GP CWD | GLOBAL PARTNERSHIP ON CHILDREN WITH DISABILITIES

Child Protection Task Force

Global Partnership on Children with Disabilities – GPcwd

Literature Review – October 2015

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Introduction

The establishment of the Global Partnership for Children with Disabilities (GPcwd) provides a timely opportunity to influence change for children with disabilities. The Convention on the Rights of Persons with Disabilities (UNCRPD) and the emphasis on the rights of children with disabilities to be protected under the Convention on the Rights of the Child (UNCRC) are key instruments for the GPcwd to achieve this change. The principle of "leave no one behind", which has been an integral part of negotiations around the UN Sustainable Development Goals (SDGs) is an important concept to ensure that children with disabilities are considered in terms of their increased vulnerability in all situations of adversity, including in emergencies, conflict and extreme poverty.

This literature review was conducted by the Secretariat of the Child Protection Task Force of the GPcwd, with input from Task Force members. The aim of the review was to identify knowledge and expertise regarding children with disabilities in the field of child protection and the existence of knowledge, policy frameworks and international guidance. It focuses on three areas that have specific impact on the lives of children with disabilities and were agreed by the Task Force:

1. The transition from large-scale residential care to community and family-based systems of care for children with disabilities.
2. Access to and effectiveness of child protection systems that are inclusive of children with disabilities.
3. Inclusive child protection responses to children with disabilities involved in crisis, conflict and emergency situations.

It is worth noting that while these three areas are interconnected, they also have distinct aspects that need to be considered independently.

It is hoped that this literature review will contribute to an increased awareness of the need for concerted international efforts to understand and meet the protection needs of children with disabilities.

1. The transition from large-scale residential care to community and family-based systems of care for children with disabilities

The scale of institutionalisation

Whilst the precise number is not known, evidence suggests that an estimated eight million children live in residential institutions[1] that deny them their rights and that cannot meet their needs.[2] The actual number is likely to be higher, owing to lack of data from many countries and the large number of unregistered institutions and orphanages. The current number of institutions is likely to rise over the years with the impact of conflict, emergencies, climate change and the effects of the HIV and AIDS pandemic on the most vulnerable populations[3], as well as a lack of initiatives aimed at building and supporting community and family-type services that could provide care for these children.

More than 80 years of research from across the world has demonstrated the significant harm caused to children in institutions.[4] These studies have highlighted the difficulties that children face in forming secure attachments conducive to healthy development, due to a lack of emotional and physical contact and a lack of interaction with an attuned, responsive caregiver. This inability of the institutional environment to meet individual needs can lead to developmental delays and challenging behaviours.[5] Research also demonstrates that institutionalisation has a severe impact on Early Brain Development (EBD).[6] There is extensive literature documenting that institutional care is associated with significant delays in physical growth, including head circumference that, in infants, is associated with brain growth.[7]

Children with disabilities represent a large proportion of all children in residential care institutions. According to information from 2007, more than one third of all children in institutions had a disability.[8] In the United States children with disabilities are 36-times more likely to be living in an institution than their non-disabled peers; this likelihood increases to 46-times for children with disabilities in Central and Eastern Europe and the Commonwealth of Independent States (Russis)

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[1] The number of residential institutions and the number of children living in them is unknown. Estimates range from 'more than 2 million' (UNICEF, Progress for Children: A Report Card on Child Protection Number 8, 2009) to 8 million (Cited in: Pinheiro, P., World Report on Violence against Children, UNICEF, New York, 2006).

[2] Institutional care' is understood to be any residential care where institutional culture prevails. The size of the institution matters, but is not the only defining feature. Children are isolated from the broader community and/or compelled to live together. These children do not have sufficient control over their lives and over decisions which affect them. The requirements of the organisation itself tend to take precedence over the children's individual needs. This usually includes large residential units (more than 10 children) but also smaller units with strict regimes, units for children who have committed minor offences, residential health facilities, and residential special schools. Mulheir G, 'Deinstitutionalisation: A Human Rights Priority for Children with Disabilities', Equal Rights Review, Volume Nine, 2012.

[3] Csáky, C., *Keeping Children Out of Harmful Institutions: Why we should be investing in family-based care,* Save the Children, London, 2009.

[4] Berens & Nelson. The science of early adversity: is there a role for large institutions in the care of vulnerable children? The Lancet. 2015. Available from: http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(14)61131-4/abstract

[5] Mulheir, G., *Deinstitutionalisation – A Human Rights Priority for Children with Disabilities*. The Equal Rights Review: 119–121, 2012.

[6] Nelson, C. and Koga, S. *Effects of institutionalisation on brain and behavioural development in young children*, 2004: Findings from the Bucharest early intervention project, paper presented at the International Conference on 'Mapping the number and characteristics of children under three in institutions across Europe at risk of harm', 19 March 2004, EU Daphne Programme 2002/3 and WHO Regional Office for Europe, Copenhagen, Denmark;

[7] Mulheir, G., Browne, K., (et al.,) *De-institutionalising and transforming children's services: A guide to good practice*, WHO Collaborating Centre for Child Care and Protection, University of Birmingham, 2007.
Nelson, C.A., Bos, K., Gunnar, M.R., Sonuga-Barke, E.J.S., *The neurobiological toll of early human deprivation*, Monographs of the Society for Research in Child Development, 2011.

[8] Ibid.

Region.[9] In Jamaica, 65% of children with disabilities live in special institutions for children with disabilities.[10]

A study of deinstitutionalisation of new-born to five-year-old children in institutional care in seven European countries found that only half received a disability assessment as part of the deinstitutionalisation process.[11] Only in 38% of cases were children with siblings rehomed together.

