.

The CRPD states that “*persons with disabilities* include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (7).

The term **children with disabilities** will be used throughout this paper. Some children will be born with a disabling health condition or impairment, while others may experience disability as a result of illness, injury or poor nutrition. Children with disabilities include those with health conditions such as cerebral palsy, spina bifida, muscular dystrophy, traumatic spinal cord injury, Down syndrome, and children with hearing, visual, physical, communication and intellectual impairments. A number of children have a single impairment while others may experience multiple impairments. For example a child with cerebral palsy may have mobility, communication and intellectual impairments. The complex interaction between a health condition or impairment and environmental and personal factors means that each child’s experience of disability is different.

While the identification of children with developmental delay (see Box 1 on page 11 for definition) or disabilities is critical for the development of policies, strategic planning and service provision, it is important to acknowledge that children with disabilities rarely think of themselves as disabled. Therefore working with children with disabilities requires carefully tailored approaches. Labelling a child solely in terms of their health condition should be avoided. They are children first and aspire to participate in normal family and peer-group activities.

## How many children with disabilities are there?

WHO and the World Bank estimate that more than a billion people live with some form of disability, which equates to approximately 15% of the world's population (5). Among these, between 110 million (2.2%) and 190 million (3.8%) adults have very significant difficulties in functioning (5).

There are currently no reliable and representative estimates based on actual measurement of the number of children with disabilities (9,5). Existing prevalence estimates of childhood disability vary considerably because of differences in definitions and the wide range of methodologies and measurement instruments adopted (5,10). The limitations of census and general household surveys to capture childhood disability, the absence of registries in most low- and middle-income countries (LMICs), and poor access to culturally appropriate clinical and diagnostic services contribute to lower estimates (10). As a result many children with disabilities may neither be identified nor receive needed services (5).

## What are the rights of children with disabilities?

The CRC applies to all children in the world, including children with disabilities. It spells out the basic human rights that children everywhere have: the right to survival; to develop to the fullest; to protection from harmful influences, abuse and exploitation; and to participate fully in family, cultural and social life. It also recognizes the importance of family assistance and support (6). Two articles make specific reference to children with disabilities: Article 2 outlines the principle of non-discrimination and includes disability as grounds for protection from discrimination; Article 23 highlights the special efforts States Parties must make to realize these rights (6).

In General Comment 9, the Committee on the Rights of the Child which oversees the implementation of the CRC has provided guidance to States Parties in their efforts to implement the rights of children with disabilities, covering all the provisions of the Convention (11). In addition General Comment 7 (12) and General Comment 9 (11) of the CRC specifically highlight that children with disabilities: are entitled to active participation in all aspects of family and community life; require equal opportunities in order to fulfil their rights; and should be treated with dignity at all times. Furthermore, they state that children with disabilities "are best cared for and nurtured within their own family environment" (11) and they "should never be institutionalized solely on the grounds of disability" (12). States Parties must protect children with disabilities from discrimination and provide access to a range of services and supports which are specifically designed to help them achieve their full potential. This was reinforced in the *2010 UN General Assembly Resolution A/65/452* (13).

Similarly, the more recent CRPD includes an article dedicated to addressing the rights of children with disabilities. Article 7 outlines States Parties obligations to take measures to ensure that children with disabilities are able to enjoy the same human rights and fundamental freedoms as other children, to consider their best interests, and to ensure that they are able to express their view. Article 23 of the CRPD establishes the right to family life and Article 24 promotes the right to education (7).

The CRC and the CRPD are mutually reinforcing and together provide a framework for a growing synergy between key human rights instruments. Furthermore, all initiatives intended to improve the lives of children, such as the Millennium Development Goals (MDGs) (14) apply equally and in full force to children with disabilities. Specific efforts must be made to reach and include these children if international commitments are to be achieved.



UNICEF/NYHQ2011-1089/Holt (taken in Moldova)

# 3. Early childhood development and disability

Child development is a dynamic process through which children progress from dependency on caregivers in all areas of functioning during infancy, towards growing independence in the later childhood (primary school age), adolescence and adulthood periods (8,15). Skills emerge in a number of linked domains: sensory-motor, cognitive, communication and social-emotional (2,16,17). Development in each domain proceeds through a series of milestones or steps and typically involves mastering simple skills before more complex skills can be learned. It should be recognized that children play an active role in the development of their own skills (18) and their development is also influenced by interactions within their environment (19).

## BOX 1: EARLY CHILDHOOD TERMINOLOGY

**Early Childhood:** Early childhood spans the pre-natal period to eight years of age (1). It is the most intensive period of brain development throughout the lifespan and therefore is the most critical stage of human development. What happens before birth and in the first few years of life plays a vital role in health and social outcomes (20). While genetic factors play a role in shaping children's development, evidence indicates that the environment has a major influence during early childhood (21).

