Opportunities and Challenges for Disability-Inclusive Early Childhood Development in Emergencies

**Inter-agency
Network for Education
in Emergencies**

Cover image:
A girl helps her displaced sister to reach school in Syria. 2021 (c) Takaful Al Sham (TAS)

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Acronyms and Abbreviations

CCCM	Camp Coordination and Management
CRC	Convention on the Rights of the Child
DSQ	Development Screening Questionnaire
ECD	Early Childhood Development
ECDAN	Early Childhood Development Action Network
ECDiE	Early Childhood Development in Emergencies
ECI	Early Childhood Intervention
HI	Humanity and Inclusion
HNO	Humanitarian Needs Overviews
HRP	Humanitarian Response Plans
IDEC	Identification of Disabilities in Early Childhood
INEE	Inter-agency Network for Education in Emergencies
IRC	International Rescue Committee
KII	Key Informant Interview
MDAT	Malawi Developmental Assessment Tool
MENA	Middle East and North Africa
MHPSS	Mental Health and Psychosocial Support
NGO	Non-Governmental Organization
OCHA	United Nations Office for the Coordination of Humanitarian Affairs
OPD	Organizations of Persons with Disabilities
RNDA	Rapid Neurodevelopmental Assessment
SEL	Social Emotional Learning
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNICEF	United Nations International Children's Emergency Fund
WASH	Water, Sanitation, Hygiene
WHO	World Health Organization

Executive Summary

There is an urgent need to prioritize and invest in young children (ages 0 to 8 years old) with disabilities and developmental delays, and their caregivers living in humanitarian and development settings.

Young children with disabilities are among the most marginalized and at-risk people in communities affected by humanitarian crises. They are more vulnerable to higher rates of mental health issues (Jordans and Tol, 2015) and their impairments can be exacerbated by humanitarian settings. As well as emotional and physical stress, children with disabilities face other challenges, such as experiencing new impairments, existing impairments worsening further, losing access to essential medications and devices (or not being identified for devices or services), and increased reliance on caregivers. Girls with disabilities are more vulnerable to exploitation and abuse, including gender-based violence, and their risk of malnutrition is higher than boys with disabilities (UNICEF, 2017).

Disability-inclusion in Early Childhood Development in Emergencies (ECDiE) programmes is necessary to ensure that all children are enabled to participate, learn, and contribute according to their evolving capacities and to reach their fullest potential. Early identification and early intervention are critical to the success of disability-inclusive ECDiE. Delayed detection of disability and development delays can pose a serious risk to young children.

However, disability-inclusive ECDiE provision for young children with disabilities in humanitarian settings does not meet demand. A comprehensive global survey of 426 early childhood development and early childhood intervention programmes found that only 28% of programmes (119) were being implemented in countries affected by humanitarian crises (Vargas-Baron et al., 2019).

There are examples of good practice around the world that enable and mainstream inclusion across ECDiE programmes, activities, and project management processes as well as disability-specific initiatives. They provide targeted support and resources for children with disabilities to enable their equal participation in projects and in their communities.

This brief advocates for and highlights the benefits of disability-inclusive ECDiE. It includes examples of good practices in disability-inclusive ECDiE programming from around the world, and provides recommendations for more inclusive ECDiE, encouraging governments, multilateral agencies, donors, and implementing organizations to:

- Improve the collection, storage, use, and dissemination of age, sex and disability (by type) disaggregated data to ensure inequities are targeted and to strengthen humanitarian planning and investment.

- Standardize screening and identification tools for use globally to identify disability and developmental delays, improving early detection and enabling informed programming and investment.
- Collaborate to build stronger and more efficient humanitarian coordination between relevant sectors.
- Develop a set of standards for disability-inclusive ECDiE for quality in early childhood interventions and development programmes.
- Promote wider dissemination of models for and approaches to disability-inclusive ECDiE, including evidence on cost and the immediate and long-term benefits of inclusion, to help make the case to donors and governments.

Overall, disability-inclusive ECDiE promotes equal opportunities for children to attend, learn, develop and participate in learning and social activities; respects and celebrates diversity and differences; value all children equally – it does not exclude, stereotype, stigmatize or discriminate against any children on the basis of their differences; protects children from abuse, neglect, and stress by providing nurturing care and protection; and creates strong connections with families and communities as partners in child development and learning, and is attentive to their backgrounds, needs and situations.

Introduction

There is an urgent need to prioritize and invest in young children (ages 0 to 8 years old) with disabilities and developmental delays, and their caregivers living in humanitarian and development settings. They are among the most vulnerable and marginalized people in the world, as they often are at high risk of discrimination and violence, malnutrition, lack of nurturing care, and other major threats to their development.

In addition, the rights of children with disabilities to enjoy a full and decent life, equal opportunities, and facilitate their active participation in the community are highlighted in both the Convention on the Rights of the Child (Article 23) and the Convention on the Rights of Persons with Disabilities (Article 24).

Although there is scant reliable global data available on the numbers of young children with disabilities and developmental delays in humanitarian contexts, the most recent statistics from the United Nations International Children's Emergency Fund (UNICEF) on childhood disability indicate that 240 million children aged 0 – 17 years, or 1 child in every 10, have a disability worldwide (UNICEF, 2022). This suggests that of the children affected by humanitarian emergencies, a significant proportion have disabilities, developmental delays, and additional needs, some as a direct result of crises themselves. There is a small but growing pool of data available to show how many of these young children are supported by programmatic initiatives.

Organizations that work in humanitarian and development settings worldwide indicate that disability prevalence among affected populations is as high, if not higher, than in normal development settings (Key Informant Interviews (KII), June 2022; UNICEF, 2017). For instance, one survey found that 17.3% of children aged 2-17 years in Afghanistan had a mild, moderate, or severe disability (Asia Foundation, 2019); another survey in 2017-2018 of Syrian refugees in Lebanon and Jordan found that 12.4% of children aged 0–9 years have a disability (Humanity and Inclusion (HI) & iMMAP, 2018). All the more, in 2022, Ukraine had the highest number of children in institutional care in Europe (nearly half were children with disabilities); since the war began, tens of thousands of children dependent on institutional care have been returned to families, many of them hastily and without the care and protection they require (UNICEF, 2022).

Disability-related factors interact with other structural inequalities and contextual factors to increase the risk of children with disabilities. In humanitarian and developmental settings, children with disabilities are often overlooked in needs assessment processes and subsequent responses, partially due to stigma or safety concerns (UNICEF, 2022).

This brief advocates for and highlights the benefits of disability-inclusive Early Childhood Development in Emergencies (ECDiE). It includes examples of good practice in disability-inclusive ECDiE programming from around the world; in addition, it provides recommendations for governments, donors, and programmers for more inclusive ECDiE.