Reasons for admission into institutions

In 2013, a study found that abuse and neglect were the most common reasons for children in developed European countries to be placed in institutional care; poverty and disability were common causes for institutionalisation in European countries undergoing economic transition.[12] One of the major factors associated with the admission of children with disabilities to alternative /institutional care is poverty. There is a strong inter-relationship between poverty and disability.[13] Research shows that providing support to persons with disabilities dramatically reduces the impact of the disability on families and reduces the significance of the relationship between poverty and disability.[14] But while poverty and disability are important contributing factor to the institutionalisation of children, other social factors such as single parenthood, unemployment, migration and deprivation of parental rights also play a decisive role.[15]

Where institutions do not exist, families and community members are more likely to initiate or seek other ways to care for orphans and vulnerable children within families.[16] According to one study, between 45% and 98% of children in 'orphanages' have at least one living parent, often known to the authorities.[17] The reasons for admission into an institution are often directly influenced by the lack of access to free or affordable social services.[18] In the Republic of Georgia, for example, parents explained the reason for placing their children in institutions as:

> *"social attitudes that shame the family that has a child with disabilities; lack of skills to provide appropriate nursing care; financial difficulties; and the belief there is very little chance a child with disabilities can be integrated into society."* [19]

Discrimination against certain groups of children – children with physical and/or intellectual disabilities, children from minority ethnic groups, children with single mothers and those from separated families – leads to these children being disproportionately represented in institutions. When children with disabilities are in institutions, they are also more likely to stay longer than non-disabled children.[20] Evidence shows that children with intellectual disabilities are most likely to remain in institutionalised care throughout their childhood and adult life until their death.[21]

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[9] Better Care Network Secretariat, *Global facts about orphanages*, Better Care Network, 2009.
[10] Ibid.
[11] Browne, K. D., Hamilton-Giacritsis, C. E., Johnson, R., Agathonos, H., Anaut, M., Herczog, M., et al., Mapping the number and characteristics of children under three in institutions across Europe at risk of harm (European Union Daphne Programme, Final Project Report No. 2002/017/C). Birmingham, UK: University Centre for Forensic and Family Psychology, 2004.
[12] Browne, K. *The risk of harm to young children in institutional care,* Save the Children, London, 2009.
[13] UNICEF, Innocenti Insight *Children and Disability in Transition in CEE/CIS and in Baltic States*, 2005;
[14] Mont D. and Nguyen C., Munich Personal RePEc Archive; *Spatial Variation in the Disability-Poverty Correlation: Evidence from Vietnam*, 2013;
[15] Carter, R., *Family matters: a study of institutional childcare in Central and Eastern Europe and the former Soviet Union*. London, EveryChild, 2005; Tinova, M, Browne, K.D. and Pritchard, C. as cited in Browne, K. (2009), *The Risk of Harm to Young Children in Institutional Care,* Save the Children, London.
[16] Better Care Network Secretariat, *Global facts about orphanages*, Better Care Network, 2009.
[17] Csaky, C. *Keeping children out of harmful institutions.* Save the Children, London, 2009; Browne, K., *The Risk of Harm to Young Children in Institutional Care,* Save the Children, London, 2009.
[18] Ibid.
[19] UNICEF, Innocenti Insight *Children and disability in transition in CEE/CIS and Baltic states*, UNICEF, 2005.
[20] Lumos Research 2011-2014.
[21] *Op. cit*. Mulheir, G., 2012.

A minority of children in some large state institutions spends long periods of time living in their cots. After many years in institutions, it is often impossible to assess if the child was born with a disability or if the disability is a result of institutionalisation. It is however certain that lying in cots for extended periods exacerbates many pre-existing conditions or disabilities. [22]

The GPcwd Child Protection Task Force recognises that misdiagnoses of children with disabilities, particularly with intellectual and developmental disabilities, can lead to institutionalisation of a child. This is an area of concern that requires further analysis and research.

Lack of adequate services for children with disabilities

Disability is a common cause for institutionalisation of children. In some countries, health professionals advise parents to place their child with a disability in a care institution.[23] Children with disabilities are often harder to place for adoption or foster care leading to longer institutionalisation. Where community-based services exist, they are often not adapted to the needs of children with disabilities. As a result some children spend their entire lives confined in institutions.[24]

In 2005, the Government of Croatia reported that children in special institutions lived there either because of the severity of their disabilities or because education, healthcare and/or other services were not provided in their community and suitable foster care near such facilities was not available.[25]

In 2007, Mental Disability Rights International (MDRI) in Serbia "found children and adults with disabilities tied to beds or never allowed to leave a crib".[26] In 2013, the same organisation reported that despite ongoing reforms by the Serbian Government, many children with disabilities continued to be cared for in institutional settings, and no alternative or more appropriate means of care had been established.[27]

An SOS Children's Villages study focusing on care in Sub-Saharan Africa has highlighted that parents with a disability also often require additional support to provide good care to their children. The study however found little evidence of support programmes for parents and children with disabilities, aimed at preventing family separation.. In addition, it was found that children with disabilities, once admitted into an institution, were not provided with the additional support they required.[28]

Another report shows that institutions for children with disabilities in Kyrgyzstan primarily take in children "whose parents either have many children, or are single parents, pensioners or disabled themselves".[29]

Specific child protection concerns for disabled children in alternative care

Children with disabilities in institutions are more vulnerable and at higher risk of harm, both deliberate and through neglect, than their peers. There is an overwhelming and harrowing body of evidence that shows this.

