



# INCLUDING ORPHANS AND VULNERABLE CHILDREN WITH DISABILITIES IN EARLY CHILDHOOD DEVELOPMENT PROGRAMS

TECHNICAL BRIEF



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#### **AIDSTAR-One**

John Snow, Inc. 1616 Fort Myer Drive, 16th Floor Arlington,VA 22209 USA Phone: 703-528-7474 Fax: 703-528-7480

E-mail: info@aidstar-one.com Internet: aidstar-one.com

#### INTRODUCTION

There are no reliable estimates of the number of children living with disabilities. Estimates vary greatly, depending on the definition of disability, the methodology, and the measurement tool used (World Bank 2011; WHO 2012b). The most commonly used estimates are that approximately 93 million children aged 14 or younger live with a moderate or severe disability of some kind (UNICEF 2013c); and that globally, up to 150 million children (aged 0-18) experience some form of disability: learning, speech, physical, cognitive, sensory, or emotional (Global Partnership for Children 2012). Other data suggest that between 5 and 10 percent of all children in Africa are children with disabilities (UNICEF 2013b). However, the true numbers remain unknown.

What we do know is that children with disabilities are particularly vulnerable, the extent influenced by the types of impairment as well as by such factors as the sex of the child. Research in developing countries suggests that 90 percent of children with disabilities do not attend school and are more likely to drop out of school than any other vulnerable group, even in countries with high primary school enrollment rates (Global Partnership for Children 2012). In its Multiple Indicator Cluster Surveys for ages 2–9, UNICEF used 10 questions to screen children for risk of disability. Children who screened positive for increased risk of disability were more likely than others to come from poorer households, face discrimination and restricted access to social services, be underweight, and have stunted growth (UNICEF and Pineda 2008). Overall, children screening positive in the disability survey participated in fewer early learning activities (UNICEF and Pineda 2008).

Children with disabilities are also more vulnerable to physical, sexual, and psychological violence and exploitation than their non-disabled peers (WHO 2012b; UNICEF 2013c). The levels of violence and

I know that creating an AIDS-free generation takes more than the right tools, as important as they are. Ultimately, it's about people ....We need to make sure we're looking out for orphans and vulnerable children who are too often still overlooked in this epidemic.

— Secretary of State, Hillary Rodham Clinton, 2012 International AIDS Conference Address

exploitation vary depending on the child's sex and specific impairments. A 2012 systematic review and meta-analysis indicated that violence is a serious concern for children with disabilities and that the risk of violence is higher for children with mental or intellectual disabilities. The review authors note, however, that these data are based on a small subgroup of research (Jones et al. 2012). A rise in sexual violence against and exploitation of children and adults with disabilities has been documented in cultures with the persistent myth that having sex with a virgin "cleanses" one of HIV, because of assumptions that those with disabilities are virgins (Groce 2004). Access to justice is routinely denied to children with disabilities who have been victims of a crime. This is because they are not considered credible witnesses, or their cases are not taken seriously, or the court system lacks appropriate services (CRIN 2011). Many children with disabilities and their families are unaware of their rights and unable to speak out about violations.

As of the end of 2011, an estimated 34 million people were living with HIV; 3.3 million of them children under 15 years. Also as of 2011, approximately 17.3 million children under the age of 18 had lost one or both parents to AIDS, and millions more were vulnerable to the physical, psychological, and economic effects of HIV within their households and communities (UNAIDS

2012). Yet scant data exist on the intersection of children, HIV, and disabilities, such as the number of young children with disabilities in high HIV prevalence settings, the number of older orphans and other vulnerable children (OVC) with disabilities, or the prevalence of OVC caregivers with a disability. There is little to no research on the particular vulnerabilities of OVC with disabilities. While it is commonly accepted (and noted in the literature) that OVC with disabilities are particularly underserved and discriminated against, there is little to no research to support this understanding. More research is clearly needed.

What is known is that children with disabilities may require additional support. They often have specific medical, educational, or rehabilitation needs, and may be given lower priority in overstretched households and social service systems.

Addressing the needs of all young children with disabilities—and addressing them in a timely manner is critical to improved health and development outcomes for individuals, families, communities, and nations. Rapid advances in biological and behavioral research point to early childhood as a time of tremendous brain growth. During a child's first few years, the neural connections that shape physical, social, cognitive, and emotional competence develop most rapidly and possess the greatest ability to adapt and change. Connections and abilities developed in early childhood form the foundation for subsequent development. As a result, providing the right conditions for healthy early development is likely to be much more effective than treating problems later in life (Center on the Developing Child 2007).

Early childhood development (ECD) programs can nurture diverse abilities, overcome disadvantages and inequalities, and respond to developmental needs of young children with disabilities (see Box I). ECD programs can and should be focal points for service provision and referral for children and families with various needs generated by disability. Meeting even

#### **BOX I. DEFINITIONS: EARLY CHILDHOOD**

Early childhood development refers to "the processes by which [infants and young] children grow and thrive, physically, socially, emotionally, and cognitively, during this time period" (UN Children's Fund [UNICEF] and Department of Social Development, Republic of South Africa 2006).

Early childhood generally refers to children between birth and the official start of formal schooling. Researchers and organizations also often include the early primary school years—ages six to eight—because of the importance for children of the transition into primary school (Consultative Group on Early Childhood Care and Development 2011).

moderate needs is vital. Failing to address these needs early on can lead to a downward spiral, whereby children with disabilities as well as their family or caregivers become more vulnerable. Impairments can increase, leading to further social exclusion. For example, early assessment and intervention with families can optimize the learning potential of children with disabilities and increase their chances to participate and thrive in inclusive, mainstream settings. Evidence shows that one in three infants and toddlers who receive early interventions do not present later with a disability or require special preschool education (UNESCO 2009).

This technical brief presents information and guidance on implementing ECD programs for young OVC with disabilities and their families. It provides a basic overview of the fundamental elements a program manager should consider to integrate disability positively into ECD programs and address specific disabilities individually, as needed. This technical brief describes "twin-track" and "triple-track" approaches that promote participation, attention to specific

needs, and equal access for OVC with disabilities and their families. It also lists six critical elements for HIV programs seeking to address the needs of children with disabilities. The focus is largely on young OVC, but includes annexes on older OVC with disabilities and OVC caregivers, including those with disabilities. A list of resources for further information is also provided.

# LINKAGES AMONG HIV, DISABILITIES, OVC, AND ECD

#### HIV, Disabilities, and OVC

The relationship between disability and HIV is bidirectional. HIV can lead to disability, and those with preexisting or acquired physical, intellectual, sensory, or mental health disabilities are also at risk of HIV infection (O'Brien 2009; Hanass-Hancock 2010; Groce 2013). Historically, it was believed that those with a disability were at a decreased risk of HIV infection, but emerging evidence suggests that having a disability creates an equal or increased risk of acquiring the virus (Groce 2004; Rohleder 2009; Maart 2010).

