

CHILDREN WITH DISABILITIES

Syria Relief's "Children with disabilities in Syria"¹ report (2018) identified over 10,000 children with disabilities in Syria living without access to the most necessities. The most prevalent difficulties identified by the children surveyed (N=789); was 55% had mobility difficulties, 46% had Intellectual difficulties, 48% had psychological and/or intellectual difficulties (N=380), 21%, had a combination of mobility, intellectual, and/or psychological difficulties. The authors also uncovers that 88% of all children surveyed indicated a need for medical rehabilitation services; 68% indicated that these services were not available in their area. 79% of all children surveyed indicated a need for accessible health care services; 61% indicated that these services were not available in their area. 64% of all children surveyed indicated a need for educational services and 81% did not have access to these services in their area.

UNDERSTANDING DISABILITIES

According to the World Health Organization (WHO) armed conflict generates injuries and trauma that can create disabilities and exacerbate the suffering of those with existing disabilities.² 15% of the global population has a disability ranging from moderate to severe. According to the Global Burden of Disease, 95 million children (0–14 years old) are disabled (5% of the global population), of which 13 million have severe disabilities.³ 1 in 3 victims of explosive weapons are children, creating an increased likelihood that they will be left disabled from their injuries.⁴ Nearly 30,000 injuries per month in Syria⁵, were experienced by victims by the end of 2016; while 1.5 million were injured with life changing and permanent disabilities,⁶ and 86,000 had amputations.⁷ Adding to this issues 57% of public hospitals are only partially functioning or completely out of service and the number of available health professionals has fallen to approximately 45% of 2011 levels.

KEY RECOMMENDATIONS

UK GOVERNMENT AND PARTNERS

- *Increase support for existing institutions that support children with disabilities.*
- *Increased commitment for in-depth research to provide insight.*
- *Show a stronger commitment to the 'Leave No One Behind' agenda.*
- *Ring-fence a percentage of UK aid towards investing in proper needs assessments.*
- *Invest in developing the capacity of all stakeholders within education systems.*

HUMANITARIAN ACTORS

- *Strengthen existing identification, registration, referral, and case management processes.*
- *Respond to the needs of children with disabilities through dynamic, inclusive and sustainable projects and educational programmes.*
- *Increase commitment for high quality research.*

THE CRISIS AT HAND

There are currently 6.6million people internally displaced inside Syria, 11.3million in need of medical assistance and 1 in 3 school damaged or destroyed.⁸ With three new displacements reported for everyone person who spontaneously returned, the first three months of 2018 have witnessed some

¹ Syria Relief report released on June 2018

² WHO World Report on Disability. http://www.who.int/disabilities/world_report/2011/report.pdf

³ The Global Burden of Disease (GBD) provides a tool to quantify health loss from hundreds of diseases, injuries, and risk factors, so that health systems can be improved and disparities can be eliminated

⁴ Project Update: *The WHO and Humanity & Inclusion*

⁵ Project Update: *The WHO and Humanity & Inclusion draw attention to the needs of people inside Syria living with injuries and disabilities* http://www.hi-us.org/news_a_the_who_and_hi_draw_attention_to_the_needs_of_people_inside_syria_living_with_injuries_and_disabilities

⁶ WHO, Syrian Arab Republic: *Annual Report 2016* <http://www.who.int/hac/crises/syr/whosyriaannualreport2016.pdf?ua=1>

⁷ Project Update: *The WHO and Humanity & Inclusion*

⁸ https://reliefweb.int/sites/reliefweb.int/files/resources/2018_syr_hno_english.pdf

CHILDREN LIVING WITH DISABILITIES INSIDE SYRIA POLICY BRIEF

of the highest levels of displacement since the beginning of the Syria crisis. Absorption capacity to host the newly displaced in areas of arrival such as Idlib is nearing exhaustion, with IDP sites in Idlib Governorate operating at approximately 400% beyond their capacity.⁹ Of the 2.2 million people in this small province, two thirds are internally displaced people, with approximately 50,000 arriving from Douma alone.¹⁰ Of the 114 communities reporting that income was insufficient to cover household needs, 46% reported that children were sent to work or beg to supplement incomes.

WHAT WE DO

With over 120 field-staff, 1,800 volunteers and 8 offices in hard-to-reach and besieged areas of Syria, Syria Relief supports 2 prosthetic limb clinics that have fit over 1,000 parts for Syrians in need. Approximately 1,000 children with special needs are currently being taught in our several of our 55 schools in Syria. We currently implement a multitude of programmes across the following sectors in Syria: Emergency response & aid, healthcare, education, food security & livelihood, WASH programmes, orphan support, integrating children with disability and GBV clinics.

RECOMMENDATIONS FOR THE UK GOVERNMENT AND PARTNERS:

DfID has committed to providing up to £450 million for Syria and the region in 2018 and £300 million in 2019. We are calling for greater commitment to the needs of the most vulnerable on the ground in Syria.

- **Increase support for existing institutions that support people with disabilities**, such as schools, healthcare organisations, NGOs and voluntary organisations that have been effective in alleviating the struggles of the disabled throughout the conflict
- **Increased commitment for in-depth research to provide insight** into the needs and circumstances of these families that need the support.
- **Show a stronger commitment to the 'Leave No One Behind' agenda** through a clear strategy to support children with disabilities in FCAS.
- **Ring-fence a percentage of UK aid towards investing in proper needs assessments** and ensure the equitable allocation of resources for children with disabilities in FCAS.
- **Invest in developing the capacity of all stakeholders within education systems**, and implement and scale-up inclusive education policies and provisions for people with disabilities.

RECOMMENDATIONS FOR HUMANITARIAN ACTORS:

Persons with disabilities are often invisible in programme delivery; ignored in refugee and internally displaced persons (IDP) assistance programmes; and neglected when humanitarian and aid agencies establish targeted services, especially in fragile and conflicted settings.¹¹

- **Strengthen existing identification, registration, referral, and case management processes** for persons with disabilities within programme and follow-up activities
- **Respond to the needs of children with disabilities through dynamic, inclusive and sustainable projects and educational programmes.** This should also extend to full and equal access to mainstream services for persons with disabilities
- **Increase commitment for high quality research** regarding people with disabilities in FCAS and Syria, to bring this issue to light and provide insights to the needs and circumstances of people with disabilities in FCAS.

⁹ https://reliefweb.int/sites/reliefweb.int/files/resources/Syria%20Crisis_180423_V9.pdf

¹⁰ <https://reliefweb.int/report/syrian-arab-republic/note-correspondents-transcript-stakeout-un-special-envoy-s-senior>

¹¹ Calvot, T. 2014. Hidden victims of the Syrian crisis: disabled, injured and older refugees. HelpAge International and Hand-icap International.

Children living with disabilities inside Syria

Understanding the types of disabilities and access to services for children living in Syria.



A REPORT BY SYRIA RELIEF



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About Syria Relief

Syria Relief, a UK registered charity, was established in 2011 shortly after the start of the conflict in Syria. With eight offices inside Syria and three offices in neighbouring countries, Syria Relief is dedicated to supporting the millions of Syrians affected by the ongoing crisis. Syria Relief provides health care, food aid, education, and training to Syrians internally displaced by the conflict. Among its activities, Syria Relief has worked with the National Syrian Project for Prosthetic Limbs (NSPPL), since 2013, and has fitted more than 5,300 prosthetic limbs in Syria and Turkey. The charity has also sponsored 53 schools and children's centres inside Syria and one in Turkey, educating more than 15,000 children daily. A few of Syria Relief's schools cater to children with learning difficulties and hearing impairments. Teachers in these schools are trained in child protection, psychological support, and first aid. Syria Relief also provides specialist psychological support for children with disabilities.

As part of our efforts to support Sustainable Development Goals (SDG) 10 and 4 in Syria, we have worked to ensure that children identified with disabilities receive the support they need in our schools. When the opportunities arise, Syria Relief will also support the development of educational projects for other children with disabilities. Such initiatives may involve: joining disability-alliances to lobby governments to improve educational access for all children with disabilities; awareness-raising in local communities, highlighting the needs of all children with disabilities; promoting the principles of 'universal design' in school-construction, as recommended by the United Nations' Convention on the Rights of Persons with Disabilities (CRPD); and establishing inclusive schools that ensure children identified with disabilities receive the support and education they rightfully deserve.