Box 1: Defining Disability

Article 1 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) defines disability as follows:

"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."

Historically, the **medical model** of disability has predominated. This model sees the person's impairment or health condition as 'the problem.' The focus is therefore on 'fixing' or 'curing' the individual. Reliance upon the medical model alone is considered outmoded and even harmful.

The **human-rights based** model acknowledges the failure to recognize the rights of persons with disabilities and the barriers they face in gaining access to disaster management initiatives, which can result in further marginalization (Njelesani, Janet et al, 2012).

The **social model** of disability, endorsed by the UNCRPD, states that disability is caused by the way society is organized, rather than by a person's impairment or difference. It looks at ways of removing barriers that restrict life choices for people with disabilities. When barriers are removed, persons with disabilities become independent and equal in society, with choice and control over their own lives. The social model of disability is consistent with related models of neurodiversity and inclusion.

> *We are producing disability for people on the margins because we are not providing prevention or rapid response services. People are coming to us too late.*

— Humanity and Inclusion, Uganda staff member

The impact of humanitarian crises, conflict, and displacement are especially harmful during the early years (0 – 8 years), when a child's rapidly developing brain is exceptionally sensitive to environmental influence. The first 1000 days, from a child's conception to age 2, is a critical period. During this time of increased vulnerability, the foundations of a child's health and development - physical, cognitive, socioemotional, behavioral, and communicational (language and speech) development - are laid.

The needs of babies and young children with disabilities and developmental delays and their caregivers are often overlooked in humanitarian responses and ECDiE programming. Young children with disabilities are more vulnerable to higher rates of mental health issues (Jordans and Tol, 2015) and their impairments can be exacerbated by the humanitarian situation. As well as emotional and physical stress, children with disabilities face other challenges, such as experiencing new impairments, existing impairments degenerating further, losing access to essential medications and devices (or not being identified for and referred to devices or services in the first place), and increased reliance on caregivers. Girls with disabilities are more vulnerable to exploitation and abuse, including gender-based violence, and their risk of malnutrition is higher than for boys with disabilities (UNICEF, 2017).

"In an emergency, children with disabilities are at higher risk than their peers of physical injury, abuse, health problems, and malnutrition. They are more likely to be abandoned by or separated from their families or those responsible for their care, may be overlooked in the registration or disaster preparedness process, and often are excluded from emergency assistance. Some [ECD] activities help reduce the risk and effect of a disability... [ECD] programmes in emergencies must make sure that children with disabilities [and their families] have equal access to their services. Whenever an [ECD] activity is designed or implemented, it is important to ask: 'Is this accessible to young children with disabilities?' taking the full range of needs into consideration. If the answer is no, what other elements can be added, and how can an alternative be found so that those with disabilities are not excluded." (Plan International, 2013: 26-27)

In acute emergencies, young children may be malnourished, and exhausted. They may have sustained injuries during traveling or even in a camp because of a lack of safety (KII, HI staff member, Uganda, June 2022). Mainstream humanitarian interventions such as psychosocial support, vaccination, feeding programmes, child-friendly spaces, and temporary learning spaces may not be accessible to children with disabilities in humanitarian settings. Even in cases where services are accessible, they may not be designed to fully meet their needs. Children with disabilities need access to the same services as all children, and may need additional support or adaptations. (UNICEF, 2017). Increased stress, discrimination, and stigma put these young children at exceptionally high risk of impaired cognitive, emotional, and social development (Bouchane et al., 2018). But with proper, timely, nurturing care and support[1] childhoods that were affected by conflict can be improved, including for those young children with disabilities and developmental delays. There is evidence that inclusive, quality early childhood development programmes benefit young children's life chances, experiences, and development (HEART, 2016; Zudeima, 2022), while reducing the impact of impairments.

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1   See *Tools and frameworks to support disability-inclusive ECDiE* section for further elaboration on 'nurturing care'.

Box 2: What is disability-inclusive early childhood development?

Disability-inclusion in ECD programmes is necessary to ensure that all children are enabled to participate, learn, and contribute according to their evolving capacities and to reach their fullest potential.

Inclusion in quality early childhood development programmes is described as comprehensive, multi-sectoral, integrated, child-centered and play-based, and ensures that all children and their families are involved in the process. Provided at home, at school, in a center or in the community, inclusive ECD programmes attend to children's developmental needs holistically by offering adequate nutrition, health care, consistent nurturing, protection, psychosocial support, opportunities for early learning and stimulation, social integration and cohesion, and specific support like assistive devices. Inclusive ECD programmes promote values, attitudes and behaviors, such as equality, social justice, respect for all, and celebrate diversity and differences. They also address specific cultural settings and are complemented by inclusion in subsequent levels of education and life-long learning opportunities.

Disability-inclusive early childhood development:

- is accessible and affordable for all, and promotes equal opportunities for children to attend, learn, and participate in learning and social activities;
- provides for children's holistic development, ensuring quality and physical access to ECD facilities;
- protects and enables children's rights as clearly stated in the CRC and CRPD;
- ensures transitions from mostly home-based Early Childhood Intervention (ECI) provision to disability-inclusive ECD, and supports continuous monitoring and assessment of children's development and learning;
- respects and celebrates diversity and differences; all children are valued equally – it does not exclude, stereotype, stigmatize or discriminate against any children on the basis of their differences;
- views diversity as an opportunity for learning and promoting understanding;
- embraces culturally-relevant practices and knowledge of participating families, and supports children's mother tongue;
- protects children from abuse, neglect, and stress by providing nurturing care and protection; and
- creates strong connections with families and communities as partners in child development and learning, and is attentive to their backgrounds, needs and situations

(adapted from UNESCO, 2019).

Opportunities

Effects of disability-inclusive ECDiE programming

Disability-inclusive ECDiE services are essential to ending preventable deaths of babies and young children, supporting their healthy development, and driving economic recovery and peacebuilding (UNICEF, 2019). For young children with disabilities, disability-inclusive ECDiE services are critical to helping overcome, eliminate or mitigate the barriers to their inclusion in mainstream education, the wider community, and even family matters. Early identification[2] and early intervention are critical to the success of inclusive ECDiE. Delayed detection of disability and development delays can pose a serious risk to young children. As an ECD Global Specialist noted, "if children had been taken care of at 0-1 years, they would not have the issues that they do. Simple interventions and stimulation done early make a massive difference. Delayed intervention improves the situation, but it never is as good as if identified earlier" (KII, HI staff member, June 2022).