Research indicates that children with HIV have lower motor, cognitive, and adaptive functioning compared to children who are uninfected. These limitations increase with declining health status and correlate with the child's home environment (Sherr 2009; Burns 2008). While very little research has focused on the impact of disability at the household level, one pilot study in Chongwe district, Zambia, found that disability was present in over 35.7 percent of HIV and AIDS-vulnerable households. This data suggests that those with disabilities were less likely than their non-disabled peers to seek care and support, attend school, or engage in economic activities (Fleming et al. 2012).

There has been a tremendous response to children's needs within the HIV epidemic, however, national responses to HIV often do not include as target groups either children with disabilities or HIV-

affected families that include a child with a disability. Children with disabilities who have lost a caregiver are particularly vulnerable, because they are less likely to receive the same levels of care and support than their non-orphaned peers, or orphaned but non-disabled peers (Groce 2004b). HIV-positive children with disabilities are also more likely to experience exclusion and discrimination (UNAIDS 2009), as are HIV-negative children who live with an HIV-positive caregiver with a disability.

There are promising developments signaling increased attention to HIV and disability. But so far there is insufficient focus on disability as it relates to the HIV epidemic, let alone on how young children and their caregivers' needs are addressed. This will become even more critical as more HIV-positive children receive highly active antiretroviral therapy (HAART), and as the needs of children with disabilities are addressed, including those with developmental and learning deficits associated with HIV, a growing sub-population (Burns 2008).

A few international donors include "disability" as a cross-cutting focus area and have strategies/policy guidance for addressing disabilities. For example, USAID developed a disability policy in 1997, and the Australian Agency for International Development (AusAid), the UK Department for International Development (DFID) and the Swedish International Development Cooperation Agency (SIDA) also have policies and guidance. The Technical Considerations for the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) fiscal year 2013 operational plan notes that programs, where possible, should include people with disabilities and disability-related issues for improved HIV outcomes for all people (PEPFAR 2012b). Yet it is unclear to what extent these policies have translated into programs that promote equality of access and inclusion for children with disabilities.

#### **ECD** and Children with Disabilities

The tradition of neglect and disregard of young children with disabilities, including OVC, emerges partially from the fragmented and isolated nature of policies and programs. Children with disabilities were "too young" for the educational system, "too damaged" for the health system, "too hidden" for the protection system, and often perceived as someone else's problem. The recent focus on integrating services such as maternal and child health, nutrition, ECD initiatives, and care and education programs, has demonstrated the benefits of multi-sectoral collaboration and integration for reaching more children, both with and without disabilities.

The wide-ranging and multiple benefits of ECD programs (targeting children from birth to age of entry into formal schooling) have been well documented. ECD interventions are among the most cost-effective approaches for improving outcomes for vulnerable and at-risk children (Cunha and Heckman 2007; Engle et. al. 2008), and have an important role to play in improving the wellbeing of children with disabilities and their families. These programs can nurture diverse abilities, overcome disadvantages and inequalities, respond to developmental needs of young children with disabilities, and reach families and communities with information and education. ECD programs can also help with early identification of children with disabilities, as well as with assessment and intervention with families.

#### UNDERSTANDING DISABILITY

This technical brief uses the broad definition of disability as articulated by PEPFAR in Box 2, noting that this may encompass a wide range of disorders, conditions, or situations. This PEPFAR definition evolved from the 2006 UN Convention on the Rights of Persons with Disabilities (CRPD), which provided an open, social-oriented definition "recognizing that discrimination and therewith the disabling of access

#### **BOX 2. PEPFAR AND DISABILITY**

Disability is broadly understood to be an evolving concept encompassing the interaction between people with physical, sensory, mental, intellectual, or other impairments and various barriers that may hinder their full and effective participation in society on an equal basis with others. Disability may be expressed and experienced differently in different socio-cultural contexts. Societal norms surrounding disability can greatly influence the status of disabled people in society, their roles, norms, behavior, and access to resources relative to the wider population. Disability intersects with all other population groups; anyone can acquire a disability at any stage of life. Disability-inclusive programming is relevant for both HIV-positive people, who may be considered disabled as a consequence of their HIV-positive status, and for people with disabilities who may find themselves at increased risk of HIV infection because of societal discrimination. Including people with disabilities and disability issues in PEPFAR programming has the potential to positively influence the success of all programs addressing the HIV epidemic (PEPFAR 2012b).

for persons with disabilities is largely due to barriers of various kinds, including the built environment, but even more so to social and attitudinal ones such as stereotypes, prejudices and other forms of paternalistic and patronizing treatment." (Schulze 2010).

Achieving an international, globally accepted definition of disability is challenging because models of disability are strongly influenced by culture and local contexts, and what is considered a disability in one society may not be seen that way in another. What is considered a disability—and how people with a particular disability

are viewed and treated—is highly dependent on the country context, national, and local definitions, what is valued and devalued in a society, and the overall social interpretation of a particular disability (Groce 1999). In one context, a disability may be have highly negative connotations—be associated with witchcraft, bad karma or evil spirits, for example and a person with a disability may face ostracism, daily restrictions, and stigmatization. In other settings, the same disability may be considered a blessing. For instance, among the Hmong, an infant with seizures associated with epilepsy is regarded as a spiritually gifted and valued member of the community. In some Pakistani communities, children with microcephalic disabilities are abandoned as "rat children" and yet are valued in certain fertility rites. Research from northern Mexico and Botswana suggests that a child born with a disability indicates God's trust in specific parents' ability to care well for a child (Groce 1999; Ingstad 1988; Madiros 1989). Overall, research about disability and culture suggests that prevailing social, cultural, and economic norms may be more limiting for individuals with disabilities than specific physical, sensory, psychological, or intellectual impairments (Groce 1999). Disabilities can present in many forms over a lifetime: long-term or temporary, visible or invisible, or static, episodic or degenerating. Any two individuals with the same disability may have different experiences, needs, and abilities (World Bank 2011).

Historically, disability was seen through a medical and welfare framework that focused on correcting or handling the disability clinically and therapeutically. Less attention was paid to social needs (Storbeck 2011). These traditional and outdated biomedical, welfare, and charity frameworks left many invisible, stigmatized, and underserved. The UN Convention on the Rights of People with Disabilities (CRPD), adopted by the United Nations in 2006, propelled awareness of disability away from persons with disabilities as "objects" of charity, medical treatment, and social protection to "subjects" who are capable of claiming

...does short-sightedness qualify as a disability? Is a person with an artificial finger considered to be disabled? Is a deaf person who can communicate efficiently using sign language disabled?

(Handicap International 2013)

their rights and making decisions based on free and informed consent as active members of society. The 1989 UN Convention on the Rights of the Child (CRC), including its 2005 General Comment 7 on Early Childhood (UNCRC 2006) and its 2007 General Comment 9 on Children with Disabilities, now converges with mandates of the CRPD (Lansdown 2012). These advances have led to an increasing focus on the social model of disability.