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[22] Mulheir, G., Browne, K., *De-institutionalising and transforming children's services: A guide to good practice*, 2006.

[23] Janković, B., [Presentation] *From de-institutionalization towards an inclusive society for all: Outcomes and challenges regarding the rights of children with intellectual disabilities*, Serbian Ministry of Employment, Labour and Social Policy, 2012.

[24] Chou, S. and Browne, K. The relationship between institutional care and the international adoption of children in Europe. *Adoption and Fostering, 32*(1), p.46.

[25] UNICEF, *Children and disability in transition in CEE/CIS and Baltic states*, UNICEF, 2005.

[26] Mental Disability Rights International, *Torment not Treatment: Serbia's Segregation and Abuse of Children and Adults with Disabilities*, 2007.

[27] Mental Disability Rights Initiative, *The Hidden and Forgotten: segregation and neglect of children and adults with disabilities in Serbia,* Belgrade, 2013.

[28] Chiwaula, L., Dobson, R., Elsley, S., *Drumming together for change: A child's right to quality care in Sub-Saharan Africa*, Glasgow: SOS Children's Villages International, CELCIS at the University of Strathclyde, University of Malawi, 2014.

[29] UNICEF, *Children and disability in transition in CEE/CIS and Baltic states*, UNICEF, 2005.

The UN Study on Violence against Children[30] reported severe discrimination and abuse against children with disabilities in institutions including: violence at school; lack of private facilities for children (increasing the risk of abuse from adult patients); lack of heat and food in the belief that those children do not feel cold, pain or hunger; electroshock therapy without anaesthesia; inaccessibility of services; and routine hysterectomies for young girls with disabilities.

Several MDRI studies[31] report extreme abuse and maltreatment of children with disabilities in Serbia, Romania and Turkey, such as being tied up in cribs for years, as was pointed out above, or becoming severely malnourished through poor feeding. The 2013 Serbia study reports differential treatment of children living in the same institution depending on the severity of their disability."<ore skilled children receive more attention and reside in better conditions than those with a higher level of disability."[32]

In 2012, Human Rights Watch reported extreme rights violations inflicted on children with disabilities in Ghana. Many children with disabilities were admitted to psychiatric hospitals and prayer camps, often against their will. The violations included denial of food, adequate healthcare and shelter.[33]

In 2010, an investigation by the Bulgarian prosecution office found that "malnutrition and starvation, treatable infections, pneumonia, accidents, and neglect" were the causes of death of 238 children with disabilities who lived in a state institution.[34] Over half of these children were never admitted into hospital and died in the institution.

MDRI has [35] appealed against human rights abuses in 'special needs' schools in various countries, where 'treatment' for children with disabilities involves intentionally causing pain to punish students for their behaviour.

A study conducted in the USA showed that the stress of a new residential placement causes worse behaviour, mental health and academic outcomes for children with disabilities.[36]

These are just a few among many examples of cases of harrowing treatment of children with disabilities in institutions. The high prevalence of abuse against children with disabilities and the heightened risk of abuse in institutions where parental care is absent make institutionalised children with disabilities extremely vulnerable.

The cost of institutionalisation

Institutional care tends to be a lot more expensive than community-based care. Research has shown that on average institutional care is eight times more expensive than providing social services to parents

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[30] UNICEF. Summary Report. Violence against Disabled Children. 2005.

[31] Mental Disability Rights International. Hidden Suffering: Romania's Segregation and Abuse of Infants and Children with Disabilities. Mental Disability Rights International, 2006; Mental Disability Rights International. Torment not Treatment: Serbia's Segregation and Abuse of Children and Adults with Disabilities. Mental Disability Rights International, 2007; Mental Disability Rights International. Behind closed doors: Human Rights Abuses in the Psychiatric Facilities, Orphanages and Rehabilitation Centers of Turkey. Mental Disability Rights International 2005; Mental Disability Rights International. The Hidden and Forgotten: segregation and neglect of children and adults with disabilities in Serbia, 2013.

[32] Mental Disability Rights International. *The Hidden and Forgotten: segregation and neglect of children and adults with disabilities in Serbia,* 2013, p.14.

[33] Human Rights Watch. *"Like a Death Sentence." Abuses against Persons with Mental Disabilities in Ghana*, 2012.

[34] Lewis, O. Ending Institutionalized Childhood. Project Syndicate [Internet]. 2010. Available from: http://www.project-syndicate.org/commentary/ending-institutionalized-childhood

[35] Mental Disability Rights International. Torture not Treatment: Electric Shock and Long-Term Restraint in the United States on Children and Adults with Disabilities at the Judge Rotenberg Center. Urgent Appeal to the United Nations Special Rapporteur on Torture. Mental Disability Rights International, 2010.