> *There are a limited number of professionals and facilities in Myanmar - a few hundred physios, little or no occupational therapists, very few psychologists. Speech and language therapists are also non-existent. The main challenges and drivers are for us to figure out how to provide training to professionals and then transfer skills to local people who can do home visits... it is a long journey and a major challenge to deliver in a context of multiple acute crises – a military coup, humanitarian emergency, COVID-19.*

— KII, the Leprosy Mission staff member, Myanmar

The participation of young children in accessible ECDiE programming, including health, learning, and social welfare services such as feeding and vaccination programmes or play-based musical storytelling sessions in child friendly spaces - both at home and in formal and non-formal ECDiE settings - can assist with earlier identification of needs, skills and competencies. Support for families and communities can enhance the impact of early interventions for young children with disabilities (UNICEF, 2019).

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2   Early identification implies the use of developmental screening tools to supplement clinical judgment so that early assessment can lead to rapid early intervention.

Challenges

Humanitarian response planning and investment

Disability-inclusive ECDiE is inadequately represented in humanitarian response plans and is massively underfunded, with early learning and education for children aged 0-5 years receiving less than 1% of funds allocated to education in humanitarian contexts (Moving Minds Alliance, 2021; Pontuga et al., 2022). Where ECDiE is included in humanitarian response plans, implementation of each component can be inconsistent and lack coordination (Pontuga et al., 2022). There are often critical shortages of appropriately trained professional staff, and in complex and protracted crises, this can put the prospect of inclusive early childhood interventions a long way off.

Disability-inclusive ECDiE provision for young children with disabilities aged 0-8 years in humanitarian settings does not meet demand. A comprehensive global survey of 426 ECDiE and early childhood intervention programmes found that only 28% of programmes (119) were being implemented in countries affected by humanitarian crises (Vargas-Baron et al., 2019). Many of these did not include any inclusive ECDiE programmes at all (Ibid).

Where there are investments in ECDiE, these do not routinely or intentionally target children with disabilities (Zudeima, 2022). 'Inclusion' is also often defined broadly in programming as incorporating gender, ethnicity, refugee status, disability, and other factors, making it difficult to determine whether children with disabilities and developmental delays are purposefully targeted at all (Moore et al., 2020). There is also a limited focus on evidence generation on the success of inclusive implementation, making the replication of successful programmes challenging (Moore et al., 2020).

"Available data shows that globally the likelihood of a child having a disability before their fifth birthday was ten times higher than the likelihood of dying (377.2 vs 38.2 per 1000 live births) in 2019. However, disability funding declined by 11.4% between 2007 and 2016, and only 2% of the estimated US$79.1 billion invested in early childhood development during this period was spent on disabilities. This funding pattern has not improved since 2016." (The Global Research on Developmental Disabilities Collaborators, 2022, p. e438).
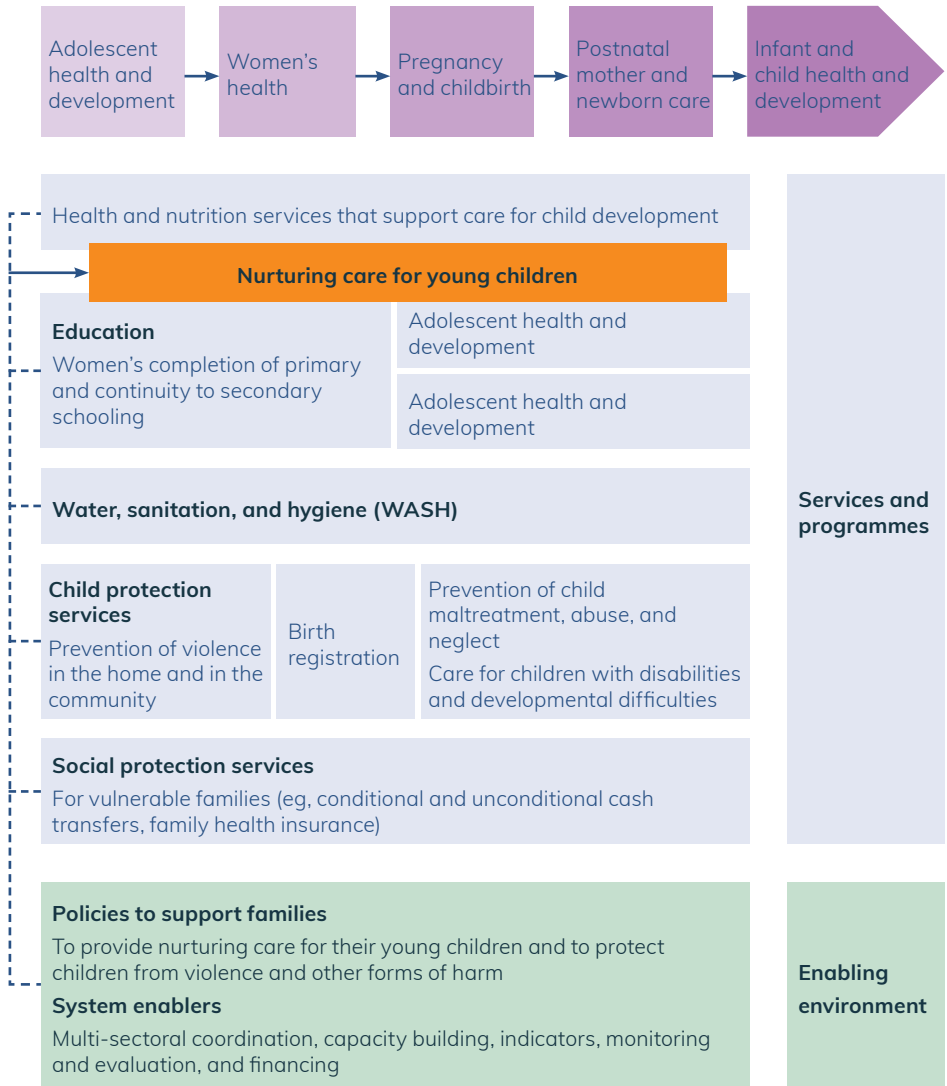
Gaps in data

The lack of data that has hampered global efforts to improve inclusion for children with disabilities is even more pronounced in humanitarian settings. Data on disability and developmental delays is infrequently collected as part of needs assessments (UNICEF Innocenti, 2017), and "intervention work often takes place in the absence of accurate - or in fact any - 'data'" (Hunt et al., 2021, p. 190). Large institutional donors do not support disability-inclusive ECDiE programming without adequate data to assess the scale of intervention needed. For instance, in Uganda, Humanity and Inclusion and its partners have been successful in lobbying for inclusion of disability data in needs assessments, which has enhanced data collection and programming for all people with disabilities in West Nile settlements (KII, HI Uganda staff member, June 2022). In addition, since 2018 there has been a substantial improvement in the inclusion of disability data in Humanitarian Needs Overviews (HNOs) and Humanitarian Response Plans (HRPs).