The International Classification of Functioning, Disability and Health (ICF) promotes a "bio-psychosocial model" that straddles both the medical and social frameworks. This model considers functioning and disability as a dynamic interaction between health conditions and contextual personal and environmental factors (World Bank 2011). In this framework, disability "is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)." (World Bank 2011).

These advances have contributed to evolving perceptions, attitudes, and behaviors towards persons with disabilities. Using a bio-psycho-social framework, or "lens," can help program planners consider not only the disability itself, but also the related risk factors (such as social exclusion or stigma) that may affect the quality of life and wellbeing of children with disabilities and their families. Children with disabilities

should be seen not in isolation, but in the context of their family and caregivers, and their overall social environment (World Bank 2011). It is now globally accepted that young children with disabilities are entitled to a full range of rights, including the right to survival and development, health and health services, education, and social protection. A growing consensus and the professional literature support the rationale and strategies for securing what the CRC declared as children's rights to a "full and decent life," to conditions that ensure dignity, promote self-reliance, and facilitate active participation in the community (UNCRC 2006).

Annex I describes some of the general considerations and needs common to children with disabilities.

# TRIPLE-TRACKING TO INCLUDE CHILDREN WITH DISABILITIES

Limited consensus exists on practical ways to address the multiple manifestations of disability in various sectors such as health, education, and social protection. Oftentimes, the approach has been to insert children with disabilities into existing programs.

"Twin-tracking" is a conceptual and practical tool for meeting the challenges of addressing the multiple manifestations of disability and designing inclusive programs (as illustrated in Figure 1). Perhaps most often recognized as the "disability mainstreaming" approach, twin-tracking requires simultaneous, harmonized attention to:

- I. Equitable access and inclusion of children with disabilities into existing services
- 2. Programs and services designed for and targeted at particular, relevant disability needs or issues.

For example, for Clara, a five-year-old child with cerebral palsy, to participate in a community ECD program with other children, the following may need to be in place: an equal opportunity to attend the program, appropriate accommodations that minimize the impact of her disability, assistive devices or technologies that promote her access and engagement, and staff who are aware of and competent to respond to how she learns and develops, both as an individual child and as a child with a disability.

Promoting equitable access and inclusion of children with disabilities in existing child-centered, family-and community-focused ECD programs should be a major focus of any approach. This recognizes the family and community's vital role in supporting the child's development and honoring the family as a basic building block of the child's community. Figure 2 illustrates this ECD-focused twin-tracked approach.

To meet the needs of young OVC with disabilities better, a twin-tracked approach can be amplified by a multi-layered "triple-track" approach that enhances program quality and impact for children with disabilities by simultaneously incorporating three tracks:

Figure 1. Inserting Disability Services into Existing Programs

# SPECIALIZED DISABILITY SERVICES

UNIVERSAL SERVICES

Child-centered and family- and community-focused programs and services that promote equity and inclusion of all children

- 3. Child-centered and family- and communityfocused specialized, cross-cutting disability services that support the specialized needs of children
- 4. Age- and stage-appropriate and gender-sensitive, tailored programs and services for young children.

These three aspects together (illustrated in Figure 3) build upon the twin-track approach by incorporating age- and stage-appropriate, and gender-sensitive tailored programs and services. A triple-track approach can guide the way for ECD programs to take into account and meet the needs of children across abilities, sex, age and other cultural factors.

For example, for Clara, the five-year-old child with cerebral palsy mentioned above, the triple-track approach would ensure the following elements: I) Clara would attend ECD programs offered within her community that are available for all children,

2) the ECD program would be inclusive, incorporating Clara and addressing her unique needs due to her disability, while, while simultaneously including her in the mainstream program, and 3) the disability services offered to her are appropriate for a five-year-old girl who is developmentally delayed. Clara is included in programs for all children while still receiving specialized disability services that are appropriate for her specific profile. She benefits from the program along with her peers, family, and community. This approach also emphasizes the features of early childhood education, whereby the special age- and stage-specific needs of young children are taken into account.

One might be able to have a good or adequate ECD program based on any one of these elements. However, if the focus is on programming best practices that meet the needs of young children with disabilities, then each of the three tracks must be respected and incorporated.

Figure 2. A Twin-Track Approach to ECD for Children with Disabilities

PROMOTING
EQUITY & INCLUSION:
EQUITABLE ACCESS AND
INCLUSION OF CHILDREN
WITH DISABILITIES INTO
EXISTING CHILD-CENTERED,
FAMILY- AND COMMUNITYFOCUSED ECD PROGRAMS

SUPPORTING
SPECIFIC NEEDS:
ECD PROGRAMS DESIGNED
FOR AND TARGETED
AT PARTICULAR, RELEVANT
DISABILITY NEEDS OR ISSUES

PROMOTING
EQUITY AND INCLUSION

ENSURING AGE- AND
STAGE-APPROPRIATES AND
GENDER-SENSITIVE
ECD PROGRAMS AND
POLICIES

Figure 3. A Triple-Track Approach to ECD for Children with Disabilities

# PROGRAM ELEMENTS FOR YOUNG CHILDREN WITH DISABILITIES IN HIV SETTINGS

Numerous analyses have identified essential elements for ensuring high-quality, inclusive programming for young children with disabilities (CARE n.d.; Brown & Guralnick 2012; Guralnick 2005, 2011; Hardin & Hung 2011; Odom et. al. 2003; Vargas-Baron & Janson 2009; Wertlieb 2003, 2012; WHO 2012a, b). PEPFAR suggests the following to address the needs of OVC with disabilities generally (PEPFAR 2012b):

Monitor, prevent, and mitigate girls' and boys' vulnerability to sexual abuse, exploitation, and HIV.

- Support orphaned girls and boys with disabilities so that if the immediate family is unable to care for them, alternative care within the wider family is provided and, failing that, care within the community in a family setting.
- Assess the dynamics of caregivers and personal attendants for people with disabilities; and conduct outreach as appropriate to ensure that caregivers are adequately trained to handle additional responsibilities, such as HIV- and AIDS-related treatment, and care and support of children with disabilities or the children of HIV-positive parents.
- Provide livelihood and economic empowerment programs for parents or other family members caring for children affected by HIV and AIDS.

- Provide support for children with disabilities and/ or orphaned and/or vulnerable boys and girls with disabilities to ensure equal access to mainstream education; interventions to ensure that school environments are safe for students with disabilities; and vocational training for boys and girls, both in-school and out-of-school.
- Advocate, develop, and implement policies, and monitor for inheritance and property rights of women and orphans with disabilities.

Systematic research to establish evidence-based practice for ECD programs for OVC with disabilities has only recently begun. However, a growing consensus among scholars and practitioners in diverse countries points to six program elements that can be considered "practice-based evidence." Effective programs must carry out six major functions:

- Promote inclusion
- Empower and support caregivers and families
- Develop capacity
- Educate and engage the community
- Put family care first
- Enable cultural sensitivity and responsiveness.