[36] Trout, A.L., Casey, K., Chmelka, M.B., DeSalvo, C., Reid. R. and Epstein, M.H. Overlooked: Children with Disabilities in Residential Care, Child Welfare League of America, 2009

and children; it is up to five times more expensive than foster care; and twice as expensive as community residential homes or small group homes.[37]

Evidence that supports the notion that foster care is more economically viable than institutional care has been gathered from across the world. In 13 Central and Western European countries, foster care for children with disabilities has been found to be 50% cheaper than institutional care.[38] In the Kagera region in Tanzania the World Bank reported that the cost of a child living in an institution was nearly six times higher than supporting a child to live in a foster family.[39] A case study in Eritrea showed that the annual cost per child in residential care was $1,900USD, while the cost for family integration was below $100USD.[40]

Research and Data Collection

Data collection methods concerning children in institutions are often found to be weak or non-existent. However, when it comes to data collection on children with disabilities in care the record is even worse. For example, in 2013 it was reported that children with disabilities residing in long-term health care institutions in France were excluded from 'in care' data, while children in residential care provided by mental health services in the USA are not included in care statistics either.[41]

The research has identified a significant gap in data collected about children with disabilities generally. Data may indicate less information about the type of disability of a child, or provide no information about whether a child has a disability at all.[42] Evidence of information about the service quality and outcomes of the residential facilities in which children with disabilities are placed was also hard to find.

In conclusion, children with disabilities are more likely to be placed in residential care institutions, not only because of their disability, but also because of the intrinsic link between disability and poverty. Once admitted, children with disabilities are likely to live there for longer than their non-disabled peers, and are at a higher risk of living in residential care for the rest of their lives. Institutional care settings often fail to provide the specialist care that children with disabilities need. In institutions children are at particular risk of experiencing abuse, neglect or violence and a child's disability may lead to specific forms of abuse and adverse treatment. The cost of institutionalisation is a lot higher than the cost of the better care alternatives, such as foster care and community and family-based services. However, in many countries these services are not properly established. The human price that children with disabilities pay is however hard to estimate, as data collection methods on institutions and children with disabilities in institutions specifically are underdeveloped and underused.

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[37] Carter, R., *Family matters: a study of institutional childcare in Central and Eastern Europe and the former Soviet Union*. London, EveryChild, 2005; Csáky, C., *Keeping Children Out of Harmful Institutions: Why we should be investing in family-based care,* Save the Children, London, 2009.

[38] Browne K.D., Hamilton-Giachritsis C., Johnson R., Chou, S., Ostegren, M., Leth, I., Agathonos- Georgopoulou H., Anaut M., Herczog M., Keller-Hamela M., Klimackova A., Stan V. and Zeytinoglu S. (2005a). A European survey of the number and characteristics of children less than three years old in residential care at risk of harm. Adoption & Fostering. 29(4): 23–33.

[39] Better Care Network Secretariat, *Global facts about orphanages*, Better Care Network, 2009.

[40] Prywes, M., Coury, D. Fesseha, G., Hounsounou, G. and Kielland, A. Cost of projects for orphans and other vulnerable children: case studies in Eritrea and Benin. *Social Protection Discussion Paper Series.* 2004. Available online: http://www-wds.worldbank.org/servlet/WDSContentServer/WDSP/IB/2004/10/12/000012009_20041012101822/Rendered/PDF/301630 PAPER0SP00414.pdf

[41] Ainsworth, F., Thoburn, J., *An exploration of the differential usage of residential childcare across national boundaries*, International Journal of Social Welfare, Vol. 23, 2013.

[42] Chiwaula, L., Dobson, R., Elsley, S., *Drumming together for change: A child's right to quality care in Sub-Saharan Africa*, Glasgow: SOS Children's Villages International, CELCIS at the University of Strathclyde, University of Malawi, 2014.

2. Access to and effectiveness of child protection systems which are inclusive of children with disabilities

Abuse, neglect and violence

Since the 1960s there has been an increasing awareness that children with disabilities are at an increased risk of abuse and neglect.[43] The most recent comprehensive review of the relevant research available on the matter by Jones *et al*[44] confirms that, to date, children with disabilities continue to be at a significantly higher risk of all forms of child abuse compared to children without a disability. Twelve years earlier, Sullivan and Knutson's study on maltreatment and disabilities had also reported on the prevalence of abuse among children with disabilities. The two studies confirm a similar trend of children with disabilities being 3 to 4.6 times more likely to suffer violence, abuse and neglect than their non-disabled peers.[45] Among non-disabled children in the research sample, Sullivan and Knutson found a 9% prevalence rate of abuse, whereas the comparable rate for disabled children was 31%. In another study, the USA-based National Center on Child Abuse and Neglect (NCCAN) has suggested that children with disabilities are four to ten times more likely to experience sexual abuse and 1.7 times more likely to experience any other form of abuse compared to children without a disability.[46]

Figures such as the above are likely to be conservative, as child protection concerns are thought to be underreported by and on behalf of children with disabilities. Experiences from the United Kingdom show that children with disabilities, their families and advocates acting on their behalf experience barriers in accessing established child protection systems.[47] In addition, there is a lack of accessible information and education for children, referrers and professionals, contributing to the challenges in protecting children with disabilities. Logistical difficulties and costs also prevent children with disabilities and their parents or carers form accessing child protection services.[48]

Children in institutions across the world are likely to be at greater risk of experiencing violence and abuse than those raised in families.[49] In turn, children with disabilities in institutions tend to be at greater risk of experiencing abuse than their non-disabled peers.[50] For a significant proportion of disabled children institutional care can be fatal. One study comparing the death rate of young children in institutions found that the rate for disabled children was nearly one hundred times that of their non-disabled peers.[51] Research by Lumos in one institution, which looked at recorded 'discharges' of children with disabilities, found that not one child had gone home to their family; 22% had moved on to an adult institution and 78% had died in the institution.[52]

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[43] NSPCC, National Working Group on Child Protection and Disability. *It doesn't happen to disabled children: child protection and disabled children*. London, 2003.

[44] Jones L., et al. *Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies*. Lancet. 380:9, 2012.

