Early childhood development (ECD) and children with disabilities

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Introduction to the topic

This reading pack briefly highlights some of the research and programme work that are showing positive benefits for young children with disabilities in low-resource settings. The international evidence that high quality early childhood development (ECD) programmes benefit all children's development, life experiences, and life chances is overwhelming. The evidence comes from studies of all kinds, including well-known large quantitative longitudinal studies (e.g. High/Scope Perry studies in the USA and the work of Heckman at http://heckmanequation.org/) to more localised qualitative case studies (e.g. Ames, Rojas & Portugal, 2010; Munthali, Mvula & Silo, 2014; Save the Children, 2003). As the HEART *Early Childhood Development Topic Guide* (Woodhead et. al., 2014) points out, early childhood development is an enormous field covering a range of sectors including early learning and education, nutrition, water, sanitation and hygiene (WASH), health, social protection, and community. The ECD field extends across multiple sectors and spans the life period from conception through to eight years.

ECD and disability

Children with disabilities are often excluded or overlooked in mainstream ECD programmes, therefore missing out on important opportunities to receive the specialist support and services they need to meet their rights and needs. Without the appropriate early interventions, support and protection, their impairment or disability could become more severe or complex, potentially leading to long-term consequences, increased poverty and marginalisation (WHO, 2012). Studies have demonstrated that parents of children with intellectual disabilities experience more distress and higher rates of depression compared with families of typically developing children (Dykens et al., 2014; Hastings, 2004; Emerson,

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2005). Much of this distress is related to stigma and cultural misconceptions about disability and its causes (Kelly et al., 2012). Other studies have also reported negative impacts including physical health problems for parents as well as physical, social, and financial distress for the whole family (Witt et al., 2003). This often leads to marital breakdowns and divorce (Schwartz et al., 2003). Despite the increasingly recognised burden of childhood disability on individuals, families and populations, research in this area (especially from low-income countries) has been described as 'woefully inadequate' (Maulik et al., 2007).

More positively, global attention on child health has been shifting from 'child survival' alone to inclusive early childhood development strategies that enable all children to thrive and develop healthily (UNICEF, 2007). This serves as a foundation for a diverse and fair society, and is in line with the guiding principles laid down in the *United Nations Convention on the Rights of the Child* (1989) of establishing a universal standard and a general principle of the *UN Convention for the Rights of People with Disabilities* (2006) of 'respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities' (Article 3). Furthermore, the World Health Organization (WHO) has made early identification of children with disabilities a high priority especially as early support may reduce the impact of the impairment (Durkin et al., 1994). This is particularly true for those with vision and hearing impairments, many of which can be treated, as well as for cerebral palsy and other neuro-disabilities where support in terms of feeding and postural management can make a big difference (see example on Key Informant Method).

One of the biggest problems for organisations and agencies providing essential healthcare and other key services for children with disabilities is accessing precise, robust and reliable disability data (WHO, 2011). Limitations of census and general household surveys to capture childhood disability, the absence of registries in many low and middle income countries (LMICs) and poor access to culturally appropriate clinical and diagnostic services contribute to poor estimates of disability (UNICEF, 2007). Unfortunately, children with less obvious or what are commonly called 'hidden disabilities' (e.g. mild to moderate intellectual impairments) are not always identified until children reach school age. Developmental screening tools (short tests to tell if a child is learning basic skills when he or she should, or if there are delays) used in isolation are not helpful in identifying disability, but if used for training of community workers (e.g. health) to provide an outline of what is 'typical' child development, then, this in itself is useful and enables them to think about it more, identify cases and consider referrals to clinics.

Many children with developmental delays are not being identified as early as possible. As a result, these children often have to wait till they start going to school before they receive help. The American Academy of Pediatrics recommends that all children be screened for developmental delays and disabilities at nine months, 18 months and 24 or 30 months. Additional screening is needed if a child is at high risk for developmental problems due to preterm birth, low birthweight, or other reasons.

It is important for stakeholders working in ECD and disability to be given pertinent data about childhood developmental delay disability to promote better levels of access to healthcare and to prevent impairment at the primary and rehabilitative levels. The following tools and methods are showing positive benefits for young children with disabilities in low-resource settings:

- **Washington Group Questions** is a tool comprising 16 questions which helps to pick up potential developmental delays or impairments in children and young people (child functioning and disability, age 2 – 4). The questions help to identify persons with similar types and levels of limitations in basic activity functioning regardless of nationality or culture. These questions can be routinely included in other data collecting exercises, e.g. household surveys. (http://www.cdc.gov/nchs/data/washington_group/meeting13/wg13_unicef_child_disability_backgr ound.pdf)
- **Key Informant Method (KIM)** is an approach where knowledgeable members of the community (key informants) are trained to effectively identify children with moderate-severe physical impairments, sensory impairments and epilepsy. KIM allows for a pre-emptive mapping of referral services by collating information on service availability and affordability (ICED, 2013). The KIM has had an impact on the of Hambisela programme in the Eastern Cape, South Africa, by increasing referrals of children with cerebral palsy for therapeutically-correct care and enabling them to realise their maximum life potential (http://justrain.co.za/hambisela).