Each element is described in detail below. Woven within this section are five portraits which give examples of programs that are playing (or have played) a role in promoting awareness, access, and rights for children with disabilities.

#### **Promote Inclusion**

Inclusion does not simply mean inserting children with disabilities into existing structures or ECD or OVC programs. It requires thinking about how program managers can transform and adapt these programs and social systems to make them accessible, beneficial, and productive for children with disabilities. Sometimes referred to as "universal design," this strategy makes programs and services welcoming and usable to a diverse range of individuals, including those with disabilities. In the context of this technical

brief, this means identifying and removing barriers, and establishing measures that support young children with disabilities throughout their environment: at home, at school, and in their communities (UNICEF 2007a). Inclusion emphasizes services and attitudes that emphasize ability rather than disability (i.e., what the child can do); on competencies rather than incompetencies; and on child and family strengths rather than weaknesses, shortcomings, and deficits. This inclusive approach also ensures that gender considerations and disparities are acknowledged—and programmed for—as a cross-cutting issue (Mac-Seing 2012). As a general consideration, these principles of universal design can help inform services for all young children, not only those with disabilities.

It's important to change attitudes and rules so that children who have disabilities can go to school, play and take part in activities that every child wants to do.

(UNICEF & Pineda 2008)

Programs that treat all children with disabilities as one group are likely to miss the important point that these children are individuals and part of the social fabric of family and community. A well-intentioned program may have developed individualized routines for children with disabilities (not necessarily a bad idea), but may not recognize that these routines result in shortened or no playtime for those children. In another childcare setting, a child with a disability may be spending more time with a caregiver, rather than having the opportunity to play freely with the other children. An inclusive school setting can change attitudes towards those who are in some way different by educating all children together (World Bank 2011). User-friendly manuals such as It's About Ability (UNICEF & Pineda 2008), See Me, Hear Me (Lansdown 2009), and Travelling Together (Coe and Wapling 2010) provide clear and compelling examples of inclusion. Annex 3 provides a list of resources for ECD programs for OVC with disabilities.

Government and nongovernment health, education, and social protection agencies also increasingly recognize that integrated approaches strengthen their impact, and that the absence of integration limits their programs. Families of young children benefit from a "one-stop-shop" where any individual member can access health, nutrition, education, or protection services efficiently and flexibly, and where a family member with a disability or special need can access care in an inclusive community-based setting, such as a school, clinic, or childcare center with comprehensive services.

#### PORTRAIT I. INTELLECTUAL DISABILITY ASSOCIATION OF LESOTHO (IDAL)

In 1992, concerned parents of children with intellectual disabilities established the Intellectual Disability Association of Lesotho, or IDAL, formerly the Lesotho Society of Mentally Handicapped Persons. IDAL now has 21 branches throughout the country to protect the rights of children with disabilities and adults with intellectual disabilities. The organization's purpose is to empower parents with skills to understand and provide for their children, and to advocate for inclusive services for all children with disabilities. To reach young children and their families with services, IDAL piloted the Community Based Rehabilitation Program. This program has been adopted by the government and introduced in two districts, with the goal of having trained resource people who are able to identify and support families of children with disabilities. IDAL is currently advocating to the Ministry of Social Development for training for District Rehabilitative Officers in early identification skills. This would allow families to receive support and young children to access services at a critical phase in their lives.

Many of the families served by IDAL cannot afford occupational or physical therapy for their children, so in 2009 IDAL launched a home visit program. An occupational therapist conducts home visits to help caregivers develop tools and exercises unique to their children's conditions, using available resources within the home. Caregivers were then able to conduct stimulation exercises for their children with regular follow-up and support from the occupational therapist. Empowering caregivers with these skills and resources "allows them to not be scared of their own children anymore." (AVERT 2012). Unfortunately, the program ended when the occupational therapist's contract ended with Skillshare International in 2010. IDAL continues to advocate for early identification and intervention services at District Hospitals.

IDAL also works with youth with intellectual disabilities, training them in self-advocacy so that they can speak up on issues that affect them and request services and life skills to mitigate against peer pressure; sexual, emotional, and physical abuse; and HIV infection. In addition, IDAL focuses on strengthening national- and local-level mechanisms for the protection of people with disabilities. IDAL convenes forums with police, magistrates, prosecutors, parents, and youth to raise awareness about legal protection of people with intellectual disabilities, to advocate for their support during court proceedings for sexual abuse cases, and to enable those with disabilities to discuss how the current systems can be improved to uphold their rights. Through this systemic, collaborative, and participatory program, IDAL promotes changes in attitudes and behaviors and a sense of the legal equality of people with intellectual disabilities in Lesotho.

For more information contact: <a href="mailto:idal@idal.org.ls">idal@idal.org.ls</a> (online at <a href="www.idal.org.ls">www.idal.org.ls</a>)

## **Empower and Support Caregivers and Families**

Children's health and wellbeing is highly dependent upon the health, wellbeing, and competence of their families and caregivers. A child's disability imposes additional strains on caregivers, and requires new, often complex, caregiving skills (see Annex 2). Consensus is growing around a community-based rehabilitation approach that focuses on supporting children and their families by providing information, working closely with families and caregivers, and facilitating participation of children with disabilities. Families and caregivers can become powerful advocates for initiating and sustaining change and modeling the self-advocacy skills their children will need throughout their lives.

ECD programs can help empower families and caregivers of OVC in a range of ways: creating links with self-help groups for information and advice; empowering them to support advocacy and awareness in the community; and educating them on caring for a child with disabilities. Approaches combining center-based programs with parenting interventions can help caregivers and teachers detect developmental delays, support children's development, prevent abuse and neglect, and promote school readiness (see Portrait 1: Lesotho; Portrait 2: Kenya; Portrait 3: Zimbabwe; and Portrait 4: Swaziland for examples of programs working with caregivers).

#### **Develop Capacity**

The dearth of well-trained and supported service providers constrains the inclusion of young children with disabilities. This limits children's access to health and education programs and reinforces stigma and exclusion. Many children with disabilities require services over long periods of time and from diverse professions or specialties. In an ideal setting, teams would draw from expertise in pediatrics, child development, early intervention, nutrition, education, physiotherapy, audiology, speech and language therapy, physical therapy, occupational therapy, and psychology, to name a few. The talents and skills for communication, coordination, and collaboration among the disciplines and between program staff and caregivers require training and support as well.

In many settings, where there are severe human resource shortages, a multidisciplinary team is not feasible. Yet even basic ECD programs can help teachers or caregivers provide care and support for early identification, assessment, and early intervention planning, and services for children with disabilities (UNICEF 2013a). As noted in the previous section, approaches that combine center-based programs with parenting interventions can help caregivers and teachers detect developmental delays, support children's development, prevent abuse and neglect, and promote school readiness. Programs can provide pre- and in-service training so caregivers and teachers are, at a minimum, aware of their responsibilities towards all children and able to build and improve their skills in teaching children with disabilities.