**Early Childhood Development:** Early childhood development (ECD)<sup>1</sup> is a generic term that refers to a child's cognitive, social, emotional and physical development. The same term is often used to describe a range of programmes which have the

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1 Different terms are frequently used among different countries and stakeholders, for example Early Childhood Education (ECE), Early Childhood Care and Education (ECCE), Early Childhood Care (ECC), Early Childhood Care and Development (ECCD), and Early Childhood Care for Development.

ultimate goal of improving young children's capacity to develop and learn and which may occur at many different levels such as child, family and community, and across different sectors such as health, education, and social protection.

**Developmental Delay:** Developmental delay refers to children who experience significant variation in the achievement of expected milestones for their actual or adjusted age (8,15). Developmental delays are measured using validated developmental assessments (22) and may be mild, moderate or severe. Developmental delays are caused by poor birth outcomes, inadequate stimulation, malnutrition, chronic ill health and other organic problems, psychological and familial situations, or other environmental factors. While developmental delay may not be permanent, it can provide a basis for identifying children who may experience a disability (8). This further emphasizes the importance of early identification to commence timely interventions with family involvement, aimed at preventing delays, promoting emerging competencies and creating a more stimulating and protective environment.

**Early Childhood Intervention:** Early childhood intervention (ECI) programmes are designed to support young children who are at risk of developmental delay, or young children who have been identified as having developmental delays or disabilities. ECI comprises a range of services and supports to ensure and enhance children's personal development and resilience (23), strengthen family competencies, and promote the social inclusion of families and children (24). Examples include specialized services such as: medical; rehabilitation (e.g. therapy and assistive devices); family-focused support (e.g. training and counselling); social and psychological; special education, along with service planning and coordination; and assistance and support to access mainstream services such as preschool and child-care (e.g. referral). Services can be delivered through a variety of settings including health-care clinics, hospitals, early intervention centres, rehabilitation centres, community centres, homes and schools.



## What factors affect child development?

Children's development is influenced by a wide range of biological and environmental factors, some of which protect and enhance their development while others compromise their developmental outcomes (15). Children who experience disability early in life can be disproportionately exposed to risk factors such as poverty; stigma and discrimination; poor caregiver interaction; institutionalization; violence, abuse and neglect; and limited access to programmes and services, all of which can have a significant effect on their survival and development (25,4,26,27).

### **Poverty**

Although disability can occur in any family, poverty and disability are strongly interlinked: poverty may increase the likelihood of disability and may also be a consequence of disability (5,28,29).

Pregnant women living in poverty may experience poor health, restricted diet, and exposure to toxins and environmental pollutants, all of which can have a direct effect on fetal development. Children living in poverty are more likely to experience developmental delays than children from higher socio-economic backgrounds because they are disproportionately exposed to a wide range of risks (15,16). These include: inadequate nutrition; poor sanitation and hygiene; exposure to infection and illness; lack of access to health care; inadequate housing or homelessness; inadequate child care; exposure to violence, neglect and abuse; increased maternal stress and depression; institutionalization; and inadequate stimulation (27,30).

There is also evidence to suggest that children with disabilities and their families are more likely to experience economic and social disadvantage than those without disability (5). Disability can contribute to increased poverty at the household level as parents take time away from income-generating activities, siblings are taken out of school to care for a brother or sister with a disability, and families are required to meet the additional costs associated with disability, for example payments for health care and transportation (5).

## ***Stigma and discrimination***

Children with disabilities are among the world's most stigmatized and excluded children (31). Limited knowledge about disability and related negative attitudes can result in the marginalization of children with disabilities within their families, schools and communities (31). In cultures where guilt, shame and fear are associated with the birth of a child with a disability they are frequently hidden from view, ill-treated and excluded from activities that are crucial for their development (32). As a result of discrimination, children with disabilities may have poor health and education outcomes; they may have low self-esteem and limited interaction with others; and they may be at higher risk for violence, abuse, neglect and exploitation (5,31).

Some children with disabilities may be more vulnerable to discrimination and social exclusion than others due to multiple disadvantages arising from impairment, age, gender or social status (32,33). Other influential factors may include geographic location (living in rural and remote areas), belonging to a minority language group and/or living in conflict zones or areas of natural disaster. For example girls with disabilities can be particularly at risk of being discriminated against (32) as well as children from poorer households and those from minority ethnic groups (10).