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“Syria’s bloody civil war has destroyed and damaged so many lives. This research is an important reminder of the plight facing children with disabilities, who must not be forgotten in the aid and refugee efforts from the international community.”

The Rt Hon. the Lord Ashdown
of Norton-sub-Hamdon GCMG KBE CH

Foreword

With the conflict in Syria now in its seventh year¹, the humanitarian crisis has become increasingly acute and is reaching new levels of complexity and hardship for millions of displaced and hard-to-reach families, besieged communities, and refugees. The challenges are ongoing and the extended conflict is making it increasingly difficult for Syrians to survive and deal with everyday life.



According to a report by Handicap International², Syrians with injuries, disabilities, and chronic diseases are particularly vulnerable. For the many children with disabilities who face the daily threat of conflict, there is a need for direct and immediate assistance. Disabled and injured civilians are often neglected by humanitarian responses^{3,4}. Conflict-related injuries and psychological stress, as well as lack of primary health care and poor management of chronic conditions, have contributed to the worsening of the disability situation in Syria. Worse-still is the way that children with disabilities and their families, who are survivors of this dreadful conflict, have been forced to adopt more intricate coping strategies just to get by. As the conflict continues and the number of injured persons rises, increasing the capacity to deliver long-term medical and rehabilitative care is critical.

This report aims to showcase the impact of living in a fragile and conflicted state as a child with disabilities in Syria. The report highlights, on the surface, the types of disabilities that children in Syria experience and provides insight into the conditions that many of the children live with. The overall objective is to guide humanitarian organisations in delivering an informed response to children with disabilities during crises and to consider ring-fencing aid to this vulnerable group of children. The Department for International Development has a dedicated disability strategy and last year renewed its commitment to disabled people all over the world; this report shows why that strategy is so important, and why it could go much further.

The estimated number of children with disabilities between the ages of 0 and 18 years ranges from 93 to 150 million globally, depending on the source⁵.

The findings of this report suggest that this group of children have too often been neglected and left behind. The report shows a lack of 'vital', needed, and specific support for children with disabilities from the international community, despite current rhetoric and commitments made by governments and humanitarian actors. The report makes clear that all humanitarian actors, governments, and international donors should consider ring-fencing a percentage of their aid budget towards supporting this group of vulnerable civilians and ensure that funds allocated are evaluated and monitored. Ring-fencing aid budget for children with disabilities will ensure that the most vulnerable of this group will receive necessary aid and that some of their needs will be met. More needs to be done to help this group of vulnerable children, to leave no one behind. The report demonstrates that all donors and humanitarian organisations who deliver aid should ensure that this group is fully assessed and considered during programme delivery and aid distribution. It calls on governments to respond more swiftly and provide more political support for this group of vulnerable children.

The report draws on the findings of field research conducted with 789 survey respondents and emphasises the aid inequality, i.e., the lack of services and attention given to this group of children in Syria. As the report demonstrates, many of the children surveyed received little or no support in the areas in which the survey was conducted. While some children had previously received some services, the large majority of children received little or no services. The report establishes that many of the children did not have access to shower seat facilities, a reported basic and vital service. The need for wheelchairs for use at home was also identified. Many of the children encountered in the research project had difficulties ranging from mobility, intellectual and/or psychological difficulties, or a combination of both, to hearing and vision difficulties. Four out of five respondents stated that the difficulties they experienced were from birth, less than 50 that they were related to the conflict, and a similar number that they were linked to an accident or injury. The overall pattern of difficulties (mobility, intellectual and/or psychological, and a combination of both) was replicated at the sub-district level of analysis. Many of the children surveyed were

from the host communities, followed by internally displaced persons, and a handful of refugees. The account presented in this report is one of the clearest snapshots yet of children with disabilities across four parts of Syria during the seven-year conflict.

The findings in this report should be used to inform the UK Government's response and commitment to supporting vulnerable children in fragile and conflict-affected settings. It should also be used as a source for the Syrian Humanitarian Needs-assessment Overview for 2018 and extend to all humanitarian actors who have a responsibility to support the most vulnerable people in conflict settings. Finally, the findings in this report should be used to encourage further research that explores the conditions of children living with disabilities in fragile and conflict-affected settings. Further research will help practitioners, policy-makers, and international donors understand how best to support this forgotten group of vulnerable children, who are often only heard of in extra-conflict settings⁶. Further research will also help shape a clear policy programme, which I believe will help support the 'leave no one behind' agenda. The commitment to 'leave no one behind'⁷, has been a key feature of all discussions on the Sustainable Development Goals (SDGs) and is now hardwired in the agreement. The idea that 'no goal should be met unless it is met for everyone' is well established in the rhetoric around the new goals. A political consensus is also emerging that leaving no one behind is one of the key elements of meeting all SDGs by 2030. In theory, this means ensuring that every individual achieves the full package of rights and opportunities that the SDGs promise. However, what this means in practice is still

The challenges are ongoing and the extended conflict is making it increasingly difficult for Syrians to survive and deal with everyday life.

unclear and, to date, little has been done to support, aid, and elevate the status of this group of forgotten children.

The title of this publication "*Children Living with Disabilities Inside Syria*" is a tribute to the Syrian children who shared their experiences and who illustrate what it is like for millions of children living with disabilities in fragile and conflicted states, whose voices, to date, are yet to be heard. Talking about disabilities, to some degree, remains an unmentionable subject in Syria. So, those who speak out do so with bravery in an environment that grows in instability. Thank you to everyone who has contributed to these important findings and to the team at Syria Relief for delivering this report.



Mr Tim Farron MP

Refugee spokesperson for the Liberal Democrats

- ¹ Yusuf, A. 2017. As Syrian conflict enters its seventh year. Assad's future is the sticking point. The Conversation. March 20, 2017. Available at: <https://theconversation.com/as-syrian-conflict-enters-its-seventh-year-assads-future-is-the-sticking-point-74588> [Accessed 25 April 2018].
- ² Handicap International. 2016. Syria Country Card. [PDF] Handicap International. Available at: https://www.handicapinternational.org.uk/sites/uk/files/country/files/2016_09_cc_syria_en_ok_0.pdf. [Accessed 25 April 2018]. Note: On January 24th, 2018, Handicap International changed its name to Humanity & Inclusion.
- ³ Calvot, T. 2014. Hidden victims of the Syrian crisis: disabled, injured and older refugees. HelpAge International and Handicap International.
- ⁴ Humanity and Inclusion. 2018. Physical rehabilitation needs and services for persons with injuries and disabilities. Issue Brief: Syria [PDF]. Available at: https://hi.org/sn_uploads/content/Hi_IssueBrief_Syria_-_REHABILITATION_april2018.pdf. [Accessed 11 May 2018].⁵ World Health Organisation (WHO). 2011. World Report on Disability. Available at: http://www.who.int/disabilities/world_report/2011/report/en/ [Accessed 25 April 2018].
- ⁶ United Nations Sierra Leone. In Sierra Leone Supporting Children Living with Disabilities. Available at: <https://sl.one.un.org/2018/02/02/in-sierra-leone-supporting-children-living-with-disabilities/> [Accessed 25 April 2018].
- ⁷ Overseas Development Institute. Deliver 2030 [Blog: January 2012 to January 2018]. Available at: <https://www.webarchive.org.uk/wayback/archive/20180120120115/http://deliver2030.org> [Accessed 25 April 2018].

Support from Members of Parliament and Peers

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Lord Paddy Ashdown

Abbreviations used in this report

CRPD	Convention on the Rights of Persons with Disabilities
DPO	Displaced Persons' Organisations
IASC	Inter-Agency Standing Committee
IDP	Internally Displaced Persons
LPHU	Lebanese Physically Handicapped Union
NGO	Non-Governmental Organisation
SDG	Sustainable Development Goals
UN	United Nations
UNDP	United Nations Development Programme
UNICEF	United Nations Children's Fund
WG	Washington Groups
WHO	World Health Organization

“This report is an excellent step towards equality and inclusion for disabled children in humanitarian crises such as Syria. It demonstrates careful research and data collection that are vitally important for international aid programmes but often lacking for marginalised groups, and makes comprehensive recommendations that would make a real difference to childrens’ lives.”