Data is usually collected from parents or caregivers, rather than directly from children. Therefore, any questions about disability are mediated by adults, which inhibits learning about issues of inequity within the household and the child's own opinions and experiences. Moreover, parents might not identify (due to lack of diagnosis or early identification) or want to identify their child as having a disability (in fear of stigma, prejudice and discrimination). As a result, it is generally found that childhood disability is not reported in survey responses, especially when direct questions about disability such as "do any family members have disabilities?" are asked. When the word 'disability' is used, under-reporting is common due to high levels of stigma, and different understandings of disability. Instead, specific questions about a child's development and functioning must be asked to learn about childhood disability.

Humanitarian coordination

Poor cross-sector coordination emerged as a major theme in research conducted for this brief, and offers insight into why young children with disabilities are under-served in humanitarian settings. The absence of standard cross-sectoral coordination mechanisms focused on the needs of younger children creates the potential for inadequate identification, conflicting approaches to the various models of disabilities, and monitoring of children, systems, and structures requiring interventions. A holistic, multi-sectoral approach based on the social model of disability is needed. As Moving Minds Alliance (2021) noted, there is no mention of newborns and very young children in the 2019 IASC Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action. This is indicative of the ways in which they have been excluded. Better coordination and a shared commitment to inclusion is necessary among the key sectors of health, child protection, nutrition, education, and water, sanitation and hygiene (WASH) to ensure young children with disabilities get support along a continuum of care. Figure 1 provides a framework for promoting young children's development through a multi-sectoral approach. It demonstrates the overlaps between sectors, particularly health, education, and nurturing care, and the enabling environment to make disability-inclusive ECDiE a reality. For more on nurturing care, see the *Tools and frameworks to support disability-inclusive ECDiE* section below.

Figure 1: Framework to promote young children's development through a multi-sectoral approach.

| Adolescent health and development | Women's health | Pregnancy and childbirth | Postnatal mother and newborn care | Infant and child health and development |

Health and nutrition services that support care for child development

Nurturing care for young children

Education
Women's completion of primary and continuity to secondary schooling

Adolescent health and development

Adolescent health and development

Water, sanitation, and hygiene (WASH)

Child protection services
Prevention of violence in the home and in the community

Birth registration

Prevention of child maltreatment, abuse, and neglect

Care for children with disabilities and developmental difficulties

Social protection services
For vulnerable families (eg, conditional and unconditional cash transfers, family health insurance)

Services and programmes

Policies to support families
To provide nurturing care for their young children and to protect children from violence and other forms of harm

System enablers
Multi-sectoral coordination, capacity building, indicators, monitoring and evaluation, and financing

Enabling environment

© The Lancet (2016)

Tools and frameworks to support disability-inclusive ECDiE

There are tools available and adaptable to different contexts that provide evidence-based guidance for the implementation of disability-inclusive ECDiE. The Nurturing Care Framework, the Malawi Developmental Assessment Tool, the Washington Group Short Set of Questions, and UNICEF's Child Functioning Module for Teachers are all widely used tools in various settings that provide guidelines for disability-inclusive ECDiE interventions. Research and evidence generation happen in this area, along with calls for universal tools that can be rapidly deployed.

Nurturing Care Framework

The Nurturing Care Framework is a framework to help children survive and thrive. It builds upon state-of-the-art evidence of how child development unfolds and how effective policies and interventions can improve early childhood development. It provides a standardized model for inclusive ECD interventions, as it recommends ways for embracing and leveraging nurturing care that is fully inclusive of young children with disabilities. The Nurturing Care Framework includes:

1. Ensuring access to good-quality services;
2. Making services supportive of nurturing care;
3. Increasing outreach to families and children with the greatest risk of suboptimal development;
4. Establishing inclusive services for children with developmental difficulties and disabilities; and
5. Collaborating with other sectors to ensure a continuum of nurturing care (Moore et al, 2020; Wertlieb, 2019).

For children to reach their full potential, they need the five interrelated and indivisible components of nurturing care: good health, adequate nutrition, safety and security, responsive caregiving and opportunities for learning. Nurturing care reduces the detrimental effects of stress and deprivation, often exacerbated by experiencing other disadvantages (such as those created by disability and humanitarian emergencies) on brain function and structure, which then improves children's growth, health and development.

The five components of nurturing care are: (WHO, UNICEF, World Bank, 2020)

1. **Good Health -** Refers to the health and well-being of children and their caregivers, acknowledging that the physical and mental health of caregivers affect their ability to care for the child.
2. **Adequate Nutrition -** Refers to maternal and child nutrition, since the nutritional status of the mother during pregnancy affects her health and well-being and that of her unborn child. After birth, the mother's nutritional status affects her ability to provide adequate care to her young child.
3. **Safety and Security -** Refers to safe and secure environments for children and their families. These include physical dangers, emotional stress, environmental risks (e.g., pollution and climate migration), and access to food and water.
4. **Opportunities for Early Learning -** Refers to opportunities for the child to interact with a person, place, or object in their environment. It recognizes that every interaction (positive or negative) or absence of interaction contributes to the child's brain development and lays the foundation for later learning.
5. **Responsive Caregiving -** Refers to the ability of the caregiver to notice, understand, and respond to their child's signals in a timely and appropriate manner. It is considered the foundational component because responsive caregivers are better able to support the other four components.

As an example, in Eastern Ukraine, the Nurturing Care Framework approach has been used by UNICEF, the government, and partners. This includes outreach to ensure families of children with disabilities and developmental delays are appropriately supported and home-based learning is designed to be inclusive (ECDAN, 2020).

Tools for screening and early identification

As children with disabilities are a particularly vulnerable group, there is a greater risk that being identified as having a disability could lead to discrimination or stigma in their schools or communities. Since children are constantly growing and developing, and develop at their own pace, it can be quite challenging for parents and project staff to identify developmental delays or impairments, particularly among children under the age of 5 (Plan International, 2015). Still, there are practical and accessible tools that support practitioners and other stakeholders with screening and early identification of disabilities and developmental delays in young children.

The Malawi Developmental Assessment Tool (MDAT) provides a model for assessing developmental delays and disabilities in children 0-3 years. Its application is universal across settings since developmental milestones are similar among children globally (KII, HI Uganda staff member; UNICEF MENA staff member, June 2022). MDAT was initially created through a series of studies in Malawi to address the need for a simple, inexpensive, and culturally appropriate way to identify developmental delays. Now, it is used in over 20 countries including low- and middle-income settings, and across humanitarian settings (UNICEF MENA, 2022).