## ***Child-Parent/Caregiver interaction***

Stimulating home environments and relationships are vital for nurturing the growth, learning and development of children (15,16). The quality of child-caregiver interaction may be compromised when a child has a disability. Several studies have shown that there are differences in parent-child interaction when a child is disabled—mothers or caregivers of children with disabilities usually dominate interactions more than mothers or caregivers of children without disabilities (34). Some children with disabilities have high support needs as a result of disabling health conditions and impairments and this dependency, in addition to other social and economic barriers, can place considerable stress on caregivers.

Caregivers may be isolated in communities that hold negative attitudes and beliefs towards disability. They may experience poverty and lack needed economic support; have limited access to information needed to provide appropriate care for their children; and have limited social supports (32). These factors can have a detrimental effect on the physical and mental health of mothers and fathers and their ability to respond to the child's developmental needs. Research in high-income countries finds that rates of divorce and abandonment among parents of children with disabilities may be significantly higher than for parents of children without disabilities in the same communities (35). While research is lacking in LMICs, an emerging body of data shows similar issues of stress and needs for support and information (36). Siblings may also feel the effects, with parents having less time to devote to them as they struggle to meet the needs of their child with disability.

However, an emphasis on barriers and problems risks overlooking the joy and satisfaction that can come from having a child with disability (37). Children with disabilities are usually loved and valued by their parents and siblings, and mothers in particular may develop many new skills and capacities through their caring roles. Considering that family settings are generally the first learning and protective environments for children, guidance and orientation are critical for families following the immediate identification of a developmental delay or disability in order to promote positive interactions. In addition to a child's immediate family, his or her neighbourhood, community and societal structures also need to be considered (38).

## ***Institutionalization***

All children, including children with disabilities, have the right to be part of a family whether biological, adoptive or foster. In some countries, however, many children with disabilities continue to be placed in residential care institutions (39). For example in the Central and Eastern European Commonwealth of Independent States up to one third of all children living in residential care are classified as having a disability (39). Institutional environments are damaging to child development, with many children experiencing developmental delay and irreversible psychological damage due to a lack of consistent caregiver input, inadequate stimulation, lack of rehabilitation and poor nutrition (32,40,30). Furthermore, institutionalization isolates children from their families and communities and places them at increased risk of neglect, social isolation and abuse (32,41,42,43).

## ***Violence, abuse, exploitation and neglect***

The first year of life is a particularly vulnerable period for children—they are not only at risk of infectious diseases and other health conditions, but also at risk of violence, abuse, exploitation and neglect. The United Nations *Study on Violence Against Children* highlights that in some OECD (Organisation for Economic Co-operation and Development) countries, infants under one year of age are at around three times the risk of homicide than children aged one to four, and at twice the risk of those aged five to 14 (44). However, the true extent of violence during the early childhood period is unknown given that it mainly occurs in private settings such as homes and institutional environments, and that social and cultural norms may influence the hiding and/or condoning of certain violent behaviours.

Children with disabilities are more vulnerable to physical, sexual and psychological abuse and exploitation than non-disabled children. Social isolation, powerlessness and stigma faced by children with disabilities make them vulnerable to violence and exploitation in their own homes and in other environments such as care centres or institutions (32). Research shows that children with disabilities are three to four times more likely to experience violence than their non-disabled peers (45). Data for 15 countries showed that in seven countries parents of children with disabilities were significantly more likely to report hitting them (10).

Children with disabilities are at an increased risk of violence for a number of reasons including cultural prejudices and the increased demands that disability may place on their families (32,43). Children with disabilities are often perceived to be easy targets: powerlessness and social isolation may make it difficult for them to defend themselves and report abuse (32). Exposure to violence, neglect or abuse can lead to developmental delays and behaviour problems in childhood and later life (46,47).

## ***Humanitarian situations***

There is a bidirectional link between humanitarian situations—such as conflict and natural disasters—and disability. While all children are vulnerable during humanitarian situations, children with disabilities are particularly at risk and disproportionately affected. Caregiver

and child interaction during humanitarian situations can be worsened due to caregiver psychological stress and depression which can have a negative impact on children's health and well-being (36).

In addition to the physical and emotional stress, children with disabilities may face other challenges. For example they may experience new impairments; they may lose essential medications and assistive devices; their impairments may prevent them from being able to walk long distances or stand in queues for food and water; where resources such as food or medicine are limited they may be considered as a lower priority than children without disabilities; and in situations in which they are separated from parents or extended family they may be at an increased risk of violence or abuse. Humanitarian situations can also result in a significant number of people experiencing disability due to injuries and a lack of access to needed medical care and rehabilitation (48). (See Box 2 on page 26 for further considerations in humanitarian situations.)

### ***Limited access to programmes and services***

Access to mainstream services such as health care and education plays a significant role in determining child health, development and inclusion. Children with disabilities often miss out on essential vaccinations and basic treatment for common childhood illness (32). Adequate health care, including nutrition, reduces child mortality rates and enables children to refocus their energy on mastering important developmental skills (46,49).