Dr Lisa Cameron MP, Chair of the APPG on disability

Executive Summary

The ongoing conflict in Syria is one of the world's largest humanitarian crises since World War II⁸. Children have paid the heaviest price in the conflict and their suffering has increased with the escalation of violence. More than 5.3 million children in Syria are in need of humanitarian assistance; close to half of these children have been displaced and many of their families have lost everything^{9,10,11}. However, in reports on the situation and humanitarian needs in Syria, children living with disabilities are often excluded, marginalised, and forgotten.

The World Health Organisation (WHO) estimates that 15 per cent^{8A} of the global population are persons with disabilities, and 110 million people (2%) have significant difficulties functioning⁸. According to the Global Burden of Disease, 95 million children (0–14 years old) are disabled (5% of the global population), of which 13 million have severe disabilities¹². Among displaced persons, who have fled civil conflict, war, or natural disasters, these numbers may be even higher¹³. Yet, persons with disabilities remain among the most hidden, neglected, and socially excluded of all displaced people today. As they are often not recognised or calculated in record-keeping and data collection exercises, they continue to be neglected.

Persons with disabilities are often invisible in programme delivery; ignored in refugee and internally displaced persons (IDP) assistance programmes; and neglected when humanitarian and aid agencies

establish targeted services, especially in fragile and conflicted settings. Persons with disabilities are often unable to access mainstream assistance programmes because of physical or mental barriers. Adding to this challenging situation, community coping mechanisms, such as extended families and neighbours, are often destroyed during conflict and displacement. This leaves many civilians with disabilities vulnerable and with no assistance.

The United Nations' (UN) Convention on the Rights of Persons with Disabilities (CRPD), established in 2008, requires states to promote, protect, and ensure the rights of all persons with disabilities within their territory, including those who have been displaced across a border¹⁴. Syria, which ranks sixth on the International Crisis Group's 2018 watch list¹⁵, ratified the CRPD on July 10th, 2009. However, little has been done to address the needs of civilians with disabilities in Syria, children who are more vulnerable during times of conflict.

As humanitarian agencies scale up their responses to meet the ever-growing and complex needs of populations displaced by the crisis in Syria, it is critical that children and persons with disabilities are included in and have access to humanitarian assistance and programmes. Above all, it is crucial that children living with disabilities be included in programme design and that donors, humanitarian aid agencies, and non-governmental organisations (NGOs) adopt an inclusive approach.

⁸ The United Nations Refugee Agency (UNHCR), 2016. Syria conflict at 5 years: the biggest refugee and displacement crisis of our time demands a huge surge in solidarity, [Press release] 15 March 2016. Available at: <http://www.unhcr.org/afr/news/press/2016/3/56e6e3249/syria-conflict-5-years-biggest-refugee-displacement-crisis-time-demands.html> [Accessed 25 April 2018].

^{8A} http://apps.who.int/iris/bitstream/handle/10665/70670/WHO_NMH_VIP_11.01_eng.pdf;jsessionid=85E3473F137919F3995C18800690F2AD?sequence=1

⁹ European Civil Protection and Humanitarian Aid Operations, 2018. Syria, [Fact sheet] April 10, 2018. Available at: http://ec.europa.eu/echo/files/aid/countries/factsheets/syria_en.pdf [Accessed 25 April 2018].

¹⁰ Strategic Steering Group, 2017. Humanitarian Needs Overview 2018: Syria, [PDF]. November 21 2017. Available at: https://reliefweb.int/sites/reliefweb.int/files/resources/2018_syr_hno_english.pdf [Accessed 25 April 2018].

¹¹ United Nations Children's Fund (UNICEF). Humanitarian Action for Children 2018: Syrian Arab Republic. Available at: <https://www.unicef.org/appeals/syria.html>. [Accessed 11 May 2018].

¹² The Global Burden of Disease (GBD) provides a tool to quantify health loss from hundreds of diseases, injuries, and risk factors, so that health systems can be improved and disparities can be eliminated.

¹³ Institute for Health Metrics and Evaluation, [Database]. http://www.healthdata.org/search?search_terms=disabilities [Accessed 25 April 2018].

¹⁴ Crock, M. McCallum, R. and Ernst, C. 2011. Where disability and displacement intersect: asylum seekers with disabilities. Available at: <http://tinyurl.com/BLD-Crock-McCallum-Ernst-2011> [Accessed 25 April 2018].

¹⁵ Malley, R. 2018. 10 Conflicts to watch in 2018. Crisis Group. January 8, 2018. Available at: <https://www.crisisgroup.org/global/10-conflicts-watch-2018> [Accessed 25 April 2018].

This report was commissioned by Syria Relief to address the lack of information on the current situation of children living with disabilities in Syria. This report provides initial empirical findings on the lives of children with disabilities in the seven-year conflict in Syria and policy recommendations for both humanitarian and government actors.

This report presents the findings of field research conducted with 789 survey respondents across the four Syrian governances in which Syria Relief operates. The study aimed to understand what it is like for children living with disabilities in the Syrian conflict and the impact of the conflict on their lives. The study identified key demographic characteristics of the children sampled; the type of disabilities the children faced; and the services they needed and received. However, given the constantly changing conditions in Syria, this report is only a snapshot of the situation at the time of the survey. The findings presented in this report reveal the needs of children living with disabilities in Syria and the gaps in services they receive. This snapshot provides the basis for recommendations on ways to improve services during the humanitarian crisis in Syria.

Key Findings

- The most prevalent difficulties identified by the children or their guardians were:
 - Mobility difficulties (55%, N=434)
 - Intellectual difficulties (46%, N=361)
 - Psychological and/or intellectual difficulties (48%, N=380)
 - Combinations of mobility, intellectual, and/or psychological difficulties (21%, N=163)
- Hearing and vision difficulties were less prevalent (N=122 and N=121, respectively).
- Many of the children surveyed (83%, N=653) had disabilities from birth. 79% (N=344) of children with mobility difficulties had these difficulties from birth; and 91% (N=149) of children with a combination of mobility, psychological, and/or intellectual difficulties had these difficulties from birth.

Key Needs of Children with Disabilities in Syria¹⁶

- **89%** (N=700) of all children surveyed indicated a need for **medical rehabilitation services**. 69% (N=544) indicated that these services were not available in their area.
- **80%** (N=630) of all children surveyed indicated a need for **accessible health care services**. 62% (N=487) indicated that these services were not available in their area.
- **77%** (N=617) of all children surveyed indicated a need for **assistive devices**. 78% (N=617) indicated that assistive devices were not available in their area.
- **65%** (N=511) of all children surveyed indicated a need for **educational services**. 82% (N=645) did not have access to these services in their area.
- **61%** (N=478) of all children surveyed indicated a need for **counselling services**. 87% (N=685) did not have access to these services in their area.
- **56%** (441) of all children surveyed indicated a need for **mental stimulation**. 76% (N=289) of children with intellectual and/or psychological difficulties indicated a need for **mental stimulation**.

Recommendations¹⁷

Syria Relief calls on the UK Government to:

- put forward better provisions and services to address aid inequality for children with disabilities who are among the most vulnerable groups in society during periods of conflict.
- show a stronger commitment to the 'leave no one behind' agenda and a clearer strategy to support children with disabilities in fragile and conflicted settings through the Sustainable Development Goals (SDGs) agenda¹⁸.
- take bold steps to address aid inequality by ring-fencing a percentage of UK aid towards children with disabilities to implement the UK Government's strategy on supporting the 'leave no one behind' agenda (and mainstream disability support throughout all of its programmes).

¹⁶ Respondents indicated the need for a specific service on a scale of 1–4 (not relevant=1; relevant, but not needed=2; needed, but not vital=3; and vital=4) the need for specific services (Section 9iv of the survey).

¹⁷ A full list of recommendations for the UK Government and humanitarian actors can be found in section four of this report.