The Development Screening Questionnaire (DSQ) and the **Rapid Neurodevelopmental Assessment (RNDA)** are tools developed in Bangladesh. DSQ is administered to mothers of children aged 0 to 24 months of age to screen neurodevelopmental status, including motor, vision, hearing, cognition, socialization, behavior and speech. RNDA assesses neurodevelopmental status of children aged less than 2 years with limited access to health screening and can be conducted by semi-skilled health workers (UNICEF MENA, 2022).

The **Module on Child Functioning** is intended to provide a population-level estimate of the number and proportion of children with functional difficulties, assessing different domains including hearing, vision, communication, learning, mobility and emotions, in children 2-17 years of age. "It conforms to the biopsychosocial model of disability, focusing on the presence and extent of functional difficulties rather than on body structure or conditions" (UNICEF, 2021).

> *Every project is important, if you can save a child you save a child, but if we want to make a change to millions of children we have to address the policy environment and development of plans that are costed*

— (KII, RISE Institute staff member, June 2022)

Promising practices

In spite of the lack of extensive evidence of disability-inclusive ECDiE programming, some good practices do exist worldwide. Examples of current approaches, below, offer starting points or foundations on which to build.

Humanity and Inclusion (HI)'s <u>Growing Together</u> was a five-year disability-inclusive ECDiE project that ran from 2016-2020 in 11 refugee camps and 52 host communities in Cox's Bazar, Bangladesh, on the Thai-Myanmar border with Peshawar and Nowshera districts in Pakistan. 147 parent clubs focused specifically on indoor and outdoor play, and early learning activities to promote child development with 3000 parents. Parents clubs included parents of children with and without disabilities, helping to break down barriers and reduce stigma. One of the aims of Growing Together was to protect children at risk of developing cognitive impairments due to a wide variety of potential risk factors (e.g., malnutrition, prematurity, infection, extreme poverty, violence, forced displacement, maternal mental health, etc). The project created 50 inclusive, outdoor play spaces to stimulate imagination, language, socio-emotional, cooperation, and problem-solving skills (Nguy et al., 2020).

One of the 25 play spaces that was designed by HI, together with locals in a participatory way, in Bangladesh, Thailand and Pakistan, for the Growing Together programme © Humanity & Inclusion.

A partnership between HI and Bibliothèques Sans Frontières led to the creation of the Ideasbox (IDB) project, which provides communities with an inclusive multimedia center, resources, and digital tools, to address the key components of the Growing Together project on child participation and inclusion. The activities included key messages, such as inclusive, positive parenting for parents with children 0-5 years old, child participation, child rights and protection, positive peer relationships, and inclusive disaster risk reduction for children 6-12 years old. The Ideasbox uses accessible hardware and software, inclusive early learning and pre-literacy materials and toys, sports and games, art activities, and adapted training materials. These include lightweight bright colored balls and dice, low-cost toys made by parents, art materials, puppets, and modeling clay. Additional materials include flashcards, communication books with large format images and words, voice recorders, tablets and desktop computers with screen reading software, and large format keyboards and trackball mice.

The HI Growing Together projects in Pakistan and Thailand led to large increases in parental engagement in playgroup activities (from 21% to 96%), and greater recognition of the importance of play among parents and caregivers in terms of learning, social-emotional wellbeing, and skills development. Children without disabilities increasingly felt comfortable playing with children with disabilities, and perceived quality of life improved for all children by the end of the project (Nguy et al., 2020).

Although coordination within and between sectors can be a challenge in humanitarian settings, feedback from HI indicates that the programme implemented in Bangladesh provides a positive model for multi-sectoral working: "It's worked well having a good relationship with the Education Cluster to mainstream inclusive education across what the partners are doing. We use the same [inclusive education] training manual with all partners across sector" (KII, HI staff member, June 2022).

UNICEF Lebanon recently developed a Parental Engagement Curriculum for Parents of Children with Disabilities to provide skills and strategies for parents of children with disabilities aged 0-18 years. The curriculum provides information on how to advocate for children's rights, enhance development, encourage learning, protect them from violence and understand/manage caregivers' emotions. These resources aim to provide parents with tools and strategies with specialized content targeted towards their specific needs that are not met through general parental engagement programs. They also ensure gender responsive and child protection components are incorporated (UNICEF MENA, 2022).

In **Palestine** the inter-ministerial Early Childhood Development system led by the Ministry of Social Development, uses mobile communication (i.e.: smartphones) to gather and track information and data on families with children with disabilities and developmental delays, and provision of ECDiE services to the most vulnerable young children. As part of a UNICEF initiative to support real-time monitoring systems, the ECD system uses *RapidPro* as a digital monitoring solution (UNICEF, n.d).

A disability-inclusive kindergarten for children aged 5-6 years is run by a non-governmental organization (NGO) in **Azraq refugee camp**, Jordan. It is the only kindergarten in the camp recognized by the Jordanian government. The programme, which runs twice a year, enables 40 children with disabilities (10% of total enrolment) to engage in a disability-inclusive learning environment over a 6-month school cycle aimed at supporting the transition of all children, including those with disabilities, into formal primary education within the camp the following year (Zudeima, 2022). In this study by Zudeima, 7-8-year-old children have the most access to disability-inclusive services in Azraq refugee camp due to additional support from international NGOs that prepare teachers and buildings to be disability-inclusive (Ibid). Overall, however, only a fraction of children with disabilities are believed to have access to early childhood services (Ibid).

The **International Rescue Committee** (IRC) and **Sesame Workshop** implement the **Ahlan Simsim** ("Welcome Sesame" in Arabic) programme, working with parents, caregivers, and children in disability-inclusive ECDiE and preschool settings in settlements and host communities in Jordan, Lebanon, Iraq, and Syria. The partners progressively introduced disability inclusion to the programme, providing training to facilitators and teachers to improve inclusion in these settings, as well as teaching and learning materials with advice on adaptation to meet the needs of children with different types of disabilities. Ahlan Simsim reaches millions of children across the Middle East and North Africa. Recently, they introduced a new puppet character, Ameera, a witty, inquisitive science enthusiast who uses a wheelchair and forearm crutches to get around due to a spinal cord injury. Ameera aims to break down stigma while promoting understanding and inclusion. An IRC Middle East staff noted that "addressing stigma and discrimination is a long-term process" which may take some time to be fully achieved (KII, IRC Middle East staff member, June 2022).