As children become older, access to early childhood education and transition to the first grades of primary school are also essential to establishing the foundation for continual learning and development (17,46). In comparison to other children, those with disabilities are less likely to start school and have lower rates of remaining in school (5,50). It is estimated that one third of all primary aged children who are not in school are children with a disability (3). Those in school are all too often excluded within the school setting, are not placed with peers in their own age group and receive poor-quality learning opportunities.

Many children with disabilities also require access to additional learning opportunities and/or specialized services such as rehabilitation to maximize their development potential. In many countries programmes and services targeting young children are often inadequate to meet their developmental needs, and when available they are often costly, not inclusive and located in urban areas (51,32,22,52). While some countries have already adopted an approach to deliver services through a variety of settings at the community level, overall there is an insufficient number of service providers with sufficient knowledge of and skills in disability.

## Why support the development of children with disabilities?

Evidence-based research and multi-country experiences make a strong rationale for investing in ECD, especially for children at risk of developmental delay or with a disability.

**Human rights rationale:** Both the CRC and the CRPD state that all children with disabilities have the right to develop “to the maximum extent possible” (6,7). These instruments recognize the importance of focusing not only on the child’s health condition or impairment but also on the influence of the environment as the cause of underdevelopment and exclusion (12).

**Economic rationale:** Children with disabilities who receive good care and developmental opportunities during early childhood are more likely to become healthy and productive adults. This can potentially reduce the future costs of education, medical care and other social spending (53,54).

**Scientific rationale:** The first three years of a child’s life are a critical period. They are characterized by rapid development particularly of the brain and thus provide the essential building blocks for future growth, development and progress (2). If children with disabilities are to survive, flourish, learn, be empowered and participate, attention to ECD is essential.



**Programmatic rationale:** ECD programmes can lead to improved rates of survival, growth and development; and ensure later education programmes are more effective. Well-organized inclusive ECD programmes for young children with disabilities can provide parents with more time to engage in productive work and enable girls and boys with disabilities to attend school. Approaches combining centre-based programmes and parenting interventions, including home visiting programmes, may help parents and professionals to detect developmental delays early, improve children’s development, prevent abuse and neglect, and ensure school readiness (55,56).



UNICEF/NYHQ2011-0121/Noorani (taken in Pakistan)

# 4. How can we support the development of children with disabilities?

Promoting development in young children with disabilities requires a twin-track approach (5). This approach recognizes that children with disabilities and their families have ordinary needs and must have access to mainstream programmes and services such as health care, child care and education, and also may need access to targeted services such as ECI. Building on existing health and education service structures for all children is essential, avoiding as much as possible the organization of separate and/or parallel services.

A comprehensive approach is required for appropriate care and support including: early identification; assessment and early intervention planning; provision of services; and monitoring and evaluation. A life-cycle approach to programming provides a helpful framework to identify priority and sustainable interventions during the early childhood stage and to ensure a continuum of quality care, health services, protection and education as a child transitions from birth into and through the first grades of primary school. In addition, the life-cycle approach provides the foundation for organizing the roles and responsibilities of each sector in support of children and their families, aimed at guaranteeing a more holistic assistance plan while reducing potential duplication of services.

A wide range of sectors should be involved in and share responsibility for identifying children with disabilities, providing ECD services and guaranteeing support for their families. There are currently many successful projects focusing on early development for children with disabilities throughout the world often in combination with good public health and Education for All (EFA) efforts (57,58,59,36).

Community-based rehabilitation (CBR) has also been one of the major approaches to addressing the needs of children with disabilities in LMICs. This approach empowers children and their families by bringing together communities and government and non-government health, education, vocational, social and other services (60). Further efforts should be made to ensure community-based approaches become an integral part of national health and education systems, policies and services.

## Early identification of development delays and/or disabilities

Some health conditions associated with disability may be detected during pregnancy where there is access to prenatal screening, while other impairments may be identified during or after birth. Screening or surveillance of children's development may take place during visits to general child health-care or ECD services; there may be targeted early identification procedures in place, such as screening for visual and hearing impairments in health-care or education settings; and public health activities, such as immunization campaigns, may also provide opportunities for early identification. Some families may also become concerned about their child's development if there are delays in the achievement of key developmental milestones such as sitting, walking or talking.

Unfortunately many children with disabilities in developing countries, particularly those with "mild to moderate " disabilities, are not identified until they reach school age (61). Systems for early identification are required in order to facilitate timely access to services to support the development of children at significant risk for developmental delays, and to prevent potential issues, such as a loss of confidence in parenting skills (62).