Examples from low-resource settings (see Portrait 1: Lesotho and Portrait 3: Zimbabwe) also suggest the potential of well-trained volunteers to help teachers learn how best to support children with disabilities, as well as trained physical therapists to provide support in the home setting. These volunteers and providers can partner with teachers in the prevention, diagnosis, assessment, and management of developmental

<sup>&</sup>lt;sup>1</sup> While not focused on children with disabilities, AIDSTAR-One has conducted a literature search focusing on children, parenting, and caregiving, which identifies general principles and lessons learned to support and strengthen child-caregiver relationships in contexts in which children and families are affected by HIV. The Review of Literature on Supporting and Strengthening Child-Caregiver Relationships (Parenting) is available online at <a href="http://www.aidstar-one.com/focus\_areas/ovc/report/parenting">http://www.aidstar-one.com/focus\_areas/ovc/report/parenting</a> lit review.

#### PORTRAIT 2. HANDICAP INTERNATIONAL AND THE CATHOLIC DIOCESE OF KITALE, KENYA

As a stepping stone to encourage inclusion of young children with disabilities in Kenya, Handicap International, in partnership with the Catholic Diocese of Kitale, piloted multidisciplinary HIV prevention and treatment programs. These programs address the needs and rights of OVC with disabilities through services covering a range of OVC and early childhood priorities, including:

**Psychological counseling:** Child-friendly sessions used plays, poems, stories, and games to enable children to explore and address psychological challenges, such as the double stigma of living with HIV and disability. The intervention aims to improve children's social behavior, reduce emotional problems, and lower anxiety and depression.

**Nutrition and adherence to treatment:** To improve the health and quality of life for children and families while children await ART initiation, families received support in land-leasing for crop production, farming resources, nutrition demonstration, and counseling on treatment adherence.

**Strengthening of traditional family and communal supports system:** HIV-positive children and caregivers received HIV prevention education in accessible formats, and were referred for medical treatment to health facilities with accessible services, such as sign language interpretation and ramps. A clothes-harvesting pool was established, to which community members donated used clothing to families affected by HIV.

For more information contact: <u>muriel.mac-seing@handicap-international.ca</u>

difficulties (WHO 2012a). Larger organizations can provide training and leadership for small community-based groups.

#### **Put Family Care First**

ECD programs for children with disabilities can provide education, resources, and options that mitigate against institutionalization and help to reintegrate institutionalized children into their families and communities. These programs can help families care for children with disabilities, help prevent unnecessary family-child separation, and promote appropriate, protective, and permanent family care through education and advocacy. As the push to end institutionalization of children with disabilities continues, program planners are likely to confront de-institutionalization in many forms. These include providing for children who will be leaving institutions as they close down, supporting a transition into family care, providing appropriate options for babies born with disabilities (and surviving as medical care

continues to improve), and addressing children's acquired disabilities.

#### **Educate and Engage the Community**

There are many community groups working to improve public understanding of disability, address fears and misconceptions, promote the rights of persons with disabilities, and represent disability accurately. ECD programs can help these groups change negative attitudes and improve knowledge about disabilities in the broader community. ECD programs can target potential leaders of initiatives promoting non-discrimination and participation, such as those working in gender equality, human rights, education, health care, social protection, law enforcement, and the media. For example, ECD programs can promote the inclusion of children with disabilities by: providing disability-equality training; strengthening the care and support skills of parents' associations and school management committees; undertaking advocacy and public awareness initiatives;

#### PORTRAIT 3. NZEVE CENTRE, ZIMBABWE

Deaf children in Zimbabwe, like most places in the world, are a marginalized group. They are frequently excluded even from programs aimed at children with disabilities because of language barriers. Almost all deaf children have hearing parents who were not aware of the signs of deafness and did not expect communication challenges with their child. Parents frequently delay seeking medical help, going instead to prophets, traditional healers, and grandparents for advice and treatment. Also, in many countries there is no formal sign language, so teaching sign language is very difficult.

NZEVE Centre opened in 2000 in response to the need for early identification and intervention for deaf children. Activities promote awareness about deafness, encourage early diagnosis, and involve parents in their children's educational and social development. Until the 1990s, deaf children in the province of Manicaland could access appropriate education only through special schools in Harare, Bulawayo, Masvingo, or Gweru. The Ministry of Education (MOE) established Resource Units for deaf children at Manicaland schools with specially appointed, and sometimes specially trained, teachers. This enabled many deaf children to access primary education for the first time. However, the appropriate support measures and resources were never put in place and deaf children ended up in regular classrooms without sign language. As a result, many of these children dropped out of school early.

NZEVE augmented the MOE's efforts by supporting teachers through networking, school visits, and identifying classroom resources. NZEVE volunteers visit special classes for deaf children to teach health and life skills, and deaf adults work alongside teachers in the classrooms, serving as communication assistants and role models. Many teachers of the deaf have poor sign language skills and do not know the vocabulary for sexual health education, so NZEVE trains volunteer interpreters in sign language.

A lack of opportunities for older deaf youth prompted NZEVE to also offer vocational skills training and a weekend social club. This provides both a place to meet and educational and recreational activities that cater to the young people's needs—particularly life skills and information about health issues, and HIV in particular. Trained peer educators lead regular workshops and training sessions with other deaf youth, using participatory methods, videos, and drama. Existing materials are used and adapted to take into account the different ways deaf people learn, and simplified to help deaf youth with limited literacy skills. A life skills program for deaf schoolchildren was introduced at the provincial level, and volunteers visit the schools weekly to give health information.

Caregivers choose their own training program content, which includes learning about parenting deaf children, sign language, health and HIV, and legal issues, such as inheritance and child protection. NZEVE provides psychosocial support and facilitates internal savings and lending groups with parents of deaf children and their local communities. The group also provides training in business skills, and supports income-generating projects (e.g., knitting, sewing, and small animal husbandry).

For more information contact: Libby Foster director@nzeve.org

and participating in policy development, service design, and program monitoring.

ECD programs can ensure that community spaces are accessible or can address violence against persons

with disabilities (World Bank 2011; WHO 2012b). Home-based ECD initiatives can empower caregivers and other family members to improve their own beliefs and attitudes, as well as those of their friends and neighbors. ECD programs can also promote and

strengthen linkages between educational services and community-based services. This can ensure that limited resources are used efficiently and that critical services (education, health care, social services) are integrated (World Bank 2011).

# **Enable Cultural Sensitivity and Responsiveness**

ECD programs for OVC with disabilities must understand, respect, and respond to the diverse beliefs and practices that influence how any given community understands and treats these children and their families. The taboos and stigma associated with disability run deep and strong in most societies, and at times run counter to the views and values of other cultures. Comprehensive ECD services that provide care, stimulation, parental support, and access to relevant services can enhance the effects of interventions for children with disabilities (UNESCO 2009). But ignorance and misunderstanding about disability are major obstacles to effective programming.