Ahlan Simsim characters ©Sesame Workshop

UNICEF Uganda's Identification of Disabilities in Early Childhood (IDEC) pilot programme works across 5 districts in host and refugee communities. It is an integrated, multi-sectoral intervention that provides capacity building for caregivers and preschool teachers. This includes training to identify children with disabilities, raising awareness on the importance of inclusion, addressing stigma, and stimulating behavior change. Frontline workers are trained to identify children with disabilities at 9-month and 18-month health screenings. Due to lack of access to health services, UNICEF developed village health teams to conduct basic tests that refer children with disabilities and developmental delays for support and further assessment to clinics and hospitals. UNICEF supports partners in Uganda, including faith-based organizations, to establish early learning spaces. Although shortages of funding restricted the scope and scale-up of ECDiE programs, UNICEF's intervention helped improve access to ECDiE at the village level from 10-15% to 30% (KII, UNICEF Uganda staff member, June 2022). When asked what worked well, a UNICEF staff member said "the village level of engagement, expanding reach and opening up access to disability-inclusive ECDiE. Parents attest to this. Communities are more accepting, while support and stimulation of parents to children has increased. It's simple but powerful - helps parents to gain confidence and affirm their children, giving them a better chance in life" (Ibid).

iACT's Little Ripples programme integrates developmental monitoring into its ECDiE curriculum for the early identification of developmental delays and disabilities (UNICEF, 2022). Little Ripples is an early childhood development program that empowers refugees and communities affected by humanitarian crises. It implements child-centered, quality, and comprehensive pre-primary education that supports the social-emotional, cognitive, and physical development of children ages 3 to 5. A teacher training programme provides guidance to host community and refugee participants on the Little Ripples curriculum and approach. Activities can be carried out at home, in child-friendly spaces, schools, and community centers' venues are referred to as 'Ponds'. The Little Ripples curriculum is built on play-based education, trauma-recovery approaches, restorative practices, and incorporates social-emotional learning, empathy development, positive behavior management, peacebuilding, and mindfulness. Little Ripples is active in Chad (Sudanese refugees), Tanzania (Burundi refugees), Cameroon (CAR refugees) and Greece.

Recommendations

The recommendations below should be considered by all relevant global, national, and local stakeholders to support babies and young children with disabilities and developmental delays, and their families or caregivers to build a nurturing environment. These recommendations build upon and complement the Thematic brief on Nurturing Care for children living in humanitarian settings (WHO, UNICEF, World Bank, 2020).

Data

A commitment to working with the most marginalized children and their families requires data to support learning about the complexity of disability, the diverse experiences of girls and boys with disability, and the intersection of disability exclusion and gender-based inequalities. Governments, multilateral agencies, donors, and implementing organizations must improve the collection, storage, use, and dissemination of age, sex and disability (by type) disaggregated data to ensure inequities are targeted and to strengthen humanitarian planning and investment:

- All implementing agencies should monitor access to disability-inclusive ECDiE, share this data with relevant stakeholders and ensure programmatic interventions are responsive to the data.
- Governments and all implementing agencies should promote early identification of disability and developmental delays for all babies and young children so that at the onset of emergencies, government and other service providers have a more accurate understanding of at-risk/in-need affected populations (WHO, 2018).
- Governments, multilateral agencies, donors, and implementing organizations should guarantee that children with disabilities, their families, and caregivers are not excluded from sampling, reports, studies, or other exercises that seek to understand and respond to the needs of disabled or developmentally delayed children.
- Governments, multilateral agencies, donors, and implementing organizations should ensure that when they collect, disseminate, and archive data, parents and caregivers provide their consent.

Screening and early identification

Governments, multilateral agencies, and technical specialists must work together to standardize screening and identification tools for use globally to identify disability and developmental delays. Standardization improves early detection and enables the data generated from this screening and identification to be analyzed to inform programming and investment:

- All key stakeholders must ensure that screening and early identification tools are disseminated widely and that appropriate briefing and/or capacity building is provided on the tools for staff members on a regular basis.
- Governments and/or inter-sectoral/cluster coordination groups (see *Coordination and multi-sectoral collaboration* recommendation) must prioritize identification and screening of babies and young children for disabilities and developmental delays upon arrival at refugee reception points/camps and internally displaced people camps and centers, as well as at each phase of emergency management and response.
- Governments, inter-sectoral/cluster coordination groups, and/or service providers must ensure a system of referral services that respond to the needs of young children with disabilities and developmental delay is in place to support screening and subsequent continuum of care. If these systems are not in place, the findings of early detection work can be used to advocate for their development and implementation.

Policy and planning

Governments should develop and implement disability-inclusive ECDiE policies, legislation, and regulations at a national level to guarantee it is prioritized at the onset of crises. This requires the active participation of people with disabilities as decision-makers throughout, as well as to collaborate with disabled people's organizations or other groups of people with disabilities, and involve them as much as possible:

- Governments and policymakers should consider the Nurturing Care Framework and other relevant frameworks in designing and implementing disability-inclusive ECDiE policies, as these have proven efficiency in different contexts.
- Governments should ensure disability-inclusive ECDiE is fully integrated into disaster preparedness and humanitarian response planning and adhere to the CRC and UNCRPD obligations.
- Governments should map national and local organizations and ministries providing disability inclusion related ECD services pre-crisis. Identify the extent to which they are equipped to transition providing disability-inclusive ECDiE services during crises (Moore et al., 2020).
- Implementing agencies should ensure that existing ECDiE policy and planning is disability-inclusive and take remedial action where this is not the case. Partner with organizations of persons with disabilities and technical experts if additional expertise is needed to guide policy and planning. Ensure appropriately trained staff are in place to support implementation.
- All key implementation stakeholders should include parents, caregivers, and young children with disabilities or developmental delays from affected populations in planning and preparedness activities to ensure that their needs are met.

Coordination and multi-sectoral collaboration

Governments, multilateral agencies (such as United Nations Office for the Coordination of Humanitarian Affairs (OCHA)), NGO country representatives, heads of cluster lead agencies at country level, and/or sector-specific cluster leads should collaborate to build stronger and more efficient humanitarian coordination between relevant sectors: health, child protection, WASH, nutrition, education, social welfare etc. (see Figure 2 below for sample group structure). This should include representation from organizations of persons with disabilities (OPDs) to ensure young children with disabilities are appropriately supported across their domains of need:

- Governments and/or Humanitarian Coordinators (e.g., OCHA) should establish an inter-cluster/sector coordination group on ECDiE with strong leadership to provide direction and operational support in humanitarian contexts, including protracted crises. This group should track and monitor the response and compile updates gathered from sub-national level in order to modify it accordingly and/or advocate for specific outcomes on decision points that prioritize adherence to the CRC and UNCRPD and the best interests of young children with disabilities and developmental delays. This group should include gender and child protection specialists and representatives from NGOs to strengthen links with operational actors and to improve the role of local, national, and international actors in coordination.