It is important to ensure that early identification does not contribute to further discrimination and exclusion from mainstream services such as education. Ethical issues may also arise unless screening leads to: comprehensive assessment; the design of appropriate intervention plans; and timely and appropriate management and care (63,31). Decisions to undertake identification and screening should take into account the availability of services or resources to provide interventions as well as the effectiveness of these interventions (64). However, caution should be exercised against "inactivity" based on the assumption that ideal services are not fully available. Comprehensive tracking and follow-up systems can ensure that children who are identified through screening subsequently receive assessments and appropriate services (22).

## Assessment and planning for early intervention

Accurate assessment is an important starting point for better understanding and anticipating the needs of children with disabilities and their families. Assessment is not an end in itself, rather its goals are to obtain useful and accurate information about a child's sensory-motor, cognitive, communication and social-emotional skills, and functioning and surrounding environment in order to assist parents, health-care providers, teachers and others to better understand, plan for and support the development and inclusion of a child with a disability. Assessment should be linked to intervention and should be an ongoing process of systematic observation and analysis. Parents are key partners in

the early intervention assessment and planning process, and may require counselling and support on how to address the needs of their child following an assessment (see *Family services* on page 28).

During the assessment process, a diagnosis may be made for some children while for others it may not be made until later or at all. Diagnosis depends on a number of factors including the nature and severity of the child's problems as well as the availability of clinics or mobile units where diagnostic services are normally provided. Diagnosis can be clinically significant, particularly where interventions exist to treat or address health conditions, and can also be important from a social perspective, for example in terms of obtaining access to welfare benefits or services. Paradoxically, diagnosis can be beneficial for parents in providing certainty and validation and can help them seek out appropriate services and better advocate for their child. However, there are dangers in "labelling" children according to their diagnosis as it can lead to lower expectations and denial of needed services, and overshadow the child's individuality and evolving capacities.

While identification and assessment of children with disabilities in high-income countries often involves teams of highly trained professionals, in LMICs such comprehensive expertise is often unavailable. In some countries, community-based workers are trained and supported by professionals where possible (such as through the use of outreach or mobile teams) to strengthen capacity and improve the quality of interventions. CBR programmes can also be key players in early detection and assessment efforts (60).

## Service provision

### *Mainstream service provision*

#### **Inclusive health care**

Historically international development and global health communities have focused on preventing health conditions associated with disability (5). Some health conditions that arise during pregnancy and childbirth can be avoided by good preconception, prenatal and perinatal care. Public health initiatives play a major role in preventive efforts (65). Such initiatives include: childhood vaccinations; child health, nutrition and education campaigns; and decreasing the exposure of young children to diseases that may lead to impairments such as malaria and trachoma, as well as to childhood injury.

The priority for children who have disabilities is to ensure that they remain as healthy as possible so they can grow, thrive and develop. While children with disabilities often have specialized health-care needs related to their disability, they are also at risk of the same childhood illnesses as other children such as influenza, diarrhoea, and pneumonia for which they require access to mainstream health-care services. Children with disabilities

are also at an increased risk of secondary conditions related to their disability. Children who are wheelchair users, for example, are vulnerable to pressure ulcers. Many of these conditions can be addressed by mainstream health-care services.

Primary health care is a natural starting point for identifying and addressing the needs of children with disabilities (22,5), with appropriate referral for more specialized needs where required (5). Primary health-care workers can assist in the identification of children with disabilities, who are often hidden in their communities and denied access to health care, and support their inclusion in health-care activities such as immunizations (31). Where possible all centre-based health services should incorporate early identification, intervention and family support components as part of existing services. Food and nutrition programmes should also include children with disabilities and should be designed with consideration given to any specific digestive problems and nutritional requirements that may be associated with their disability.

### **Inclusive early childhood education**

Inclusive education is a process of strengthening the capacity of the education system to reach out to all learners—including those with disabilities—and can thus be understood as a key strategy to achieve EFA (66). As stated in Article 24 of the CRPD, children with disabilities should not be excluded from the general education system on the basis of disability and should have access to inclusive, quality and free primary and secondary education on an equal basis with others in the community in which they live (7).

Inclusive pre-school and early primary schooling offers children with disabilities a vital space in which to ensure optimal development by providing opportunities for child-focused learning, play, participation, peer interaction and the development of friendships. Children with disabilities are often denied early years of primary schooling, and when enrolled—due to a lack of inclusive approaches and rigid systems—they often fail, need to repeat and/or are encouraged to dropout during this critical developmental period.