[45] *Op. cit* Jones, 2012; Sullivan, P. M. and Knutson J. F. Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse & Neglect, Vol. 24,* No 10, pp. 1257-1273.

[46] As cited in Special Representative of the Secretary-General on Violence against Children, *Toward a world Free from violence: Global survey on violence against children*, 2013

[47] *Op. cit*. NSPCC, 2003;

[48] Save the Children, Handicap International, Out from the shadows: sexual violence against children with disabilities, 2011.

[49] Pinheiro, P., World Report on Violence against Children, UNICEF, New York, 2006

[50] Ibid. ; Brown, H., *Safeguarding adults and children with disabilities against abuse*, Council of Europe Publishing, p.31, 2003;

[51] Browne, K., Hamilton-Giachritsis, C., *Mapping the number and characteristics of children under three in institutions across Europe at risk of harm*, University Centre for Forensic and Family Psychology (European Union Daphne Programme, Final Project Report No. 2002/017/C), 2005.

[52] Lumos unpublished data, 2012.

It should be noted that children with disabilities, often isolated from the wider community, are also more susceptible to violence at home and that child protection systems should address this.[53]

> "[...] stigma surrounding disability can result in their needs and rights being dismissed by communities, authorities and families. This is compounded by the acute lack of access experienced by many children with disabilities to education, child protection and medical, psychosocial, legal and other services, including reporting mechanisms that rarely accommodate their individual needs."[54]

There are some specific issues for children with disabilities that require an understanding that extends beyond the traditional approaches to child protection system development. These require a particular specialised focus in order to develop appropriate and effective responses. This includes, but is not limited to, alternative care provision; an understanding of the increased risks, reverse causation (when disability is caused by abusive or harmful practice and/or environments); increased negative impact on existing impairment; abusive practices based on social norms; severity, frequency and duration of abuse; access to justice services; and nutrition-based abuses.

The disparity in access to child protection services and responses for children with disabilities is not confined to developing countries or those countries where people with disabilities may be more prone to be discriminated against.[55] The disparity also prevalent in countries with existing, functioning and relatively strong child protection systems and human rights records as well as in development, humanitarian emergency, conflict, post-conflict and crisis situations.[56]

Note: It is recognised that there is a need to extend the literature review to also explicitly include psychological and emotional abuse, including by carers, teachers, etc.

Gender and type of disability causal relationship

While findings on the impact of gender on the relationship between disability and abuse are inconsistent, there is some evidence that suggests that disabled boys may be at greater risk of abuse than disabled girls.[57] Findings on the risk of sexual abuse among disabled boys and girls seem to differ too, with some studies suggesting an equal risk of sexual abuse and others finding more prevalence of sexual abuse among girls with disabilities. It should be noted that girls have been found to be more likely to report sexual abuse. [58]

A study conducted in a number of African countries found that children with a hearing impairment or physical disability were at greater risk of experiencing certain forms of violence, such as physical, emotional and sexual abuse than children with visual or intellectual disabilities.[59] Another study, of a group of 3,000 children who had been abused, found that among them children with language and speech impairments more often faced physical abuse and neglect, and were at greater risk of sexual abuse than other children.[60] The same study also found that children with behavioural difficulties had an increased risk of being abused than their non-disabled peers. It is clear that more research and studies are needed into this complex issue.

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[53] Special Representative of the Secretary-General on Violence against Children, *Toward a world Free from violence: Global survey on violence against children*, 2013

[54] Save the Children, Handicap International, Out from the shadows: sexual violence against children with disabilities, 2011, pp. vi.

[55] UNICEF. *Children Accused of Witchcraft. An anthropological study of contemporary practices in Africa.*, 2010;

[56] UNICEF. *Summary Report. Violence against Disabled Children*. 2005; *Op. Cit.* Stalker, K. and McArthur, K. 2012.

[57] Ibid.

[58] Ibid.

[59] African Child Policy Forum, Violence against Children with Disabilities in Africa: Field studies from Cameroon, Ethiopia, Senegal, Uganda and Zambia, Addis Ababa, 2011

[60] Sullivan, P.M. and Knutson, J.F. (1998) as cited in Save the Children, Handicap International, Out from the shadows: sexual violence against children with disabilities, 2011.

Causes of higher risk

It is believed that children with disabilities are at heightened risk to experiencing abuse and neglect due to ignorance and misconceptions about children with disabilities in society.[61] When disabled children are thought to be asexual, carers might refuse to provide sex education, which would help to mitigate the risk of abuse.[62] Adolescents with disabilities are at particular risk of HIV infection for many reasons, including lack of information, difficulty in accessing sex education programmes (particularly for those not in school), lack of access to contraception, and the higher levels of violence and sexual abuse to which they are subjected.

Stress caused by caring for a child with special needs is an important factor contributing to the risk of abuse by parents or family members.[63]

Under-reporting of abuse

One study that examined cases of over 40,000 alleged abuse victims found that children with disabilities were less likely to report abuse than children without disabilities.[64] The children with disabilities that did report abuse were more likely to do this a longer period after the abuse had taken place. Another study highlights that underreporting of sexual violence experienced by children with disabilities is common.[65] This may be due to social isolation, but also the fact that sexual abuse is often inflicted upon by perpetrators close to the victim and in a position of power.[66]

Potential reasons for the lack of reporting are also thought to include "difficulty communicating, feelings of guilt, perceived threat or abandonment, potential separation from family and tolerance of abuse in order to be accepted or receive rewards or affection".[67]

Limited access to justice for for disabled victims of (sexual) violence might furthermore contribute to a reluctance by survivors and their families to speak out.[68]

Disabled children as witnesses

One study by the Scottish Government noted that whilst there were good examples of agencies working together to help communication with children with disabilities, this was not the case when these children came into contact with the law and in criminal prosecutions. The evidence required by police and court was an area of concern for health and social services professionals.[69] The same study highlighted prejudice by authorities that children with disabilities were not reliable witnesses or that the information provided by them was not always being treated the same as the information provided by children without disabilities. It was noted that the number of court cases involving children with disabilities was low.[70] Research also indicated that cases of violence against children with

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[61] Child Welfare Information Gateway (Children's Bureau), *The Risk and Prevention of Maltreatment of Children With Disabilities,* 2012.