¹⁸ Overseas Development Institute. Deliver 2030 blog. January 2012 to January 2018. <https://www.webarchive.org.uk/wayback/archive/20180120120115/http://deliver2030.org//>

Syria Relief calls on all humanitarian aid actors to:

- Strengthen existing registration, referral, and case management processes for persons with disabilities, so that organisations, such as Syria Relief can support and integrate children with disabilities in its projects.
- Identify strategic entry points for disability inclusion in the current phase of the response to the Syrian crisis and in long-term planning.
- Respond to the needs of children with disabilities through dynamic, inclusive, and sustainable projects and educational programmes. This should also extend to full and equal access to mainstream services for persons with disabilities (e.g., shelter, water and sanitation, food and nutrition, non-food distributions, health and mental health services, education, vocational and skills training and psychosocial programmes).
- More focused research should investigate not only the causes and prevalence of disability but also the support mechanisms needed by people with disabilities and understand the number of children and persons with disabilities and the anticipated increase in this number as the conflict in Syria continues.

“The humanitarian needs of the Syrian people are as grave now as they have ever been, and Britain is rightly at the forefront of the global humanitarian response. However, the International aid community must recognise that children with disabilities are some of the most neglected of all displaced people today. This report goes some way to highlighting this increasingly important issue.”

Rt Hon Andrew Mitchell MP, Co Chair of the All-Party Parliamentary Group Friends of Syria.



Introduction

The ongoing conflict in Syria is one of the world's largest humanitarian crises since World War II¹⁸. The conflict has significantly affected the demographic structure of the country, causing large displacements within and outside the country. Millions of children have been displaced inside Syria and millions more have fled the country²⁰. Children have paid the heaviest price in the conflict, and their suffering has increased with the escalation of violence. More than 5.3 million children in Syria are in need of humanitarian assistance; close to half of these children have been forced to flee their homes and many of their families have lost everything^{21,22,23}. However, in reports on the situation and humanitarian needs in Syria, children living with disabilities are often excluded, marginalised, and forgotten.

The United Nations' (UN) Convention on the Rights of Persons with Disabilities (CRPD), established in 2008, requires states to ensure that persons with disabilities are protected in situations of risk or humanitarian emergency (Article 11). It also requires that international cooperation be accessible to and inclusive of persons with disabilities (Article 32)²⁴. This means that states are obliged to

promote, protect, and ensure the rights of all persons with disabilities within their territory, including those who have been displaced across a border²⁵. Syria ratified the CRPD on July 10th, 2009. However, little has been done to address the needs of children with disabilities in Syria, who are more vulnerable during times of conflict.

The World Health Organisation (WHO) estimates that 15 per cent of the global population are persons with disabilities²⁶. According to the Global Burden of Disease, 95 million children (0–14 years old) are disabled (5% of the global population), of which 13 million have severe disabilities²⁷. Among displaced persons, who have fled civil conflict, war, or natural disasters, these numbers may be even higher²⁸. Before the crisis in Syria began, data on disability in Syria was limited due to lack of research and negative social stigma²⁹. In 1981, the prevalence of disability in Syria was reported to be 1% of the population and 0.8% in 1993³⁰. In 2004, of a population of 17.4 million people in Syria, estimates of the number of persons with disability ranged from 427,187 to 1,722,600³¹. In 2006, estimates ranged from 582,240 to 1,552,640, of which 214,847 to 572,924 were children and youth with disabilities³².

¹⁹ The United Nations Refugee Agency (UNHCR), 2016. Syria conflict at 5 years: The biggest refugee and displacement crisis of our time demands a huge surge in solidarity, [Press release] 15 March 2016. Available at: <http://www.unhcr.org/afr/news/press/2016/3/56e6e3249/syria-conflict-5-years-biggest-refugee-displacement-crisis-time-demands.html> [Accessed 25 April 2018].

²⁰ UNHCR. Emergencies: Syria Emergency [Online]. <http://www.unhcr.org/uk/syria-emergency.html> [Accessed 25 April 2018].

²¹ European Civil Protection and Humanitarian Aid Operations. Syria, [Fact Sheet] April 10, 2018. http://ec.europa.eu/echo/files/aid/countries/factsheets/syria_en.pdf [Accessed 25 April 2018].

²² Strategic Steering Group, 2017. Humanitarian Needs Overview 2018: Syria, [PDF]. November 21, 2017. Available at: https://reliefweb.int/sites/reliefweb.int/files/resources/2018_syr_hno_english.pdf [Accessed 25 April 2018].

²³ United Nations Office for the Coordination of Humanitarian Affairs (OCHA). Syrian Arab Republic. Available at: <http://www.unocha.org/syria> [Accessed 11 May 2018]

²⁴ United Nations Division for Social Policy and Development: Disability. Convention on the Rights of Persons with Disabilities (CRPD). Available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html> [Accessed 25 April 2018].

²⁵ Crock, M. McCallum, R. and Ernst, C. 2011. Where disability and displacement intersect: asylum seekers with disabilities. Available at: <http://tinyurl.com/BLED-Crock-McCallum-Ernst-2011> [Accessed 25 April 2018].

²⁶ World Health Organisation (WHO), 2011. World report on disability. Available at: http://www.who.int/disabilities/world_report/2011/en/ [Accessed 25 April 2018].

²⁷ The Global Burden of Disease (GBD) provides a tool to quantify health loss from hundreds of diseases, injuries, and risk factors, so that health systems can be improved and disparities can be eliminated.

²⁸ Institute for Health Metrics and Evaluation, [Database]. http://www.healthdata.org/search?search_terms=disabilities [Accessed 25 April 2018].

²⁹ Said Foundation, 2009. Syria programme. Five-year plan. Available at: https://www.mindbank.info/download_file/1619/fdaa3715b445f9621683662dd3865c73ea0920ea [Accessed 25 April 2018]

³⁰ WHO, 2011. World report on disability. Available at: http://www.who.int/disabilities/world_report/2011/en/ [Accessed 25 April 2018].

³¹ Metts, R. 2004. Background paper prepared for the disability and development research agenda meeting in the World Bank, November 16, 2004, World Bank Headquarters, Washington, D.C.

³² Said Foundation. 2009.

According to the Said Foundation, in 2009 the number of persons with disabilities in Syria was estimated at 2 million (10% of the population), of which over 700,000 were children³³.

Collecting accurate data on impairment and disability is more challenging in humanitarian emergencies³⁴, and not much is known about children with disabilities during this period of conflict in Syria. Rates of children with disabilities may be higher in communities left behind or unable to flee. Children with disabilities remain one of the most vulnerable and socially excluded groups in any displaced community. They may be hidden in shelters, overlooked in needs assessments, and not included in the design of programmes. Children with disabilities have difficulty accessing humanitarian assistance programmes, due to a variety of societal, environmental, and communication barriers, increasing the risks to their safety, including violence, abuse, and exploitation³⁵. The limited amount of data on their conditions and needs perpetuates their exclusion and increases their vulnerability.

This report addresses the need for information on children living with disabilities in Syria to raise awareness of their situation and improve services to address their needs. The report, commissioned by Syria Relief, presents the results of field research conducted across the four governances in Syria in which the charity operates, including: Idlib City, Idlib; Sarmada, Idlib; Talbeeseh, Homs; Azaz, Alepoo; Lattakia Suburbs, Lattakia, Idlib; Al-Ghouta, rural Damascus; Ain Beide; and Atmeh. 789 children identified as living with

disabilities were surveyed to learn about their lives during the Syrian conflict. Most of the respondents surveyed were from the host communities, followed by internally displaced persons, and refugees.

The findings presented in this report identify the types of disabilities that children in Syria live with, their needs, and the services they receive. Based on these findings, policy recommendations for the UK Government and humanitarian actors are made. Currently, the UK Government has pledged £2.46 billion³⁶ to Syria, much of which focuses on the crisis outside of Syria. More should be disclosed about about the money allocated to supporting communities inside Syria. The UK Government should strengthen its commitment³⁷ towards the Grand Bargain agreement, 'No Lost Generation' initiative, with United Nations' Children's Fund (UNICEF)³⁸ and the Education Cannot Wait fund³⁹, to "put more money directly into the hands of people who need it most, stimulating local markets and economies."