The CRPD and EFA initiatives promote inclusive education for all children, including those with disabilities (7) and call for the provision of assistance to ensure full and meaningful learning and participation. In many countries separate schools exist for children with certain types of impairments, for example schools for deaf or blind children. However, these schools usually accommodate a limited number of children, often lead to separation from the family at an early age, and fail to promote inclusion in the wider community. In some countries children with disabilities attend mainstream pre- and primary schools, however, they are segregated into special classrooms or resource centres which are staffed by teachers trained in special education (67,68,69,32).



Education for children with disabilities should focus on inclusion in mainstream settings. While inclusion is consistent with the rights of children with disabilities and is generally more cost effective than special or separate schools, it cannot happen without appropriate levels of support. While additional investments are required, such as progressive national and local policy, trained staff, accessible facilities, flexible curricula and teaching methods, and educational resources, these investments will benefit all children.

For all inclusive early childhood education and learning interventions, positive attitudes and responses from and interactions with peers, teachers, school administrators, other school staff, parents and community members are critical (5,31,32). Assessing and monitoring ECD and school environments for promoting inclusion is an important part of guaranteeing appropriate educational opportunities for children with disabilities. Multisectoral approaches with effective coordinating mechanisms between such sectors as education, health and social welfare are required to ensure early identification efforts, promote holistic responses and link school-based learning with home and community interventions.

### **Inclusive social services and child protection**

Parents/caregivers of children with disabilities, particularly mothers, need to have an adequate degree of economic security, access to resources and to basic services including health, nutrition and education, and protection from violence in order to be able to act on behalf of themselves and their children (1).

Children with disabilities and their family members require access to social services such as: child protection systems; support and assistance services; and social welfare services and benefits. Inclusive social protection<sup>2</sup> recognizes how the social dimensions of exclusion, including disability, can be barriers to security and essential social services. In this sense, social protection programmes may support families of children with disabilities allowing them to overcome financial and social barriers to access basic and essential services (70,71). Such programs include: the utilization of existing social transfers such as conditional cash transfers; anti-discriminatory legislation; and policy reform. It is important that conditional cash transfers do not exclude children with disabilities due to conditions that families cannot fulfil.

Guaranteeing the systematic support and protection for children with disabilities and their families requires on-going coordination between health, education, child

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2 Inclusive social protection entails using instruments that explicitly promote social inclusion and equity, and ensuring that programme design and implementation are sensitive to the added vulnerabilities that stem from social exclusion. This implies moving away from targeting particular groups and looking at the underlying causes of exclusion and vulnerabilities these groups share: discrimination and stigma; traditional social norms preventing use of services; limited assets and visibility, etc (70).

protection, ECD and other social services. This should include the incorporation of specific early intervention actions as part of the regular delivery system as opposed to structuring separate or parallel services for children with disabilities.

## **BOX 2: SUPPORTING CHILDREN WITH DISABILITIES DURING HUMANITARIAN SITUATIONS**

Children with disabilities are particularly vulnerable during humanitarian situations such as armed conflict, natural disaster and famine. Article 11 of the CRPD highlights the importance of ensuring their protection and safety in all humanitarian action (7). Stakeholders across many different areas including: health; nutrition; water, sanitation and hygiene; emergency shelter and non-food items; education; and protection need to ensure the inclusion of children with disabilities in their activities during humanitarian situations and, where necessary, adopt targeted approaches to ensure all their needs are met.

***Stakeholders can (60,72,73):***

**Prepare children with disabilities, their families and other relevant stakeholders for humanitarian situations by:**

- identifying and registering children with disabilities and their families, noting where they live, their needs during humanitarian situations, and a plan for addressing these needs;
- including children with disabilities and their families in planning and preparedness activities which take place in their communities;
- ensuring that transport, emergency shelters, and alert and warning systems are accessible for children with different types of impairments, such as visual, hearing and mobility impairments;
- providing training for people involved in preparedness and response so they are aware of the needs of children with disabilities and their families, and can address these needs.

**Ensure emergency response includes children with disabilities and their families by:**

- providing equal access to essential supplies, which may require specific strategies such as “fast track” queues and delivery of goods directly to children and their families;
- organizing for replacement of lost or damaged assistive devices and providing new ones for children who have newly acquired injuries or impairments;

- ensuring that temporary shelters, water distribution points, and latrine and toilet facilities are physically accessible to children with disabilities and their families;
- identifying child-friendly spaces and other child protection measures, and facilitate the inclusion of children with disabilities;
- including children with disabilities in education programmes.

**Support children with disabilities and their families during the recovery phase by:**

- providing access to appropriate health and rehabilitation services including assistive devices;
- including accessibility considerations in the reconstruction phase to promote participation for children with disabilities. For example ensuring that schools and housing are accessible in the long-term.