[62] Child Welfare Information Gateway (Children's Bureau), *The Risk and Prevention of Maltreatment of Children With Disabilities,* 2012.

[63] Ibid.

[64] Hershkowitz et al, 2007 as cited in Stalker, K. and McArthur, K. *Child abuse, child protection and disabled children: a review of recent research*. Child Abuse Review, University of Strathclyde 2010.

[65] Save the Children and Handicap International. Out from the shadows: sexual violence against children with disabilities, 2011.

[66] Ibid.

[67] Akbas S, Turia A, Karabekirolgu K, Pazvantoglu O, Kekskin T, Boke O. 2009. Characteristics of sexual abuse in a sample of Turkish children with and without mental retardation, referred for legal appraisal of the psychological repercussions. Sexuality and Disability 27: 205-213.

[68] Op cit Save the Children and Handicap International

[69] University of Edinburgh/University of Strathclyde, *Disabled Children and Child Protection in Scotland: An investigation into the relationship between professional practice, child protection and disability*, 2014.

[70] University of Strathclyde, *Child protection and the needs and rights of disabled children and young people: a scoping study,* 2010.

disabilities were less likely to be followed up by medical, judicial, psychological and other professionals, who felt either unwilling or unable to take action. [71]

Another study examined and criticised the Swedish legal system's treatment of children with learning disabilities who had been abused.[72] The researchers found that courts failed to adapt to the needs and capacities of those witnesses. For example no distinction was made in the nature of the reports that children with or without intellectual disabilities were expected to provide.

Lack of personnel and training

Effective interagency collaboration is important to establish good child protection practices.[73] Several studies identified the need for more training, more practitioners and more coordination between disability, child protection and social work teams to improving child protection for disabled children. The skills and expertise needed to respond to children with disabilities' special needs is often lacking.[74] Insufficient training of social workers and others working directly with children with disabilities results in them failing to identify and address child abuse or maltreatment.[75]

Lack of data

Many studies identify that the absence of disaggregated data related to children with disabilities renders their support needs invisible to policy-makers and service-providers alike.[76] This study found no significant examples where the feedback and views of children with disabilities were gathered about the support and services they receive once abuse had been suspected. This data is however essential to identify what services are needed to meet their needs.

In conclusion, children with disabilities are at significantly increased risk of experiencing violence, abuse and neglect. It has been suggested that certain disabilities increase the risk of a child of experiencing abuse, while there are also figures that point to the different likelihood of boys and girls with disabilities experiencing certain types of abuse. Misconceptions about children with disabilities by carers and other members of society also lead to increased levels of abuse. The real extent of abuse experienced by children with disabilities, both boys and girls, is thought to be gravely underreported. Children with disabilities who have experienced abuse face more barriers when reporting abuse and trying to access justice. Many judiciarial systems lack the knowledge and training needed to adapt to the special requirements of children with disabilities as witnesses. Authorities are also more likely to distrust a statement made by a child with a disability. The lack of data on these issues renders children with disabilities' support needs even more invisible.

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[71] Save the Children/Handicap International, *Out from the shadows: sexual violence against children with disabilities,* 2011.
[72] Child Abuse Review, University of Strathclyde, *Child abuse, child protection and disabled children: a review of recent research,* 2010/2012.
[73] Stalker, Kirsten and Green Lister, Pam and Lerpiniere, Jennifer and McArthur, Katherine. *Child protection and the needs and rights of disabled children and young people: A scoping study.* 2010.
[74] Save the Children/Handicap International, *Out from the shadows: sexual violence against children with disabilities,* 2011.
[75] Hibbard & Desch, 2007; Kenny, 2004; Manders & Stoneman, 2009 as cited in Child Welfare Information Gateway (Children's Bureau), *The Risk and Prevention of Maltreatment of Children With Disabilities,* 2012.
[76] Cantwell, N., Davidson, J., Elsley, S., Milligan, I., Quinn, N. *Moving Forward: Implementing the 'Guidelines for the Alternative Care of Children',* 2012.

3. Inclusive child protection response to children with disabilities involved in crisis, conflict and emergency situations

Natural disasters, conflict and other humanitarian crises, as well as the period of instability that often follows, have a disproportionately negative impact on children with disabilities and pose particular protection risks to their safety and wellbeing. Children may sustain lifelong impairments, injury and trauma and they may lack access to essential services and are at increased risk of separation. This in turn increases their risk of admission to inappropriate alternative care and also to violence and abuse.[77] Children with disabilities can be excluded from life-saving mainstream support, increasing the risk to their health, safety and survival.[78] During evacuation to safety from disaster, children with disabilities are more likely to have difficulties escaping, not least because they may be less mobile. In these situations, children can get separated from their families, a separation that can sometimes last for years,[79] which in turn increases the risk of institutionalisation and abuse. In 2011 the UK Department for International Development (DFID) concluded that the existing humanitarian system is not equipped to respond in an equitable manner to the needs of the most vulnerable.[80]

