



Commentary: Children with Developmental Disorders in Humanitarian Settings: A Call for Evidence and Action

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# COMMENTARY: CHILDREN WITH DEVELOPMENTAL DISORDERS IN HUMANITARIAN SETTINGS: A CALL FOR EVIDENCE AND ACTION

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The effects disability has on children, including those with developmental disorders, are magnified in humanitarian contexts (Zuurmond et al. 2016), as the infrastructure needed to support these children's ability to function and participate is undermined by crisis.<sup>1</sup> Children in these settings who have developmental disorders are particularly vulnerable, as they often have limited access to services (Peek and Stough 2010), their caregivers' ability to cope is undermined (Dababnah et al. 2019; Beatson 2013), they may be separated from their caregivers (Peek and Stough 2010), and they are likely to experience abuse, exploitation, and neglect, including sexual and gender-based violence (Reilly 2010). Moreover, people who are poor and living in resource-scarce settings are more likely than individuals in high-income contexts to be adversely affected by developmental disorders and exposure to humanitarian crises (Casillas and Kammen 2010; UN Office for the Coordination of Humanitarian Affairs 2019; Braithwaite and Mont 2009).

The relationship between developmental disorders and humanitarian settings is a complex one: conflict and natural emergencies can contribute to developmental disorders, largely by compromising women's prenatal and perinatal environment and their access to perinatal care (Zuurmond et al. 2016). Children and adults with disabilities often shoulder a disproportionate burden of the suffering experienced in such settings (UN Human Settlements Programme 2007; Peek and Stough 2010).

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<sup>1</sup> Developmental disorders are a group of conditions that begin in the child's developmental period, affect the brain and/or nervous system, result in motor, cognitive, language, and/or behavioral impairments and limited functioning, and typically are lifelong.

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It is challenging to provide appropriate and responsive care in emergency contexts to children with developmental disorders and their caregivers (Davidson et al. 2004). Nevertheless, the public health significance of supporting these children and intervening with those at risk of suboptimal developmental trajectories due to their exposure to a humanitarian emergency cannot be ignored.

In recognition of this, our commentary poses three interlinked questions:

1. Which areas of programming and research need more attention in order to effectively support young children with developmental disorders and their caregivers?
2. In emergency contexts, what principles should guide work with young children who have disabilities?
3. What is known about how to plan and program for this group and what gaps in the evidence need to be addressed?

The Inter-Agency Standing Committee (IASC 2007, 2019), in its guidance on providing mental health and psychosocial support in emergency settings, gives specific consideration to children with severe mental health difficulties, including developmental conditions, as evidenced in discussions during the International Conference on Mental Health and Psychosocial Support in Crisis Situations (Government of The Netherlands 2019). The World Health Organization, as part of the WHO Mental Health Gap Action Programme (mhGAP) response (WHO and UNHCR 2015), has also issued guidance on the clinical management of mental, neurological, and substance use conditions for people in humanitarian emergencies. Many of the recommendations made in these documents and in the wider literature point to the key domains of planning and intervention, which must give appropriate and adequate consideration to children with developmental disorders and their families.

## **KEY RECOMMENDATIONS FOR PROGRAMMING**

### **COMMUNICATION AND EVACUATION**

Emergency evacuation planners should work with developmental disorder advocates, users of mental health and neurological services, and the caregivers of children with developmental disorders to identify and accommodate these children's specific needs and leverage social networks to ensure that they have

adequate support during emergencies (Battle 2015). This recommendation is reflected in some mental health response programming. For example, the mhGAP-HIG, an intervention guide that contains first-line management recommendations for mental, neurological, and substance use conditions for nonspecialists in humanitarian settings, advocates for the inclusion of key stakeholders, such as service users, in emergency planning and response. Moreover, training for humanitarian workers should include sensitization to the need for inclusive evacuation models that make provisions for people with different types of impairments (e.g., providing evacuation messaging in Braille, audio, easy-read, and standard written forms) (Battle 2015). To develop an adequate emergency preparedness plan, families with children who have special health-care needs must be given particular information, education, and training (Hipper et al. 2018).

### **MENTAL HEALTH AND PSYCHOSOCIAL SUPPORT**

Children with developmental disorders face a higher rate of mental health comorbidities than their typically developing peers. In humanitarian settings, caregivers of all children are at risk of developing mental health disorders (Henley and Robinson 2011; Panter-Brick, Grimon, and Eggerman 2014), and caregivers of children with developmental disorders in these settings may be at particular risk (Zuurmond et al. 2016; Power et al. 2019). Evidence-based mental health and psychosocial support (MHPSS) interventions need to address both the needs of the caregiver and the condition-specific needs of the child, as well as the child's comorbidities and the stress and trauma caused by the crisis (IASC 2007). However, Stough, Ducey, and Kang (2017) note that diagnostic overshadowing, whereby service providers assume that a child's condition is due to their existing developmental disorder rather than fully exploring the cause or the child's experience of symptoms, can hinder the recognition of trauma-related problems in children with developmental disorders. After an emergency, these children may need additional MHPSS and a longer period of intervention and follow-up than their typically developing peers (Peek and Stough 2010). Therefore, where appropriate, interventions for at least some of these children and their families should include trauma-focused components (Dababnah et al. 2019).