A brief outline of the methods employed in the field research is provided in the following section. A more detailed description of the methodological approach, research design, ethical considerations, and study limitations appears in Annex I. The English version of the survey and the consent form for survey respondents appear in Annex II. Results of an analysis of data from sub-districts (with 40 respondents or more) in the overall sample are presented in Annex III. These results confirm the findings from the full sample. A series of figures depicting the study findings appear in Annex IV.

³³ Said Foundation. 2009.

³⁴ Skinner, M. 2014. The impact of displacement on disabled, injured and older Syrian refugees. *Forced Migration Review*, 47. Available at: <http://www.fmreview.org/sites/fmr/files/FMRdownloads/en/syria/skinner.pdf> [Accessed 25 April 2018].

³⁵ Women's Refugee Commission, 2017. Disabilities among refugees and conflict-affected populations, [Report] October 12, 2017. Available at: <https://www.womensrefugeecommission.org/resources/document/609-disabilities-among-refugees-and-conflict-affected-populations> [Accessed 25 April 2018].

³⁶ Rodger Godsiff and Alistair Burt. Syria. [Written questions and answers] January 24, 2018-February 19, 2018. UK Parliament. Available at: <http://www.parliament.uk/business/publications/written-questions-answers-statements/written-questions-answers/?page=1&max=20&questiontype=AllQuestions&house=commons%2cords&use-dates=True&answered-from=2018-01-01&answered-to=2018-02-08&member=304&keywords=Syria> [Accessed 25 April 2018].

³⁷ UK Government. 2016. UK leads new approach to prevent and respond to crises at the first-ever World Humanitarian Summit, [News story] May 24, 2016. Available at: <https://www.gov.uk/government/news/uk-leads-new-approach-to-prevent-and-respond-to-crises-at-the-first-ever-world-humanitarian-summit> [Accessed 25 April 2018].

³⁸ No Lost Generation, [Online]. <http://nolostgeneration.org/> [Accessed 25 April 2018].

³⁹ Education Cannot Wait, [Online]. <http://www.educationcannotwait.org/> [Accessed 25 April 2018].

Methodology

Field Research⁴⁰

Syria Relief operates in areas where it has access to provide essential support for those most in need within Syria. It operates across four governances, in Idleb City (Idleb); Sarmada (Idleb); Talbeeseh (Homs); Azaz (Aleppo); Lattakia Suburbs, Lattakia (Idleb); Al-Ghouta (Rural Damascus); Ain Beide; and Atmeh. The organisation has built networks with a variety of civilians through several of its projects. These networks enabled the identification of children with disabilities for inclusion in the study.

Field staff compiled a list of potential participants from health centres, organisations, and local councils. This list included 10,059 children with disabilities, 0–18 years old, across the locations in which Syria Relief operates. The list was then refined to focus on

children 5–17 years old⁴¹ and included 7,181 children. A sample of 11% (N=789) from the list were randomly selected, based on the identified population's distribution within each of the four districts (See Figure 1). When potential respondents declined to participate, additional respondents were randomly selected from the list to maintain the sample size. The sample size reflects the known population size of the areas sampled. This, to a degree, helped maintain a balanced ratio and equally test the identified population across the locations sampled.

Data was collected using a survey questionnaire⁴² between April and July 2017. Responses to the survey were collected via interviews conducted in Arabic by the field staff with the participating children and their guardians. The study survey is based on the Washington Group's (WG) Children with

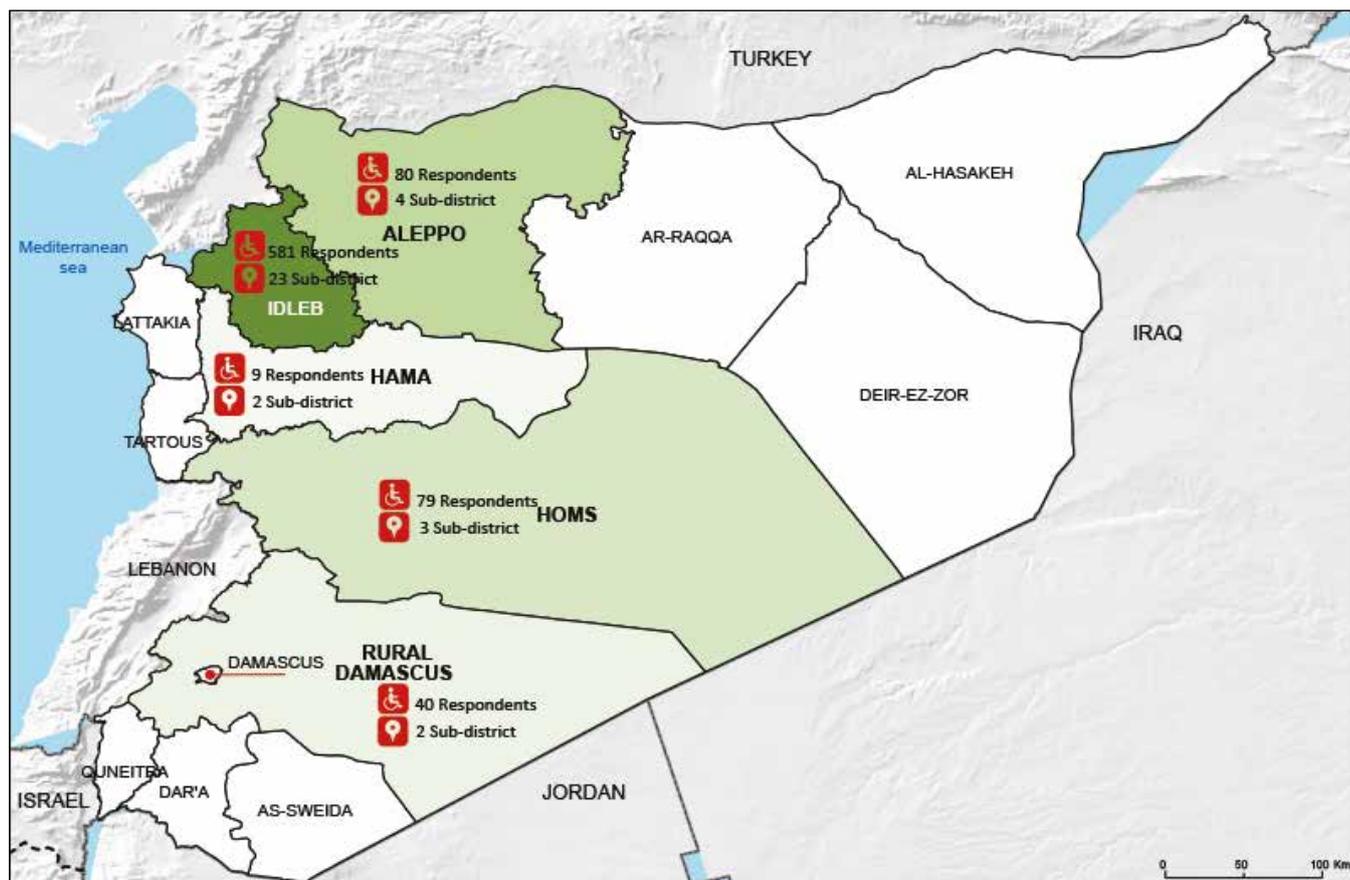


Figure 1. Distribution of surveyed respondents across districts (N=789)

⁴⁰ For a detailed description of the methodological approach, research methods, ethical considerations, main sample results, please see Annex I. Available at: <https://www.syriarelief.org.uk/wp-content/uploads/2018/06/Annex.pdf>

⁴¹ The study survey is restricted to children 5 to 17 years old.

⁴² The English version of the survey appears in Annex II.

Disabilities Survey (long version)⁴³. The WG survey was designed to help measure child functioning and identify aspects of child development. The Child Functioning Module used in this study was developed in partnership with UNICEF and comprises a set of survey questions for identifying children with disabilities. As in other WG question sets, disability is defined as difficulty undertaking basic activities. Working in conjunction with WG, the original survey was adjusted and questions were added to capture the types of disabilities that children in Syria experience and their needs and access to services.

Before the main survey was carried out, the research team conducted a pre-test with 60 children (30 children with disabilities and 30 without)⁴⁴ to assess the survey operationally in the field. The pre-test aimed to assess whether the survey indeed captures the nature of children with disabilities in Syria and the types of disabilities they experience, to provide field researchers with an understanding of how the survey functions in the field, and to later compare its results with the results of the main survey.