All children are at risk during crisis. From one day to the next, families may struggle to cope because of sudden poverty, homelessness or other causes. Without effective measures to respond to the needs of families in emergencies, children are at significant risk of getting separated from their primary caregivers during or in the aftermath of an emergency.[81] Children with disabilities who are unable to escape a crisis zone because of their impairment may be abandoned or placed in institutions.[82] However, impact assessments of emergencies on populations rarely acknowledge the additional difficulties which children with disabilities and their families face.[83] At the same time, humanitarian efforts focusing on children, including education and protection, have received comparatively little donor funding.[84]

Emergencies exacerbate vulnerabilities

Children with disabilities are more vulnerable to violence and more likely to experience psychosocial problems during and after emergency situations than children without disabilities. Children with learning disabilities, epilepsy, and communication impairments are at greater risk of developing mental health issues during situations of armed conflict.[85] The UNCRC enshrines that children who are affected by armed conflict have the rights to "psychological recovery and social reintegration". The UNCRPD states that anyone who has been affected by violence should receive "physical, cognitive and psychological recovery, rehabilitation and social reintegration" provided by the state. However, children with disabilities are often overlooked in psychosocial programmes.[86]

Injuries sustained during emergency situations may lead to disability. In 2014, the UK-based NGO Action on Armed Violence estimated that there were 1,942 casualties globally from explosive weapons among

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[77] Ibid.

[78] UNICEF, *The State of the World's Children,* 2013.

[79] Ibid.

[80] Department of International Development, *Humanitarian Emergency Response Review*, 2011.

[81] The International Save the Children Alliance (2007) *Child protection in Emergencies: Priorities, Principles and Practices*. Sweden: Stockholm.

[82] Doyle, J. (2010) *Misguided Kindness: Making the Right Decisions for Children in Emergencies,* Save the Children. United Kingdom: London.

[83] UNICEF (

[84] War Child*, A Vicious Cycle for Children: In the Central African Republic,* 2014.

[85] Healthlink Worldwide (1999) as cited in Von der Assen, N., Euwema, M. and Cornielje, H. (2010) *Including disabled children in psychosocial programmes in areas affected by armed conflict intervention.*

[86] Von der Assen, N., Euwema, M. and Cornielje, H. (2010) Including disabled children in psychosocial programmes in areas affected by armed conflict intervention.

children; a 33% increase from 2013. This figure is thought to be a conservative estimate, as data on conflict casualties does often not specify if children are among the victims.[87] Injuries may be exacerbated by lack of healthcare during emergencies, increasing the risk of complications with profound long-term physical and psychological implications for the injured child.[88]

Children are also particularly at risk of experiencing sexual violence and exploitation in situations of emergency and in the post-emergency period. In times of social crisis, when support and protective structures are limited or non-functional, children – particularly those who are displaced – are most vulnerable to abuses such as rape, molestation, trafficking and child marriage. [89]

Lack of services during emergency situations

During and following emergencies, children are exposed to a range of extreme circumstances, which will often be beyond their coping capacity. The worst effects of humanitarian crises are experienced more intensely by children, particularly children with disabilities, because of their physical, emotional and social underdevelopment.[90]

Children recover from distressing experiences more quickly when supported by their family and community in a child-friendly environment. But basic needs such as food, shelter, healthcare and support services may not be available or, if they are, may not be inclusive to children with disabilities.[91] Children with disabilities often fail to survive during times of conflict because of lack of treatment, starvation, and because they are simply not able to escape the conflict area or cope with the aftermath. Established services for children with disabilities and their families (pre-school programmes, hospital and rehabilitation services, etc) close in times of emergencies and often are not reinstituted for years. Disabled children and their families that do manage to escape a conflict area might find themselves in refugee camps, in different communities and/or different countries that are unknown; situations in which it is difficult to find services that were previously available.

Child participation

Children's participation is a critical means to enhance and improve child protection in emergencies.[92] There is, however, little evidence that a child's articulation of their survival and development needs are addressed in disaster response and rehabilitation. A 2006 study found a lack of child participation in emergency situations and that children were rarely consulted on what they had experienced.[93] It appears that views and opinions of those affected by disaster are often not heard.[94] The nature of the emergency situation, including the urgent need to rescue those in danger and the risks involved, result in the child participation being de-prioritised. [95]

In volatile conflict situations, especially, children's participation in humanitarian efforts continues to face resistance. The emphasis of humanitarian support in conflict tends to be on protecting and providing services for children instead.[96]

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[87] Hunter, J. and Perkins, R (2015) *Explosive states. Monitoring explosive violence in 2014.* Action on Armed Violence. UK: London.
[88] Save the Children, *Child protection in Emergencies: Priorities, Principles and Practices*, 2007.
[89] Ibid.
[90] UNICEF, *Background Note for the Global Partnership on Children with Disabilities – Inclusive Humanitarian Action,* 2014.
[91] Ibid.
[92] Hart, J. (2004) *Children's participation in humanitarian action: learning from zones of armed conflict.* Refugees Studies Centre, University of Oxford. UK: Oxford.
[93] Save the Children, Sweden, *Child Rights Perspective in Response to Natural Disasters in South Asia,* 2006.
[94] Kett, M. (2011) 'Disability and Disasters: the next 10 years?'. Disability in Conflicts and Emergencies: Reaching the most vulnerable. 30 May-1 June. Atlas Alliance, Oslo
[95] Save the Children (2006) *Child Rights perspective in response to natural disasters in South Asia.* Save the Children Sweden. Nepal: Kathmandu.
[96] Refugee Studies Centre, *Children's Participation in Humanitarian Action: Learning from Zones of Armed Conflict*, 2004.