- ***The Malawi Development Assessment Tool (MDAT)*** is a validated tool used in Africa to measure developmental delay ([Gladstone et al., 2008](#)). The tool has been made into an app for use as part of a community health worker project in Kenya (mCHW) (http://www.mchw.org/). Future use of the MDAT could be in supporting training packages more directly (e.g. WHO/UNICEF Care for Child Development).

Agreement on the Sustainable Development Goals (SDGs) signals that ECD is a priority focus for 2030, but SDG commitments to ECD and disability require careful planning to ensure no child is left behind. Multi-sectoral approaches with effective coordinating mechanisms between such sectors as education, health and social welfare are required to ensure early identification efforts, promote holistic responses and link school-based learning with home and community interventions.

Inclusive pre-school and early primary schooling offers children with disabilities a vital space in which to ensure optimal development through child-focused learning, play, participation, peer interaction and the development of friendships ([Kelly et al. 2012](#)). More work is required to create inclusive ECD curricula which look at ways of ensuring all children are able to participate in indoor and outdoor activities (including toileting and feeding). Centres and schools need to be completely accessible, as well as accessible and safe latrines and toilets for children with disabilities. WaterAid, in its response to WASH and disability, has been addressing the barriers to accessible water and sanitation facilities to ensure that children with disabilities, especially girls, are able to attend school (Jones & Reed, 2005) (see: http://www.wateraid.org/news/news/putting-disability-at-the-centre-of-global-development).

Some children with disabilities and their families may require more specialist support at home. In Malawi, a system called 'portage' is being used to help families with early educational home-based support in the north part of the country. The focus is on family involvement, in partnership with the home visitor, and the use of structured teaching methods. As a result of visits from community home visitors, there was greater acceptance of the child as an individual, first as part of the family, and second as part of the community. Greater efforts were also made in developing a supportive village culture aimed at promoting the respect and rights of the child as a citizen of that community ([Kelly et al. 2012](#)). INGOs supporting children with disabilities (e.g. CBM, Handicap International, Sightsavers) as well as disabled persons' organisations that provide networks of support, can provide help in setting up links between the home and early childhood centres. Inclusive early childhood systems have the potential to serve as foundations for a diverse and fair society.

Key readings

Reading 1: Gladstone M, Lancaster G, Jones A, Maleta K, Mtitimila E, Ashorn P, et al. (2008) Can Western developmental screening tools be modified for use in a rural Malawian setting? *Archives of Diseases of Childhood.* 93:23-29. http://www.heart-resources.org/doc_lib/can-western-developmental-screening-tools-modified-use-rural-malawian-setting/

Reading 2: Kelly A, Ghalaieny T, Devit C. (2012) A pilot study of early intervention for families with children with or at risk of an intellectual disability in Northern Malawi. *J Policy Prac Intellectual Dis* 9:195–205. http://www.heart-resources.org/doc_lib/pilot-study-early-intervention-families-children-risk-intellectual-disability-northern-malawi/

Reading 3: International Centre for Evidence in Disability, LSHTM, Key Informant Method, http://disabilitycentre.lshtm.ac.uk/kim/

Reading 4: WHO (2012) *Early Childhood Development and Disability: A discussion paper.* http://www.heart-resources.org/doc_lib/early-childhood-development-disability-discussion-paper/

Reading 5: WHO (2011) *World Report on Disability.* Geneva, Switzerland: The World Health Organization http://www.heart-resources.org/doc_lib/world-report-disability/

Reading 6: World Bank (2009) *Examining Early child Development in Low-Income Countries: A Toolkit for the Assessment of Children in the First Five Years of Life* http://www.heart-resources.org/doc_lib/examining-early-child-development-low-income-countries-toolkit-assessment-children-first-five-years-life/.

Questions for discussion

- What are some of the key challenges to accessing high quality ECD experiences for children with disabilities and how can they be tackled?
- How can ministries which have responsibility for ECD as a whole support the training and supervision of workers in education, health and social welfare to work together on high quality ECD and disability?
- How can ministries responsible for ECD work with non-government organisations and donor agencies to increase the effectiveness of inclusive ECD programmes for children with disabilities?

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