Humanitarian Country Team or Government
NGO / Country Rep * UN / International Organisation Head / country lead * Country Rep / head of cluster lead agency

Inter-Cluster Coordination Group

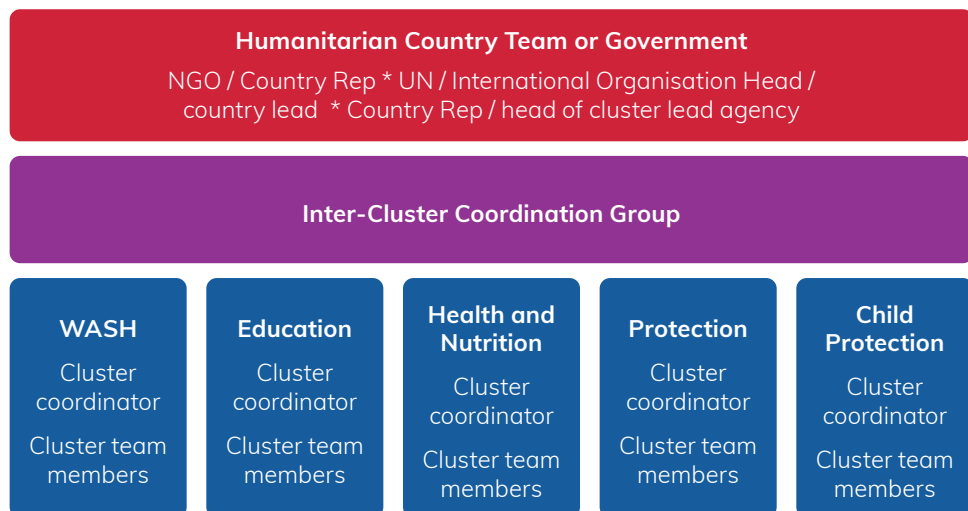| WASH	Education	Health and Nutrition	Protection	Child Protection
Cluster coordinator	Cluster coordinator	Cluster coordinator	Cluster coordinator	Cluster coordinator
Cluster team members	Cluster team members	Cluster team members	Cluster team members	Cluster team members

Figure 2: Sample organizational structure for a Disability Inclusive ECDiE Inter-sectoral Coordination Group

- Cluster/sector leads should work together to conduct a needs analysis for babies and young children with disabilities and developmental delays that also considers intersecting vulnerabilities as a result of gender, age, ethnicity, location and other relevant factors.

- Clusters/sectors should work together to develop a shared strategic approach to disability-inclusive ECDiE, agree on prioritization of interventions and good practices, geographic focus, modalities of response, and avoiding gaps and duplication in service delivery.
- The disability ECDiE inter-cluster coordination group's core responsibilities should include:[3]
  - Support service delivery across clusters or sectors;
  - Support analysis, planning, and monitoring across clusters or sectors;
  - Integration of cross sectoral issues into humanitarian response;
  - Monitor and adherence to CRC and UNCRPD; and
  - Advocacy

Programming interventions

A set of standards should be developed for disability-inclusive ECDiE, which is currently a major gap. Many countries have minimum standards in place for quality in early childhood interventions and development programmes. These standards may include minimum staff qualifications, staff:child ratios, and mandatory outdoor spaces for children (UNESCO, 2021). Minimum standards for disability-inclusive ECDiE should be grounded in the Nurturing Care Framework. At minimum, disability-inclusive ECDiE interventions should:

- Protect and promote the health and well-being of babies and young children with disabilities and developmental delay and their caregivers. This could include accessible outreach and home visits with appropriately trained staff as well as interventions located in health centers, and should include both universal and indicated support for children with disabilities or developmental delays.
- Provide disability-inclusive maternal and child nutrition and feeding, including information in accessible formats about vaccinations, early simulation, and good nutrition.
- Promote access to maternal health services in pregnancy and delivery to reduce the risk of disability due to complications in childbirth.
- Ensure that environments are accessible, safe, secure and nurturing for babies and young children with disabilities, and developmental delays.
- Provide disability-inclusive opportunities for accessible early learning and play groups for babies and young children with disabilities and developmental delays. For example, this could involve adaptation of existing play kits/boxes, the provision of safe play and learning spaces.
- Provide training for parenting and ECD facilitators, among others, on inclusion, inclusive play-based pedagogy, and adaptations, etc.
- Support parents/caregivers to offer caregiving that is responsive to the needs of babies and young children with disabilities and developmental delays. For example, this could be through inclusive parenting programmes.
- Provide peer-to-peer support or social support networks for parents of young children with disabilities.
- Consider twin track approaches that specifically target young children with disabilities while simultaneously working to strengthen inclusion in mainstream services and interventions.

3   For a sample inter-cluster coordination group TOR, see: https://bit.ly/3zgYOz0 accessed 29th July 2022

- Develop meaningful consultation and partnerships with OPDs in humanitarian settings to support a range of areas, particularly strengthening disability inclusion in programme design, delivery, monitoring, evaluation and learning.

Governments and implementation agencies should strengthen social emotional learning (SEL) and mental health and psychosocial support (MHPSS) in programming for inclusive ECDiE given the greater vulnerability of young children with disabilities (Jordans & Tol, 2015). Integrate MHPSS services into non specialized health settings; parenting programmes and school level entry points to build resilience (Ibid).

Government and implementing agencies should ensure an accessible 'continuum of care' so that young children with disabilities can reach services in their communities: accessible transport, translation, appropriate staffing, integrated accessible care at centers and systems that combine these services to provide a continuum of care.

Governments and implementation agencies should ensure that behaviour change communication around disability stigma and discrimination as well as children's rights under CRC and CRPD is required in all programmes.

Evidence for scaling up

Research organizations, implementing agencies, and other key stakeholders should promote wider dissemination of models for and approaches to disability-inclusive ECDiE, including evidence on cost and the immediate and long-term benefits of inclusion, to help make the case to donors and governments (Moore et al., 2020):

- Research organizations, implementing agencies, and other key stakeholders should develop guidance and resources on how to implement broad disability-inclusive ECDiE pedagogical approaches and early years curriculum adaptations on a larger scale before and during crises (Moore et al., 2020).
- Key stakeholders should advocate for the development of detailed implementation manuals that attend to the different dimensions of exclusion - including, but not limited to disability. It is also important to monitor the implementation of these manuals and models to enhance evidence development. Monitoring frameworks should include measurements for the accessibility of childcare programmes including number of young children, and proportion of needs met, disaggregated by sex, age, disability, refugee status, and other demographic indicators (UNICEF, 2022).
- Monitoring frameworks should include indicators based on the five dimensions of the Nurturing Care Framework.