MHPSS interventions must be grounded in strong evidence and be adapted to the specific context and delivery platform when applied in humanitarian settings (IASC 2007). In general, MHPSS interventions aim to improve developmental outcomes and functioning in children with developmental disorders, improve the wellbeing of those who have been exposed to adverse experiences and trauma at a young age or have comorbid mental health conditions, and improve their

caregivers' wellbeing and parenting skills. Various guidance documents for the delivery of psychological first aid in humanitarian settings note the special provisions needed for individuals with disabilities (WHO 2011; Save the Children 2013; IASC 2007).

### **HEALTH CARE**

Identifying children with developmental disorders on their arrival at a refugee camp, temporary shelter, or treatment facility is a priority in monitoring the health of refugee and internally displaced populations. Identifying these children can prevent unnecessary suffering and comorbidity by providing them and their caregivers with appropriate services (Davidson et al. 2004). In the rebuilding phase of emergencies, early stimulation programs, including those delivered in early childhood care and education centers, can be used to screen children, detect those with developmental disorders, and refer them to the appropriate health and psychosocial services for them and their caregivers (Hurley et al. 2013). Monitoring young children's development during routine points of contact, including getting a vaccination, social protection, nutrition/feeding, and early childhood development initiatives, can also provide a platform for identification and referral.

In emergency contexts, children with developmental disorders may be at risk for additional medical conditions. Health-care workers can appraise their developmental progress as part of an overall health assessment (Davidson et al. 2004; National Organization on Disability 2005). Institutional exclusion, such as centralized health-care centers that are not accessible to children with physical impairments or where health-care providers do not know how to cater to the needs of children with intellectual disability or autism, can create additional vulnerabilities for these children (Peek and Stough 2010; Hemingway and Priestley 2006). Therefore, health-care services provided during crises must be fully accessible to children with developmental disorders, provide the appropriate assistive devices and supports, and attend to their comorbidities (Battle 2015).

### **EDUCATION**

For children with developmental disorders, especially girls and children of secondary school age, access to education in emergency settings is uneven across regions and settings, and according to the nature of the crisis (Battle 2015). Emergencies often disrupt education infrastructure and reduce access to appropriately trained teachers, which may delay the establishment of inclusive

education during the rebuilding phase after an emergency. Thus, there is a marked need to plan for the provision of education services in crisis-affected areas, including appropriate and inclusive education for children with developmental disorders, and for the human resources needed to provide it (Peek and Stough 2010; Battle 2015). Successful early childhood intervention programs in Nepal and Thailand identified refugee children with developmental conditions and helped them integrate into mainstream schools. Their teachers were trained and mentored to provide specific classroom support (Reilly 2010). Nevertheless, those providing inclusive education to children who require special services in emergency contexts still require more training and skills development (Barrett, Marshall, and Goldbart 2019).

### REBUILDING

Inclusivity should be fostered in the reconstruction programs that follow an emergency (Miles 2002). Research with adults has shown that people with disabilities require more ongoing structural interventions in the rebuilding phase of an emergency than people without disabilities (Peek and Stough 2010; Battle 2015). The major focus of most United Nations responses to people in postconflict settings centers on “building back better” (WHO 2013; Epping-Jordan et al. 2015). Appropriate resources, technical assistance, and targeted implementation research have been brought to bear on scaling and sustaining evidence-based interventions for populations in humanitarian settings as part of multisectoral plans to strengthen the overall emergency response system following a crisis (UN Office for Disaster Risk Reduction 2015). Evidence-based approaches to supporting children with developmental disorders are essential in such efforts.

### ENABLING ENVIRONMENTS

For children with developmental disorders, the environment in humanitarian settings is often characterized by adversity, stigma, deprivation, and a lack of access to important supports (Zuurmond et al. 2016). Furthermore, creating an environment in humanitarian settings that supports children with developmental disorders and their families requires recognizing the family unit as the intervention target, and the use of integrated cross- or multisectoral approaches.<sup>2</sup> Adequate policy structures, financing, technical input, staff, supervisory structures,

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<sup>2</sup> Enabling environments are the systems and contexts that enable individuals to participate, function, and thrive.

and implementation research must be part of any effort to improve external contexts (e.g., the built environment, health-care infrastructure, community practices) so they can sustain evidence-based practices that support children with developmental disorders in humanitarian settings. Protections and safeguards for children should target those who have particular vulnerabilities, including developmental disorders. Serious threats to these children's wellbeing, such as long-term detention in refugee or asylum centers, are unacceptable because of the high risk to the mental health of refugee children and their caregivers, particularly children with mental health conditions (Kronick, Rousseau, and Cleveland 2015).