## ***Targeted service provision***

Early childhood intervention (ECI) (see Box 1 on page 11 for definition) should be an integral part of existing health, education and social system actions for all children. The provision of intervention programmes as early as possible can result in positive outcomes for children with disabilities and their families and can address the multiple factors of exclusion (74,75). There is growing evidence that children who receive ECI and other services show gains in a wide range of skills, greatly enhancing their abilities to flourish when they begin formal education and thus justifying the greater costs that such targeted interventions might entail (60,5,36). In addition to enhancing children’s developmental competencies and minimizing secondary complications, ECI programmes can help to build effective support networks for parents, promoting confidence and competence. ECI programmes that coordinate services across different sectors, such as health, education, and social protection/support, are sustainable over time, and support children and families as they move from early childhood into successful primary school experiences are particularly desirable (36).

## ***Therapy services, including assistive devices***

Therapy services aim to optimize a child’s development and ability to participate in family and community life by providing structured opportunities to practice skills appropriate to the child’s current developmental level (76). Service provision should include a combination of centre- and home-based interventions with the active involvement of parents and/

or other family members. Where available, CBR programmes can assist in establishing a bridge between centre-based services and the home environment. Therapy interventions for young children include: therapeutic activities based around play and other activities; functional training to work on skills required for independence in everyday activities; education for parents to help them better understand their child's disability and their role; prescription and provision of assistive devices<sup>3</sup> including user training; and modifications to the home and school environments. Interventions that allow the acquisition of even basic skills, such as helping a child with a disability learn to feed or dress himself or herself, can lead to a growing sense of independence and competency and reduce the burden on other family members.

## ***Family services***

Families are critical to the development and protection of their children and a close child-caregiver bond is important for both children with and without disabilities. Inclusion begins in the home environment during the early years and later broadens to school and community settings. Family services should aim to provide families with the knowledge, skills and support to meet and advocate for the needs and rights of their child in all settings (1). Service providers must work closely with families to design and implement interventions that are culturally appropriate and meet their needs (19,38,77).

Following early identification and assessment, many parents/caregivers of children with disabilities will require information about their child's disability and development progress, what steps they can and should take, and the resources available for support and treatment (4). Recognizing that formal assessment processes are often delayed or not available, the provision of information for parents is critical during the early stages of support and intervention. Information should be furnished in ways that educates parents and other family members and that promotes constructive dialogue within the family and community.

Fathers, siblings and other extended family members often play a significant role in caring for and supporting children with disabilities. Overlooking this potential support often places additional burdens on mothers. An approach which encourages father/male involvement and promotes competency building would significantly enhance families' abilities to care for children with disabilities.

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3 Assistive devices that children with disabilities might require include mobility devices (e.g. crutches, wheelchairs, orthoses and prostheses); visual devices (e.g. white canes, eyeglasses, Braille systems and talking books); hearing devices (e.g. hearing aids); communication devices (e.g. communication boards and electronic speech output devices); cognitive devices (e.g. diaries, calendars and schedules); and daily living devices (e.g. adapted cutlery and cups, shower seats and commodes) (60).

Group discussions, one-on-one listening, support groups for parents of children with similar disabilities and other potential interventions can provide opportunities to share experiences and encourage peer support and guidance. The use of stories that feature children with disabilities as protagonists is one way to demonstrate to all family members, including the child with a disability, that many capabilities are present and should be cultivated (39). Promoting appropriate activities that caregivers and children with disabilities can do together to improve developmental outcomes in children with disabilities is essential. Home visits by community workers combined with centre-based support can be an effective way to increase the confidence and competencies of parents and engage significant others in supporting the development of children with disabilities (78,32). Providing literacy and educational opportunities for adolescent girls and mothers can also have a direct impact on improving their care-giving competencies.

Organizations of and for families with children with disabilities can be an important resource for parents and other family members, allowing them to learn from others in similar situations and providing them with relevant information and support. Links with disabled people's organizations (DPOs) can: provide a network of support; provide information, guidance and advice; expand collective advocacy and public demand efforts; and connect parents and children with other people with disabilities who may serve as role models.



Australian Sports Commission (taken in Fiji)



# 5. Conclusion and next steps: Implications for policy and programming

The purpose of this document is to provide an overview of disability in early childhood and highlight the importance of providing opportunities during this period to ensure children with disabilities have the same opportunities as all children to reach their development potential and participate meaningfully in their home, school and community environments. The evidence presented underscores the urgent need to strengthen and/or scale-up early childhood development initiatives for young children with disabilities and their families.

Coordinated and sustainable responses are required from a range of stakeholders at all levels to ensure that the rights and needs of young children with disabilities and their families are met. Critical are family members and those stakeholders who deal directly with young children to meet their health, education, protection and other needs. Essential are those who contribute to the development, implementation and monitoring of policies, budgets and services (e.g. governments, NGOs, professional organizations, media, private sector, and parent and disability advocacy organizations).