The researchers and field assistants agreed on categories for the types of difficulties identified. The categories below are based on respondents' indicated difficulty. (It is important to note that some children identified multiple disabilities and an array of health difficulties that affected their permanent difficulties.)

- Mobility difficulties
- General awareness difficulties (intellectual and psychological)
- Hearing difficulties
- Visual difficulties

General awareness is divided into two categories, intellectual and psychological difficulties. During preliminary discussions, researchers and field staff agreed that the two categories could be perceived as

closely linked by respondents and would be difficult for field researchers to distinguish.

Results of the main survey are presented in the following section. It is important to note that the findings presented in this report do not represent all children with disabilities in Syria. Instead, they provide insight into the conditions of some of the children who live with disabilities in Syria. The following results can only reflect the lives of the 789 children sampled in this research project, and therefore cannot be considered representative of the wider population in Syria⁴⁵.

“To live in fear and want in a war zone is a hideous situation – but to be a child, and to be a child with disabilities, amplifies the challenge and the horror. Children with disabilities living in Syria must be a first thought in humanitarian provision – not an afterthought. Inclusion is an upfront decision. Syria Relief exemplifies this mantra.”

The Rt Hon. the Baroness Featherstone

⁴³ Washington Group on Disability Statistics, 2016. MICS questionnaire form for vaccination records at health facilities [PDF]. Available at: http://www.washingtongroup-disability.com/wp-content/uploads/2016/01/Child_Functioning_for_Children_Age_5_to_17_-Oct-2016_FINAL.pdf [Accessed 25 April 2018].

⁴⁴ See Annex I for results of the pre-test.

⁴⁵ For further details please refer to Annex I.

Dia was born with a crippling disability, preventing him from walking any distance beyond a few meters when unassisted. He has known no life outside of conflict.

Summary of findings

The Children, Characteristics

The children surveyed were between the ages of 5–17 years old. Half of the children were 10 years old or younger (N=397) and half were 11–17 years old (N=392). 60% (N=474) of the children were male and 40% (N=315) female (See Figure 2). Close to 650 of the children surveyed were from the host communities, more than 100 were from internally displaced communities, and the remainder were from refugee communities.

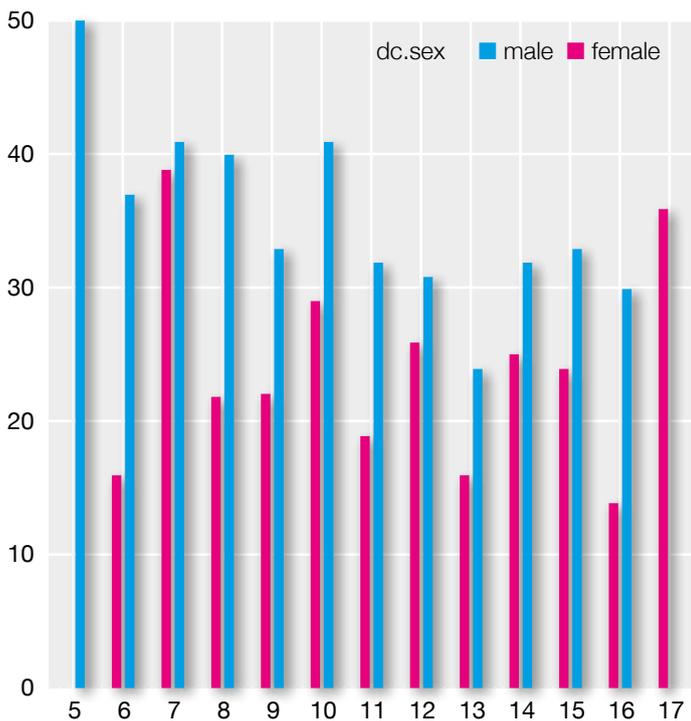


Figure 2. Age and gender of children surveyed

Disabilities, Types and Prevalence

The most prevalent difficulties identified by the children or their guardians were mobility difficulties (55%, N=434); psychological and/or intellectual difficulties (48%, N=380); and a combination of mobility, intellectual, and/or psychological difficulties (21%, N=163). Hearing and vision difficulties were less prevalent (15%, N=122 and N=121 respectively). (See Figure 3)⁴⁶ Most of the children surveyed (83%, N=653) had disabilities from birth.

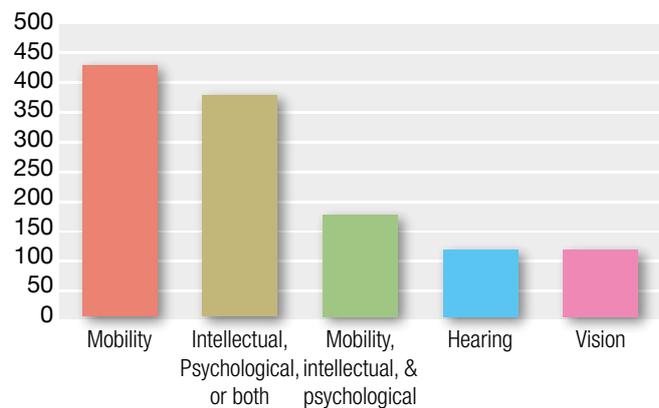


Figure 3. Disability types by number of children

DIA • 7 YEARS OLD • ALEPPO

Dia was born with a crippling disability, preventing him from walking any distance beyond a few meters when unassisted. He has known no life outside of conflict. Despite his increasing struggle in the ongoing conflict in Syria, Dia remains kind and gentle with others, as his mother describes the family's difficulties. Dia's family is living in an area severely affected by the conflict. Most services and supports have been suspended entirely. Of his family of five, two are disabled children. Dia finds it difficult to even dress himself in the mornings, resulting in regular frustration and sadness, compounded by the ongoing conflict. In terms of schooling, his mother stresses the importance of special needs classes, facilities, and trained staff in schools to support children like Dia.



⁴⁶ See also Annex IV, Figure 1 for more detailed description of the difficulties and their combinations among the children surveyed.

Mobility difficulties

434 children had mobility difficulties and indicated difficulty walking up to 100 meters on level ground. More than half of the children living with mobility difficulties (57%, N=247) experienced these difficulties exclusively, and 43% (N= 187) in combination with another difficulty. 80% (N= 344) of these children indicated having mobility difficulties from birth; 11% (N=46) indicated that their mobility difficulties were due to an accident or injury; and 9% (N=41) indicated that their difficulties were related⁴⁷.

Intellectual and psychological difficulties⁴⁸

361 children had some form of intellectual disability (154 exclusively and 207 in combination with other difficulties); and only 68 children indicated having psychological difficulties. However, intellectual and psychological difficulties appeared to be closely related when respondents indicated having either. Results reveal that close to half of the children surveyed (48%, N=380) had psychological or intellectual difficulties or a combination of both.

Many of these children had problems with comprehension, speaking, concentration, and memory. Many also experienced depression (84%, N=318) and anxiety (88%, N=333) daily, weekly, and monthly.

Speaking and Comprehension. Many of the children (N=315) had difficulties being understood and understanding people in their households. 109 respondents (the guardians) indicated that the child ‘cannot do it at all’; 103 had ‘a lot of difficulty’; and 103 had ‘some difficulty’⁴⁹. Many of the children (N=334) also had challenges being understood and when spoken to outside the home⁵⁰. 154 respondents indicated the child ‘cannot do it at all’; 130 had ‘a lot of difficulty’; and 50 had ‘some difficulty’.

Concentration. 105 children had ‘a lot of difficulty’ concentrating; 157 children could not concentrate at all; and 78 had ‘some difficulty.’ 40 children had no difficulties concentrating.⁵¹ Additionally, 277 children indicated difficulty adapting to changes within the current setting, and 100 could not adapt at all.

AHMED • 6 YEARS OLD • GHOUTA

Ahmad lives with his family in East Ghouta, in the outskirts of Damascus, which has been under siege for nearly five years. Ghouta has received little aid and thousands of civilians are trapped between the various parties to the conflict and in need of immediate aid.