### GUIDING PRINCIPLES

The literature offers general good practices and important principles for working in emergency contexts with young children who have disabilities. These guidelines, which are broader than any given intervention, can be described more accurately as the values and ethos the programming and research in these situations should embrace. They must undergird efforts to support young children with developmental disorders, and their caregivers, who are living in emergency situations.

The need for cultural and contextual sensitivity recurs throughout the literature (Dababnah et al. 2019; Kroening et al. 2016; Beatson 2013). In humanitarian settings, encounters with biomedical services can be alienating for the caregivers of children with developmental disorders unless an effort is made to adapt these programs to the worldview of the individuals they serve. In this respect, much can be learned from the immigration literature. For instance, recommendations for those providing pediatric rehabilitation services to immigrant families that are raising a child with developmental disorders include extensive training in cultural issues and the practice of culturally sensitive care (Bhayana and Bhayana 2018). There also is a need for systematic protocols to guide the rapid and efficient cultural adaptation of evidence-based interventions.

Integrated cross-sectoral actions that advance evidence-based practices in the provision of child and family-centered care and support are also necessary. Cross-sectoral and intersectoral coordination among health, education, and social protection services are needed to ensure that children and their caregivers are provided for.



Engaging the community and other stakeholders in the identification of available resources in a child's environment is also imperative. Leveraging these networks to identify existing services and other resources for children with developmental disorders and their families is vital to finding sustainable supports.

Family-centered action must be the gold standard of intervention work, as the family plays a vital role in shaping children's survival and development in conflict and postconflict settings. This is perhaps particularly true for children with developmental disorders (Denov and Shevell 2019). However, the trauma of an emergency can undermine caregivers' capacity to cope, which may limit their ability to provide optimal care for their children (Alipui and Gerke 2018; Appleyard and Osofsky 2003). Therefore, when intervening to support children with developmental disorders in humanitarian settings, it is crucial that the capacity of their primary caregivers is a central focus.

Finally, engaging youth with developmental conditions, their families, and advocacy organizations in planning and programming must be a priority in inclusive humanitarian responses. Children with disabilities are experts who have lived experience, and they and their caregivers can provide vital information and perspectives that inform programming priorities and drive meaningful monitoring and evaluation.

## EVIDENCE GAPS

As we synthesized the available evidence to develop the argument we present here, it became clear that the knowledge base for supporting this key population in humanitarian settings is limited. We found that data on developmental disorders, at least among refugee and war-affected populations, is collected infrequently, and that intervention work often takes place in the absence of accurate—or in fact any—data (Simmons 2010). For national and international agencies to gauge the extent and types of services needed to support children with developmental disorders in humanitarian settings, they will need to collect, analyze, and interpret data on developmental disorders and associated outcomes. Priority areas in which to generate evidence are noted in the literature, including the need for refined tools to raise awareness and provide technical assistance for planning screening, diagnosis, and treatment; better data about prevalence of different developmental disorders and comorbidities; literature that clearly addresses which policy and legislative provisions are most effective; and stronger monitoring by the public health system of children with developmental disorders and their families. There

also is a dearth of research literature that examines how well current guidance and frameworks are “working” for these children and their families. Such tools and resources are simply unavailable in many district hospitals and in the community health and early childhood development centers that serve children in humanitarian settings.

## RELEVANCE FOR KEY STAKEHOLDERS

This commentary has highlighted areas of programming and research that need to give greater attention to supporting young children with developmental disorders, and their caregivers, in emergency contexts. As described, in order to provide concrete programming guidance, significant gaps in the evidence must be resolved. However, having perfect evidence is not a prerequisite to acting in response to urgent needs. The priorities discussed above and the guiding principles for planning and programming foreground the following for key stakeholders:

**Caregivers:** The mental health and wellbeing of caregivers must be buoyed if children with developmental conditions are to be properly supported. Caregivers are key partners and stakeholders in any intervention, and they must be adequately equipped to fulfil their caregiving role.

**Teachers:** Education infrastructure is often disrupted during crises, and appropriately trained teachers may not be available. Priority interventions must include training teachers to support inclusive education and providing classroom support for refugee children with special learning needs.

**Health-care workers:** Communication, the provision of appropriate assistive devices and supports, accessible health-care spaces, attention to comorbidities, and identification are priorities for the training of health-care providers working with children in these settings. As part of their overall health assessment of a child, health-care workers might appraise their developmental progress.

**Policymakers:** Planning and action in emergencies must be inclusive, and humanitarian organizations should include local disabled people’s organizations in their emergency responses. Gender and caregiving roles should be kept in mind in the policymaking process. Evidence is critical to informed policymaking, including what intervention options can be scaled with sustained quality to serve vulnerable children and families.

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