Community and family education on children's rights and disabilities are crucial elements of effective inclusion of children with disabilities. It is also vital that the forms of inclusion be both culturally and developmentally appropriate. Examples from lowresource settings (see Portrait 4: Swaziland) suggest the potential for approaching developmental outcomes through attention to the different styles of parenting. Developing a safe and supportive environment requires the dismantling of stigma and discrimination. This may entail education and training for various cadres—including school boards, managers, health care providers, social workers, and teachers—to ensure that those who work with children with disabilities have positive and inclusive attitudes toward their charges.

An initiative in northeastern Uganda investigated the attitudes and willingness of teachers to include learners with intellectual disabilities in their classes

#### PORTRAIT 4. VUSUMNOTFO, SWAZILAND

Many young children in rural Swaziland fail to achieve developmental outcomes. The interlinking challenges of HIV and poverty have exacerbated shifting family and social dynamics, and many caregivers struggle to meet all their children's needs.

Vusumnotfo aims to improve developmental outcomes for young children in rural Swaziland by building community capacity to engage with children in a manner that enhances their development. The organization's approach is to strengthen parenting skills in everyone who interacts with the children, including the extended family and alternative caregivers, focusing simultaneously on strengthening preschool teaching and promoting effective parenting.

A pilot group of community preschool teachers is integrating learning standards to promote the use of child development indicators to stimulate effective parenting practices. Vusumnotfo's manual Growing Children Straight and Strong provides information on the basic concepts of children's physical, emotional, language, cognitive, and social development, and shows how to apply these concepts within the context and resources of Swazi families, rather than prescribing one style of parenting. The manual also includes HIV, abuse, and helping children deal with the sickness and death of family members. Vusumnotfo advocates "positive progression along developmental milestones" as the essence of effective parenting.

For more information contact: Vusumnotfo at <a href="mailto:vusumnotfo@realnet.co.sz">vusumnotfo@realnet.co.sz</a>

in regular schools. The results showed slightly more positive than negative attitudes, and more willingness than unwillingness to teach students with intellectual disabilities. Attendance in workshops and seminars had a positive impact on teachers' attitudes and willingness regarding inclusive education (Ojoka & Wormnaes 2012). In Zambia, teachers in primary and basic schools showed interest in including children with disabilities, but believed that this was reserved for specialists and harbored misconceptions and fears, such as that conditions like albinism were contagious (Miles 2009).

disabilities. There are six program elements considered essential to improving the status of individual children with disabilities and their families and caregivers, and creating a sustainable system within the community to address the ongoing needs of children with disabilities as they continue to develop and grow. These major functions are: promoting inclusion, empowering and supporting caregivers and families, developing capacity, educating and engaging the community, putting family care first, and enabling cultural sensitivity and responsiveness.

#### SUMMARY

Application of the triple-track approach—promoting participation, attention to specific needs, and equal access for OVC and their families—is a critical component of improved support for children with

#### PORTRAIT 5. THE ZIMBABWE PARENTS OF HANDICAPPED CHILDREN ASSOCIATION (ZPHCA)

ZPHCA demonstrates how providing preschool for children with disabilities facilitates their positive development and frees parents to pursue work that supports their families. ZPHCA began with support groups for parents of children with disabilities. These groups offered peer support and information exchange among parents, as well as discussion of the stigma and other daily challenges. Many caregivers of children with disabilities were HIV-positive, and the support groups also offered information on HIV and treatment.

Due to the heavy burden of caring for children with disabilities, many parents, often single mothers, had difficulty working outside the home. Over several years, ZPHCA provided business management training and start-up loans, as well as day care and respite care to allow parents to work outside the home. This formula has proven successful, and many families are gaining economic independence.

ZPHCA's day care center has one section for very young children, and another for older youth who are unable to attend government schools. Most of the children have cerebral palsy, so physical therapy is a major focus of the center. Parents rotate as volunteer caregivers, and pay fees based on a sliding scale. With confidence that their children are well cared for, parents are able to work outside the home to earn an income.

ZPHCA's other programs include training parents to carry out advocacy and counseling, and training youth with disabilities in self-advocacy. Advocacy skills have helped ZPHCA's community-based groups obtain support from government and international organizations. For example, now a percentage of government housing is designated for families with disabilities. ZPHCA has started sharing knowledge with other local nongovernmental organizations so that even organizations with non-disability specialties can serve families with disabilities.

For more information, contact: <u>zphcabulawayo@yahoo.co.uk</u>, <u>zphca@zphca.org</u>, <u>irenebanda.tripod.com</u>

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#### ANNEX I. HIV AND ADOLESCENTS/YOUNG PEOPLE WITH DISABILITIES

Adolescents and young people with disabilities face particular challenges and obstacles. They are often excluded from formal education and social activities, have limited access to sexual and reproductive health services, receive fewer opportunities to establish interpersonal relationships (UNICEF 2012c), and report low levels of self-esteem and limited self-efficacy (Yousafzai et al. 2004). These adolescents and young people may also be at increased risk of HIV infection. Data from Mozambique suggest lower levels of knowledge about HIV among groups of youth with disabilities as compared to youth without disabilities (Lefèvre-Chaponnière 2010). Research also shows that these youth engage in risky sexual behaviors and face equal or greater risk of contracting HIV relative to their non-disabled peers (Maart 2010, Groce 2004). Gender-related differences also strongly influence the contexts and needs of youth with disabilities, with adolescent and young girls at increased risk of HIV infection (UNICEF 2012b).

In its 2012 document *The Right of Children with Disabilities to Education:* A *Rights-based Approach to Inclusive Education,* UNICEF offers the following recommendations for working with adolescents and young people with disabilities within HIV programs (quoted verbatim from text):

#### Communicating with Adolescents and Young People who are Blind

- Texts or posters printed in ink are not accessible to adolescents and youth who are blind. Provide them with information in Braille or transmitted over the radio or in electronically accessible formats (such as computer audio or digital files that can be read with screen reader software).
- Printed expiration dates on condom packages are also not accessible. Explain to them that they need to ask someone for help to verify the date if it is not printed in Braille.
- Non-seeing youth have difficulty finding their way around health care centers. Ensure that all locations are marked with signs in Braille or tactile markings. When such features are not available, health care personnel may take a few minutes to orient adolescents and youth who are blind.

#### Communicating with Adolescents and Young People with Low Vision

• They may see contours and contrasts but may not read text or see images clearly. Use printed materials with large print and high contrast. Accompany images with brief explanations.