Advocacy

International NGOs, multilateral agencies, and coalitions should advocate to:

- Increase national and international investment in disability-inclusive ECDiE;
- Develop national policies, strategic plans, legislation, and regulations for disability-inclusive ECD, including in disaster or humanitarian response planning;
- Expand and improve disability-inclusive ECDiE programming;
- promote universal developmental screening, surveillance, and monitoring in all countries;
- Strengthen coordination on disability-inclusive ECDiE at country and subnational level;
- Strengthen the evidence base on 'what works' in successful disability-inclusive ECDiE in humanitarian contexts;
- Prevent institutionalization [4], achieve deinstitutionalization, and prevent re-institutionalization after the acute phase of a humanitarian emergency subsides; and
- Encourage the establishment of essential respite care services for parents of children with disabilities and developmental delay receiving ECDiE services.

Emergency evacuation planners should work more closely with OPDs and other advocates for young children with disabilities and developmental delays and their caregivers to identify and accommodate their specific needs and leverage social networks to ensure that they have adequate support during emergencies (Hunt et al., 2021).

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4 The culture of institutionalization implies social isolation and segregation of persons with disabilities, including at home or in family, preventing them from interacting in society and being included in the community (Committee on the Rights of Persons with Disabilities, n.d.)

Conclusion

Strong arguments exist for early intervention in childhood development, particularly for young children with disabilities and developmental delays in humanitarian settings. The impact of humanitarian crises, conflict, and displacement is particularly acute in the early years from conception to 8. This is the time when a child's social, emotional, cognitive, and physical development is most critical. These years are a unique window of opportunity to positively influence the development that shapes a child's future life course. Stressful or traumatic conditions, malnutrition, separation from family, injury, abuse, exploitation, and a lack of stimulation during this time can cause lasting damage. Young children with disabilities and developmental delays are particularly vulnerable in humanitarian settings.

Significant barriers currently prevent young children with disabilities and developmental delays and their caregivers from accessing important services that could reduce and/or remove obstacles to their full potential and participation in society over the course of their lifetime. Traditional beliefs about disability and fear of stigmatization or discrimination can make people reluctant to report or identify with having a disability or having a child with disability. While a lack of disability-inclusive humanitarian planning, including well managed multi-sectoral coordination and investment in ECDiE, are among the major barriers that exclude young children with disabilities or developmental delays from programmes and services.

However, there are examples of good practice around the world that enable and mainstream inclusion across all programmes, activities, and project management processes as well as disability-specific initiatives. They provide targeted support and resources for children with disabilities to enable their equal participation in projects and in their communities. There is also a set of frameworks for planning and implementing interventions, such as the Nurturing Care Framework which recognizes all children's need for good health, optimal nutrition, security and safety, opportunities for early learning and responsive caregiving. Investing in the early years makes aid more cost-effective, supporting children as they develop the capacities and skills needed to thrive.

However, key stakeholders need to strengthen their support for young children with disabilities and developmental delays in humanitarian settings, championing disability-inclusive ECDiE that promotes equal opportunities for children to attend, learn, develop and participate in learning and social activities; respects and celebrates diversity and differences and it does not exclude, stereotype, stigmatize or discriminate against any children on the basis of their differences; protects children from abuse, neglect, and stress by providing nurturing care and protection; and creates strong connections with families and communities as partners in child development and learning, and is attentive to their backgrounds, needs and situations.

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Appendix 1: Examples of working together across sectors at the local level

Child Protection

- Promote birth registration of all children.
- Promote responsive caregiving for all parents, including those with children with disabilities and developmental delay.
- Work with child protection clusters and/or partners to monitor protection concerns.
- Establish safe, confidential, gender- sensitive, and fully accessible reporting and referral routes. Ensure all parents and young children are aware of these.
- Provide all ECD facilitators with training in disability-inclusive child protection and safeguarding.
- Link with law enforcement agencies to ensure right to safety is being met for those at risk of gender based violence and other forms of abuse.

Food Security and Nutrition

- Engage with food security and nutrition partners to ensure access to inclusive feeding programmes at key entry points (e.g. clinics, child friendly spaces, ECD settings), paying particular attention to babies and young children with disabilities to ensure they can participate in early learning and stimulation opportunities.
- Ensure disability-inclusive maternal and child nutrition programmes are in place, including support for children with feeding difficulties.
- Explore opportunities for disability-inclusive education and awareness raising on nutrition.
- Link food and nutrition and feeding services to ante-natal and post-natal care for girls and women, including those with disabilities.

Health	• Enlist support of health colleagues to carry out assessment and screening for impairments and referrals to specialists distribution, monitoring, maintenance of assistive devices; and carry out inclusive Sexual and Reproductive Health and Rights education for parents and community members (pregnancy, sexually transmitted infections, HIV, etc.). • Ensure the physical and mental health and wellbeing of parents and carers of young children with disabilities and developmental delay.
Water, Sanitation, and Hygiene (WASH)	• Work with WASH partners to ensure WASH facilities are accessible and gender sensitive. • Design and construct safe, accessible, and private sanitation facilities at early learning centers, including separate toilets and washing areas for girls and boys. • Conduct inclusive hygiene promotion activities in early learning settings. • Support the accessible distribution of menstrual health management kits.
Shelter, Settlements and Recovery (SSR)	• Ensure the safety and security of the environment surrounding children with disabilities and their families/caregivers. • Work with SSR partners to plan and design child-friendly spaces, temporary learning spaces, and other ECDiE settings that are based on universal design and/or reasonable accommodation, and located in safe and accessible areas. • Address accessibility and GBV-related safety concerns in the ongoing rehabilitation of early childhood development and learning spaces.
Social Protection and/or Livelihoods	• Provide conditional and unconditional cash transfers for vulnerable families. • Work with social protection and/or livelihoods to identify market relevant and inclusive vocational training opportunities for parents of children with disabilities. • Implement accessible alternative education programmes that include literacy and financial literacy, life skills, sexual and reproductive health, and livelihoods and vocational training components. • Link these programmes to livelihood projects that support people with disabilities who may need economic support.

Camp Coordination and Management (CCCM)	- Work with CCCM to identify and map accessible and safe, and inaccessible and unsafe areas within camps for disability-inclusive ECDiE. - ork with CCCM to plan the location of programmes (including temporary spaces) based on safety and accessibility concerns identified by people with disabilities. - Facilitate the distribution of sanitary supplies to all women and girls of reproductive age, and plan accessible systems for washing and/or disposing of sanitary supplies in settings that are consistent with the rights and expressed needs of women and girls. - Cross-reference ECDiE attendance records with food distribution and/or camp registration records to assess (by sex, age and disability) which children and youth are attending/absent from ECD programmes, and plan human resources and infrastructure accordingly.

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