Lack of data

The stigma surrounding disability often leads to reluctance by parents to report their child's disability. It is also fairly common for a child with a disability not to be registered at birth.[97] As a result, during emergency response children with disabilities are frequently left unregistered, rendering them invisible to emergency registration systems. Not surprisingly, statistical evidence on persons with disabilities affected by emergency situations has often been found to be unreliable.[98]

As of May 2015, it was estimated that 1.6 million children had fled the conflict and humanitarian crisis in Syria to neighbouring countries.[99] However, there is no specific information on how many children with disabilities have been affected by the civil war in Syria.

Kett has argued that there is a gap in the understanding of the specific vulnerabilities of people with disabilities in emergencies and why people with disabilities are excluded from emergency response programmes.[100] There is hardly any information on the impact of humanitarian interventions on the lives of disabled people.[101] Whilst issues specific to age, gender and disability are reflected in the literature on emergencies, there are few examples of mechanisms to deal with them.[102]

To conclude, children with disabilities are among the most vulnerable in conflict, disaster and emergency situations. Humanitarian crises frequently result in children being separate from families leading to greater risk of violence, abuse and death, and an increased likelihood of being placed in institutions/orphanages. During and following emergency situations children with disabilities are more likely to be affected by its impact and aftermath and less likely to be able to access the services which reduce harm and manage risk during these times. While child participation is considered to be critical in order to improve children's experiences in humanitarian crises, in practice children are hardly ever consulted or asked to provide feedback. A lack of data on the number of children with disabilities affected by armed conflict and other disasters provides a further significant challenge in improving child protection for children during humanitarian crisis.

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[97] UNICEF Innocenti Research Centre (2007) *Promoting the rights of children with disabilities.* Innocenti Digest No. 13. UNICEF. USA: New York.

[98] Kett, M., Stubbs, S. and Yeo, R. (2005). *Disability in Conflict and Emergency Situations: Focus on Tsunami-affected Areas*.IDDC..

[99] World Vision (2015) *FAQs: Syria's war, children and the refugee crisis.* http://www.worldvision.org/news-stories-videos/syria-war-refugee-crisis

[100] Kett, M. (2011) 'Disability and Disasters: the next 10 years?'. Disability in Conflicts and Emergencies: Reaching the most vulnerable. 30 May-1 June. Atlas Alliance, Oslo

[101] Ibid.

[102] DFID Review 2011

5. Conclusion

Children with disabilities are more likely to be placed in alternative forms of care that do not provide the individual attention necessary to meet their needs to allow them to develop their full potential. Once admitted, children with disabilities are likely to live there for longer than their non-disabled peers, and are at a higher risk of living in residential care for the rest of their lives. Institutional care settings often fail to provide the specialist care that children with disabilities need. Often these settings increase the risk of violence, abuse and neglect resulting in severe forms of harm, exacerbating existing problems and creating new ones. The cost of institutionalisation is a lot higher than the cost of better care alternatives, such as foster care and community and family-based services. However, in many countries these services are not properly established.

Where child protection systems exist they are often not inclusive. Children with disabilities can have additional needs and vulnerabilities, which are not taken into account in child protection systems, leading to the question of whether such systems are fit for purpose. Misconceptions about children with disabilities by carers and other members of society also lead to increased levels of abuse. The real extent of abuse experienced by children with disabilities, both boys and girls, is however likely to be higher than studies indicate, as cases of abuse are thought to be gravely underreported.

Children with disabilities who have experienced abuse also face more barriers when reporting abuse and trying to access justice. Many judiciaries do not have the knowledge and training to adapt to the special requirements of children with disabilities as witnesses. Authorities are also more likely to distrust a statement made by a child with a disability. The lack of data on this issues renders children with disabilities' support needs even more invisible.

During and following emergency situations children with disabilities are more likely to be affected by its immediate impact and aftermath and are less likely to be able to access the services which reduce harm and manage risk during these times. Humanitarian crises frequently result in children being separated from families, leading to greater risk of violence, abuse and death, and an increased likelihood of being placed in institutions/orphanages. While child participation is considered to be critical in order to improve children's experiences in humanitarian crises, in practice children are hardly ever consulted or asked to provide feedback. A lack of data on the number of children with disabilities affected by armed conflict and other disasters provides a further significant challenge in improving child protection for children during humanitarian crisis.

All three areas are intertwined. Inappropriate alternative care leads to child protection concerns. Institutionalisation can be the result of poor child protection practice. Emergency situations that result in children being separated from families contribute to their greater exposure to risk and increased likelihood of being placed in 'orphanages'.

These issues all have roots in socially acceptable beliefs about children with disabilities and their value, or lack of it, to their societies and communities. The stigma, social exclusion, poverty, lack of choice, lack of equality and rights can only be challenged alongside effective policy, practice and system change which respects all children's fundamental and unique right to special protection from violence, harm and abuse and children with disabilities right to special care where necessary (CRC Articles 19 and 23). Particular attention should be placed on ensuring that children genuinely participate in decisions about their lives and that their views help shape the systems that are designed to protect them.

Many organisations and individuals have recognised the areas above as having a particularly negative impact on children with disabilities. This is why the GPcwd child protection task force will seek to bring together experience and understanding to affect change in policy and practice at all levels.

[end]