#### Communicating with Adolescents and Young People who are Deaf

- Adolescents and young people who are deaf may have difficulty communicating with health professionals, which is
  why they often do not consult with them. Ensure that there is a sign language interpreter present at appointments.
  When conducting important tests, such as an HIV test, ensure that they fully understand the results and the
  steps that need to be taken. When interpreters are not available, printed materials with simple language and
  images can be useful.
- Adolescents and young people who are deaf are not reached by HIV information disseminated through audio-based media like radio, TV, theater, or music. This means it is important to use printed materials and graphics, and to ensure that TV spots include a sign language interpreter.

• People who are deaf can have difficulties negotiating safe sexual relations with their partners, especially when they have hearing partners. Offer them information and help them to develop skills in negotiation and self-protection.

#### Communicating with Adolescents and Young People with Physical Disabilities

- The main challenge facing adolescents and young people with physical disabilities is lack of access, or physical barriers, to most HIV-related activities. To ensure their involvement and participation, meet physical accessibility standards by eliminating or reducing architectural barriers to the greatest degree possible.
- Some adolescents and young people with physical disabilities will have difficulty handling condoms. Help them find a way to manage, or encourage them to ask for help.
- Adolescents and young people with physical disabilities are sexually vulnerable. They are vulnerable to coercion and nonconsensual sexual relations. Offer them support and counseling to strengthen their self-esteem in order to be in control of their relationships.
- Adolescents and young people with cerebral palsy often have difficulty speaking, which means you need to listen carefully and be patient. Sometimes they emit unintelligible or overly loud sounds in their efforts to communicate. If you do not understand what they are saying, calmly let them know so they can try again, or use another way to communicate. If necessary, communication can be facilitated with flash cards, keyboards, and other communication tools.

#### Communicating with Adolescents and Young People with Intellectual Disabilities

- It may be difficult for them to understand the changes in their bodies and comprehend their own sexual desires and needs. Involve their families and caregivers as much as possible, so that they can support their development and help them avoid situations that place them at risk.
- They may have difficulty interpreting the messages of sexual education and recognizing situations that place them at risk. They can understand more easily if you explain things to them in simple words, speak in concrete terms, and use graphic materials and illustrations to help convey information on HIV and safe sex.
- They may be naïve and have limited knowledge about themselves and their bodies, and may have difficulty distinguishing between what is and is not appropriate, which makes them vulnerable to sexual abuse. Whenever possible, stress the importance of fostering their autonomy and promoting the development of self-protection skills.
- Due to overprotection by their families and paternalistic treatment from adults, they may be "infantilized" or treated like children. Communicate with them in a way that is appropriate for their physical age as well as their level of cognitive development.
- Many adolescents and young people with intellectual and developmental impairments have very few opportunities to receive sexual education or information on HIV. Encourage them to ask questions and ask for information so they can learn how to recognize risks and avoid them.

#### ANNEX 2. OVC CAREGIVERS AND DISABILITIES

Households with both disability and HIV...have a complex dynamic with compounding needs and competing priorities for allocation of resources.

(Fleming 2012).

Whether young or old, many people with disabilities must rely on others for assistance with a range of tasks, from dressing and eating to meeting basic social, psychological, and economic needs. Caregivers with several children may have little time for the child with a disability who needs extra help. The burden of caring for a child with disabilities may be psychologically overwhelming, take away time from productive economic activity, or contribute to being ostracized by the community. In a pilot study of Zambian households affected by disability and HIV, primary caregivers reported they were often exhausted and sick due to their workload to support the household, earn income, and care for their healthy and disabled family members. Other data from Uganda suggest that while families of children with disabilities were coping, most faced challenges in four areas: burden of care, poverty, impact of the child's disability, and communication difficulties (Hartley 2005). The multiple stressors of poverty, HIV in the household, and disability can have a heavy impact on households, leading to a vicious cycle. Households constantly risk escalating hardships, such as inability to afford care and increased incidence of other diseases, which reinforce the drivers of poverty (Fleming 2012).

In other cases, it may be the caregiver who has a disability and is faced with the double burden of being the primary provider in an HIV-affected household and also living with a disability. Caregiving by a parent or another caregiver is complicated and challenging if the person providing care also has a disability. Program planners who seek to enhance the quality of inclusive services for young children with disabilities must also address caregiver needs. Hesperian Foundation offers a series of materials aimed at supporting families and caregivers of young children; among these are *Handbook for Women Who Are Disabled*, which provides useful guidance on understanding and meeting those needs.

#### ANNEX 3. TOOLS AND RESOURCES

#### Improving Learning Outcome Achievement in Low-Income Countries

Aga Khan Foundation 2010.

This review of research summarizes important evidence on what makes a difference in children's learning. It considers resource investments, what children bring to care and education settings, what goes on in these programs, and discusses broader issues of equity, quality, and context.

Available at: www.akdn.org

#### The State of the World's Children

UNICEF. 2013.

Each year, UNICEF's flagship publication, The State of the World's Children, closely examines a key issue affecting children. The 2013 publication focuses on children and disability, and includes statistics and stories in addition to online only features.

Available at: <a href="http://www.unicef.org/sowc2013/">http://www.unicef.org/sowc2013/</a>

#### The Essential Package

CARE USA & Save the Children. 2012.

This tool provides OVC program managers and providers with a holistic and integrated set of tools designed to graft onto existing initiatives for children affected by HIV, poverty, disruption, or conflict. The package uses an "age-appropriate framework for action for young children and their caregivers affected by HIV." Though disability is not mentioned, the Essential Package strategy and style is consistent with guidance for children with disabilities. The package provides action plans for health, nutrition, protection, care and development, as well as economic strengthening, all of which align with building a foundation for enhancing the quality of life for young children with disabilities, including them in the family and community, and anticipating their inclusion in formal education as they mature.

Available at: http://www.ovcsupport.net/s/library.php?ld=1154

#### Mother and Child Care: Promoting Health, Preventing Disabilities; Early Detection of Disabilities and Persons with Disabilities in the Community; and Stimulating Development of Young Children with Disabilities at Anganwadi and at Home

Dr. Geeta Chopra. 2011, 2012.

Chopra has published three guidebooks for a training program being field-tested in India. Anganwadis (government sponsored mother and child care centers) are the key community-based venues for India's Integrated Child Development Services, so these tools for including young children with disabilities hold particular promise. The program's attention to systematic evaluation, replication, and dissemination will also advance evidencebased practice.

Further information at: <a href="http://www.arnec.net/ntuc/slot/u2323/conference/presentations/Geeta%20-%20singapore.">http://www.arnec.net/ntuc/slot/u2323/conference/presentations/Geeta%20-%20singapore.</a> pdf http://www.arnec.net/cos/o.x?ptid=1036089&c=/swt\_arnec/articles&func=view&rid=279

#### Including Disabled Children in Learning: Challenges in Developing Countries

Croft 2010.

This document explores pedagogical challenges and documents the rationale and methods for more effective inclusion, including reference to <a href="https://www.eenet.org.uk">www.eenet.org.uk</a>.