Ahmad was injured in a bombardment in his area. His injuries have led to a decline in vision, mildly decreased hearing, and severe mental trauma. Ahmed mother states her son has become difficult to understand and has fallen behind in school; she finds it extremely difficult to control his behaviour. His mother claims he is regularly anxious and depressed and finds it increasingly difficult to regain a connection with the world around him.



⁴⁷ See Annex IV, Figure 2. Reasons for mobility difficulties.

⁴⁸ In the analysis, intellectual and psychological difficulties were merged into one category: general awareness. Please see Field Research section in this report and Annex I for detail on the analysis of the findings.

⁴⁹ See Annex IV, Figure 3. Children with psych/intellectual difficulties, difficulties when spoken to inside the home.

⁵⁰ See Annex IV, Figure 4. Children with psych/intellectual difficulties, difficulties when spoken to outside the home.

⁵¹ See Annex IV, Figure 5. Children with psych/intellectual difficulties, difficulties with concentration.

Memory. Many of the children (N=339) with intellectual and psychological difficulties also struggled with memory. When compared to the memory of children of the same age, 163 of the respondents indicated that the child ‘cannot do it at all’; 106 had ‘a lot of difficulty’; and 70 had ‘some difficulty’⁵².

Depression and anxiety. More than half of the children (66%, N=251) with intellectual and psychological difficulties indicated feeling depressed daily or weekly. 126 children indicated feeling depressed daily, 125 weekly, 67 monthly, and 31 a few times in the year (See Figure 4). 75% (N=286) of these children experienced anxiety daily or weekly. 170 children indicated feeling anxious daily, 116 weekly, and 47 monthly (See Figure 5).

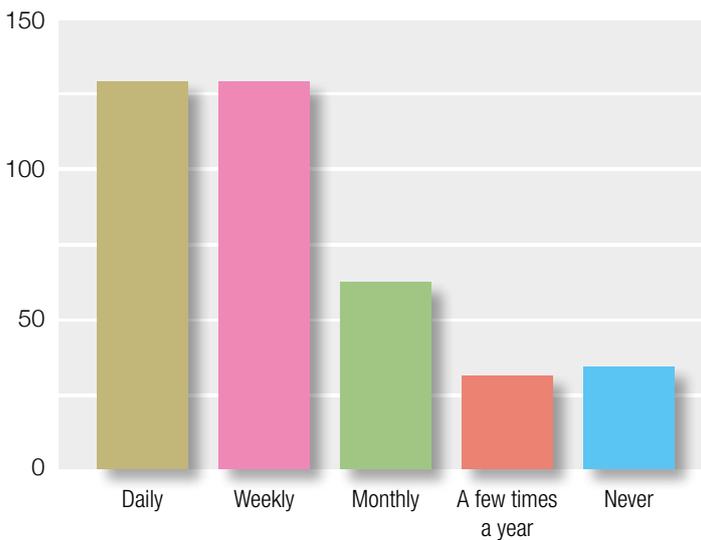


Figure 4. Frequency children with intellectual and/or psychological difficulties experienced depression

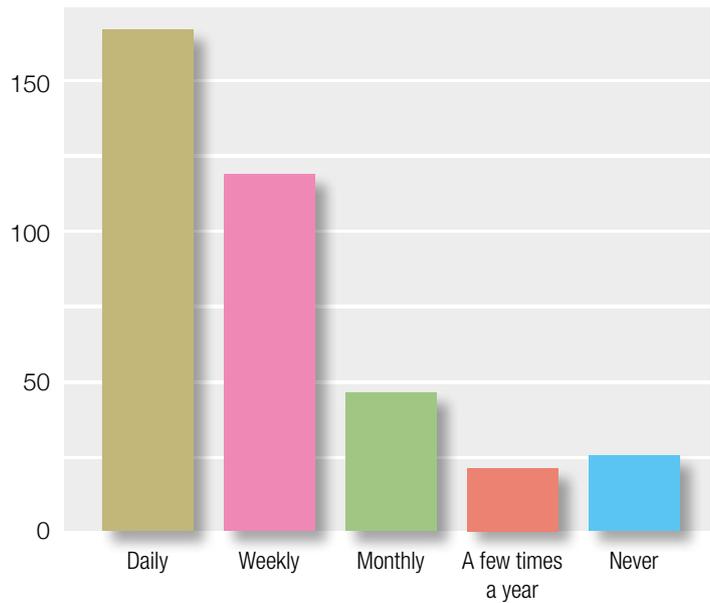


Figure 5. Frequency children with intellectual and/or psychological difficulties experienced anxiety

ABD ALMALEK
6 YEARS OLD • HOMS

Abd Almalek is a young victim of the ongoing Syrian conflict. He was rendered disabled, both mentally and physically, after his house was shelled. Abd’s family of 16 is internally displaced in the district of Homs. He has received little treatment for his crippling injuries and is unable to walk or talk. Abd can still hear the world around him and respond to his family, but they unable to provide him with the care that he needs.



⁵² See Annex IV, Figure 6. Children with psych/intellectual difficulties, difficulties with memory.



Marwa lost her home in the conflict and lives in cramped conditions with nine family members, of which only one can work to provide for the family.

Combined mobility and intellectual and/or psychological difficulties

Children with a combination of mobility, intellectual, and/or psychological difficulties were the third largest group among all children surveyed (21%, N=163). 91% (N=149) of children with these difficulties had them from birth. This may be the result of poor prenatal care (e.g., lack of nutrition for pregnant women, lack of access to maternal health care, and unsafe childbirth) or genetic complications due to widespread consanguineous marriage. The remainder of children incurred these difficulties in accidents or injuries or conflict-related incidents (See Figure 6).

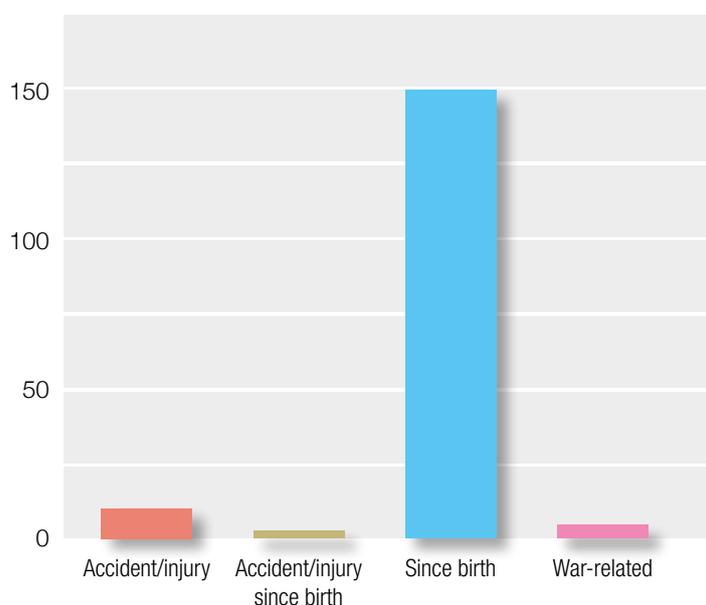


Figure 6: Reasons for combined mobility, intellectual and/or psychological difficulties

Vision and hearing difficulties

Children with vision or hearing difficulties were a small group among the children surveyed. 15% (N=121) of the children surveyed indicated that they had some form of vision difficulty, either exclusively or in combination with other difficulties. 15% (N=122) of the children surveyed indicated that they had hearing difficulties. 67 children had some form of hearing difficulty exclusively, and 55 children in combination with other difficulties.

Services, Needs and Availability

Overall, results of this study reveal that there is significant need for medical rehabilitation, assistive devices, educational services, counselling services, health services, and mental stimulation.