While the CRPD provides a “renewed” starting point for recognizing the rights and needs of children with disabilities building on existing CRC, EFA and MDG initiatives, a sustained commitment is required to mobilize and support stakeholders to develop inclusive and targeted ECD programmes which are integrated into existing health-care and education systems. This includes within existing strategies, such as CBR, the Global Partnership for Education, Out-of-School Children Initiatives (OOSC), and other efforts to meet international goals, targets and commitments.

This document is not an end in itself—it is an initial effort by UNICEF and WHO to stimulate discussion, planning and action on issues related to disability, early childhood development and early childhood intervention.

The following areas for action, which are aligned with the CRPD and draw on the recommendations in the *World report on disability (5)*, provide a basis for further discussion, expert consultation, advocacy and mobilization efforts, and planning.

**Inclusion of children with disabilities in mainstream policies, systems and services which support and maximize their development potential.**

- Review national policies in relevant sectors—health, education and social—to ensure they are aligned with international conventions and commitments (e.g. CRC, CRPD and MDGs) and inclusive of young children with disabilities.
- Analyse sector-wide strategies, programmes and budgets to determine whether they include concrete actions to support young children with disabilities and their families.
- Develop, implement and monitor a comprehensive multisectoral national strategy and plan of action for young children with disabilities that addresses family support, community awareness and mobilization, capacity of human resources, coordination and service provision.
- Advocate for and seek sustainable financial and technical support to address the service delivery gaps that have been identified.

**Programmes and services which specifically target young children with disabilities and their families.**

- Assess the capacity of current programmes and services to accommodate the needs of children with disabilities and their families. Where gaps exist facilitate the integration of specialized services, such as ECI.
- Strengthen the capacity of parents' associations and DPOs to provide care and support; undertake advocacy and public awareness initiatives; and participate in policy development, service design and programme monitoring.

**Involvement of children with disabilities and their families in all early childhood development activities including policy development, service design and programme monitoring.**

- Encourage the building of strong partnerships between parents and professionals to ensure ECD services relevant to children with disabilities are child/family focused.
- Provide assistance to strengthen the capacity of children with disabilities to participate in ways that they themselves find rewarding and meaningful while also promoting inclusive attitudes and behaviours of their peers.

### **Capacity development of human resources across relevant sectors to address disability.**

- Provide education and training on disability for relevant stakeholders. Training may cover the rights of children with disabilities, the need for both mainstream and targeted services, and strategies for the inclusion of children with disabilities and their families.

### **Public awareness and understanding about children with disabilities.**

- Undertake advocacy at all levels to highlight the urgent need to include children with disabilities in ECD initiatives and provide targeted services.
- Utilize diverse communication channels, including mass and community media, traditional media, such as puppetry, poetry, song and storytelling, and interpersonal communication to eliminate stigma and prejudice and to promote positive attitudes towards children with disabilities and their families.

### **Data collection and research.**

- Identify existing data collection systems for children and ensure they include provisions for the collection of information on children with disabilities, ensuring sex and age disaggregation.
- Monitor and evaluate ECD efforts for children with disabilities.
- Collect evidence on what works—including examples of good practices—in promoting and supporting ECD for children with disabilities. Attention should be paid to times of transition such as from preschool to primary education.

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### Acknowledgements

This paper was prepared by a team of UNICEF and WHO staff with contributions and assistance from a number of external collaborators.

The core team was composed of: Rosangela Berman-Bieler, Meena Cabral de Mello, Amy Farkas, Natalie Jessup, Alana Officer, Tom Shakespeare, and Nurper Ulkuer with support from Nora Groce, Michael Guralnick and Garren Lumpkin to help put the concepts into writing.

A number of UNICEF and WHO colleagues at the country, regional and global levels also made substantial contributions to the development of this paper. Special thanks are extended to: Mariavittoria Ballotta, Nicola Brandt, Claudia Cappa, Paula Claycomb, Clarice de Silva e Paula, Peter Gross, Deepa Grover, Rachel McLeod-MacKenzie, Gopal Mitra, Natalia Mufel, Maite Onochie, Lieve Sabbe, Juliana Seleti, Chiara Servili, Vijaya Singh, Natalia Elena Winder-Rossi, Taghi Yasamy, Nurten Yilmaz and Flint Zulu for their comments, advice and insight.

Additional thanks are also extended to Connie Laurin-Bowie, Alexander Cote, Judith Heumann, Elena Kozhevnikova and Donald Wertlieb for their expert input and guidance.



ISBN 978 92 4 150406 5



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