Available at: <a href="http://www.create-rpc.org/pdf">http://www.create-rpc.org/pdf</a> documents/PTA36.pdf

#### Early Childhood Education: A Global Scenario

Education International, 2010.

This report integrates data on services for and needs of young children with disabilities, identifying trends and resources in case studies from 17 countries.

Available at: http://download.eiie.org/Docs/WebDepot/ECE A global scenario EN.pdf

#### **Equity and Inclusion in Education**

Fast Track Initiative. 2010.

This is a guide for planning, modifying, and evaluating educational programming, produced in partnership with UNAIDS. Step-by-step guidance facilitates progress toward rights-based inclusive services.

Available at: http://www.ungei.org/resources/files/Equity and Inclusion Guide.pdf

### Convention on the Rights of Persons with Disabilities: Its Implementation and Relevance for the World Bank

Guernsey, Nicoli, and Ninio. 2007.

This report alerts OVC program planners to the wide and complex range of issues involved in adhering to emerging policies applicable to serving OVC and families with a disability.

Available at: <a href="http://siteresources.worldbank.org/SOCIALPROTECTION/Resources/SP-Discussion-papers/Disability-DP/0712.pdf">http://siteresources.worldbank.org/SOCIALPROTECTION/Resources/SP-Discussion-papers/Disability-DP/0712.pdf</a>

The companion guide, which includes checklists and resources adaptable to a range of OVC initiatives, *Making Inclusion Operational*, is available at: <a href="http://siteresources.worldbank.org/INTLAWJUSTICE/Resources/LDWPI">http://siteresources.worldbank.org/INTLAWJUSTICE/Resources/LDWPI</a>
<a href="Disability.pdf">Disability.pdf</a>

#### **Inclusive and Integrated HIV and AIDS Programming**

Handicap International. 2012.

This policy paper describes Handicap International's mandate and values in operational terms, as applied to inclusive and integrated HIV programming. It is a guidance document for program staff that defines integrated programming and outlines target populations, methods of intervention (activities, expected results), and indicators for monitoring and evaluation.

Available online at: http://www.hiproweb.org/uploads/tx hidrtdocs/PP07 06 light.pdf

#### Early Assistance Series for Children with Disabilities

Hesperian Foundation.

This series from the Hesperian Foundation, like their classic manual Disabled Village Children, contains a wealth of clear and detailed information and easy-to-implement strategies useful to caregivers, OVC program planners, and children with disabilities. Current titles include Helping Children Who are Deaf; Helping Children Who Are Blind; Handbook for Women Who Are Disabled; and the forthcoming Helping Children Live with HIV, aimed at supporting families and caregivers of young children.

Materials are produced in more than 90 languages and a wide range of visual images can be downloaded from their website: http://hesperian.org.

#### Early Childhood Care and Education and the Curriculum

International Bureau of Education (IBE). 2013.

The IBE has compiled this list of resources to assist curriculum developers, researchers, and practitioners. Several resources focus on inclusion.

The publications and documents are freely accessible online at: <a href="http://www.ibe.unesco.org/fileadmin/user\_upload/">http://www.ibe.unesco.org/fileadmin/user\_upload/</a> Documentation/Alerts/ECCE2013.pdf

Inclusive Early Childhood Development: An Underestimated Component within Poverty Reduction (2011) highlights the situation of young children with disabilities as a factor in policy and programming for OVC.

Available at: http://www.bezev.de/knowledge/conference-documentations/inclusive-early-childhood-development. html?L=I

#### Guidance on HIV in Education and Emergencies.

Interagency Network for Education in Emergencies (INEE). 2011.

The INEE provides tools for serving and protecting OVC, including children with disabilities. Their pocket guides on inclusive education (2009) and supporting learners with disabilities (2010) facilitate quality inclusion and have versions in French and Spanish as well as English. The ECD case studies (2012) provide good examples of policies and practices with the elements of quality inclusion.

Available at: http://toolkit.ineesite.org/toolkit/INEEcms/uploads/1140/Introduction%20HIV%20January2011.pdf http://www.ineesite.org/uploads/documents/store/INEE pocket guide Final.pdf http://www.ineesite.org/uploads/ documents/store/INEE Pocket Guide to Supporting Learners with Disabilities.pdf http://toolkit.ineesite.org/toolkit/INEEcms/uploads/1058/Education%20Cluster%20Thematic%20Case%20 Studies%202012.pdf

#### Online International Resource Centre on Disability and Inclusion

Handicap International. 2012.

An online database designed to strengthen the management, use, and impact of information on disability and inclusion in development and humanitarian contexts. It is primarily intended for use by practitioners and academics.

Available at: <a href="http://www.asksource.info/index.htm">http://www.asksource.info/index.htm</a>

#### Promoting the Rights of Children with Disabilities

UNICEF. 2007.

This document provides historical, conceptual, and practical resources for making OVC programs more inclusive.

Available at: http://www.un.org/esa/socdev/unyin/documents/children\_disability\_rights.pdf

#### ChildInfo: Monitoring the Situation of Women and Children

UNICEF. 2012.

This site aggregates data from the Multiple Indicator Cluster Surveys (MICS), several of which include information on disabilities in participating countries. The disability module will be more prominently implemented in MICS 5.

Available at: www.childinfo.org/disability challenge.html

#### Teaching Children with Disabilities in Inclusive Settings

UNESCO. 2009.

This document is part of a toolkit for creating inclusive, learning-friendly environments. Its summary of the principles of universal design will help OVC program planners embrace diversity and integrate the elements of successful programming described in this brief.

Available at: http://unesdoc.unesco.org/images/0018/001829/182975e.pdf

#### **USAID's Global Health eLearning Center**

This center provides its worldwide Mission-based health staff with access to state-of-the-art technical global health information, and recently launched a series on early childhood development.

Available at: <a href="http://www.globalhealthlearning.org/program/early-childhood-development">http://www.globalhealthlearning.org/program/early-childhood-development</a>

#### Early Childhood Intervention (ECI), Special Education and Inclusion: A Focus on Belarus

Vargas-Barón and Janson. 2009.

This report presents a sophisticated overview and review of the ECI and ECD intersection in global terms. It analyzes progressive reforms underway in Belarus and highlights ways to include young children with disabilities. OVC planners in many countries will find the tools employed in this study useful for planning and evaluation. Guidelines are also included to help other countries establish rights-based, child-centered, family-focused services.

Available at: <a href="http://www.unicef.org/ceecis/Belarus">http://www.unicef.org/ceecis/Belarus</a> English.pdf

#### **Building the Wealth of Nations**

World Conference on Early Childhood Education and Care. 2011.

This document offers recommendations and action plans for enhancing the inclusion of young children with disabilities applicable to OVC programs and advocacy efforts.

Available at: <a href="http://unesdoc.unesco.org/images/0021/002136/213673e.pdf">http://unesdoc.unesco.org/images/0021/002136/213673e.pdf</a>