MARWA

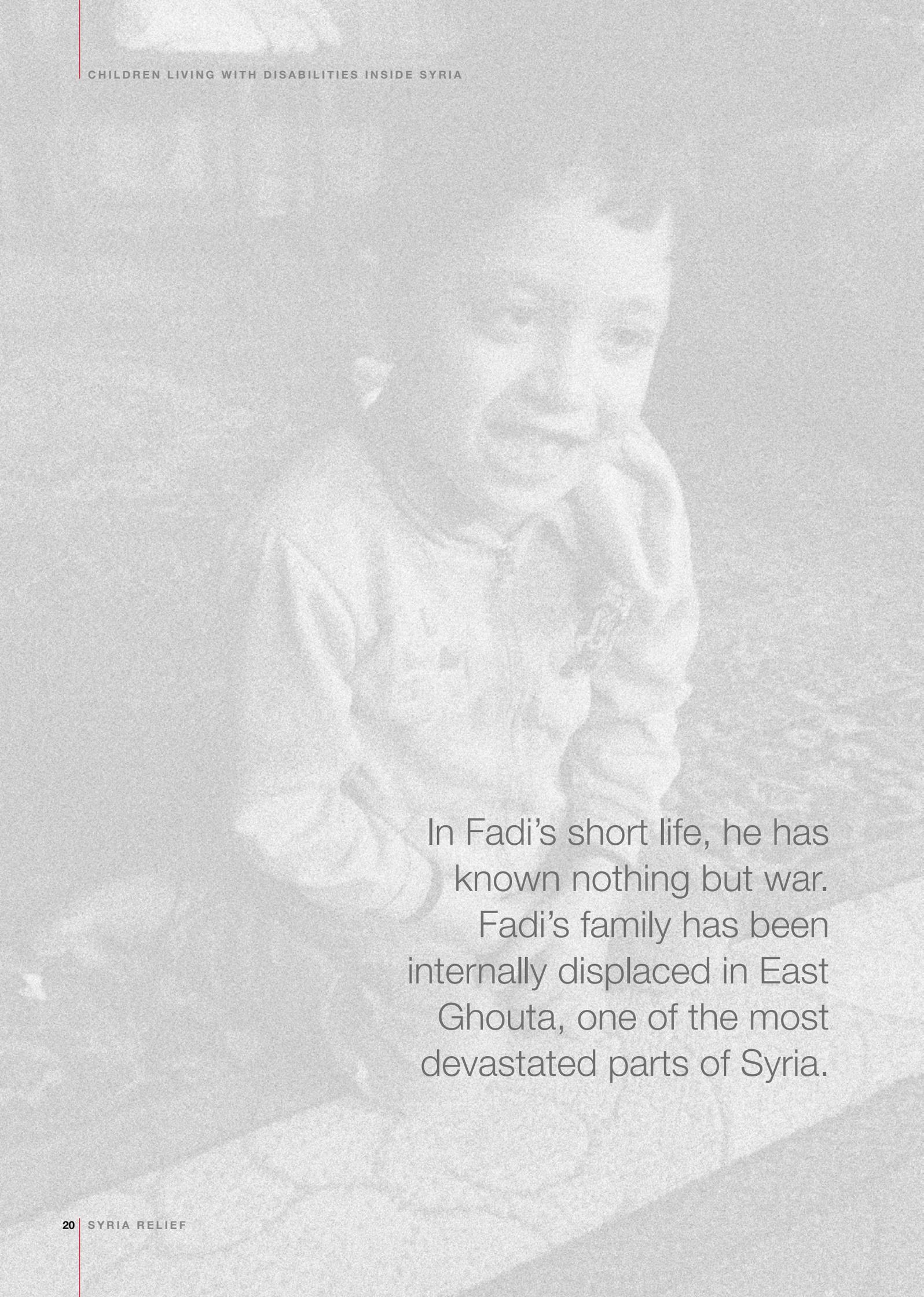
13 YEARS OLD • TALBEESA

Marwa lost her home in the conflict and lives in cramped conditions with nine family members, of which only one can work to provide for the family. Marwa was born with a disability that has left her unable to walk without support or assistance. The lack of physiotherapy means she cannot carry out the most basic tasks, including dressing herself in the morning or eating without the help of her family. Physiotherapy services are not available, and even if they were, they would cost more than her family can afford. Marwa's basic needs include, a special needs toilet, access to school, and medical treatment.



Medical rehabilitation

Many of the respondents (89%, N=700) indicated a need for medical rehabilitation services, such as physiotherapy, occupational therapy, and speech and hearing therapy. Only 11% (N=89) indicated that there was no need for these services. 69% (N=544) of the respondents indicated that these services were not available in their area. 29% (N=232) indicated that there were medical rehabilitation services in their area; and 2% (N=13) indicated that they did not know. Half of the children surveyed (55%, N=432)

A young child with a visible physical disability, possibly a limb difference, is sitting on the floor. The child is wearing a light-colored, patterned shirt and dark pants. The background is a plain, light-colored wall. The overall tone of the image is somber and documentary.

In Fadi's short life, he has known nothing but war. Fadi's family has been internally displaced in East Ghouta, one of the most devastated parts of Syria.

had not received such services; 32% (N=256) had received them in the past; and 13% (N=101) were receiving these services at the time of the survey.

Of the 122 children with hearing difficulties, 62% (N=75) indicated that speech therapy was needed; 62 indicated that it was a 'vital' need; 13 indicated that it was 'needed but not vital'; and 34 indicated that it was 'not relevant'. 71% (N=87) of children with hearing difficulties indicated that hearing therapy was a 'vital' need; and 15 that it was 'needed, but not vital'.

FADI

7 YEARS OLD • GHOUTA

In Fadi's short life, he has known nothing but war. Fadi's family has been internally displaced in East Ghouta, one of the most devastated parts of Syria. When he was only 15-months-old, an accident rendered Fadi unable to move or walk without the support of walking devices or assistance. His grandfather describes the frustration and sadness this brings Fadi,



especially when he sees other children walking and running. Fadi is fortunate to have access to physiotherapy, but without adequate equipment, such as a wheelchair, he is unable to move around independently.

Assistive devices

77% (N=611) of the children surveyed indicated a need for assistive devices, such as wheelchairs, mobility shower seats, and hearing or visual aids/facilities. 23% (N=178) of the children indicated that there was no need for these devices. 53% of the children with a combination of mobility, intellectual, and/or psychological difficulties indicated a need for assistive devices.

78% (N=617) of children surveyed indicated that assistive devices were not available in their area; 12% (N=143) had access to assistive devices in their area; and 4% (N=29) did not know. Many respondents (N=587, 74%) indicated that they had never received such devices. 112 (14%) respondents indicated that they had such devices at the time of the survey; and 90 (11%) had received such devices in the past. Results show that children with mobility difficulties who had a mobility aid or had received one in the past, continued to experience mobility difficulties.

Wheelchairs

44% (N=343) of all surveyed children indicated a need for a wheelchair, including those who did not have mobility difficulties. 67% (N=289) of children with mobility difficulties expressed a need for a wheelchair. 252 of these children indicated that it was a vital need; 37 indicated it was 'needed but not vital'; and 40 respondents indicated it was 'not relevant' (See Figure 7). 65% (N=106) of children with a combination of mobility, intellectual, and/or psychological difficulties stated that it was 'vital' to have a wheelchair at home; 8 of these children indicated that it was 'needed but not vital'; and 6 that it was 'not relevant'.

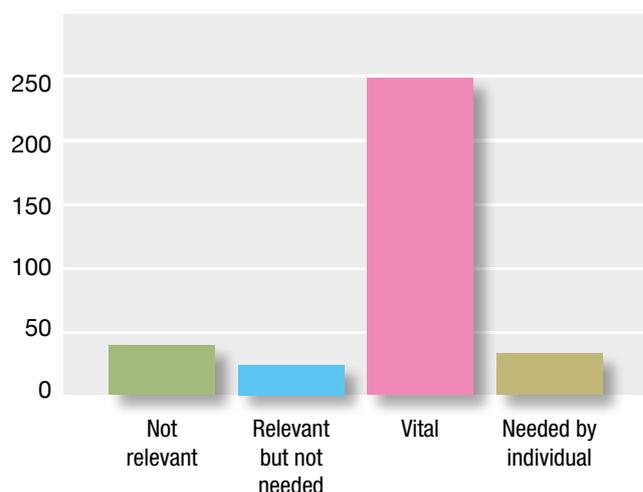


Figure 7. Children with mobility difficulties need for wheelchairs.

Duha's mother reports that there are no services in their area to support them except for a general hospital, which is not equipped to help Duha.

Mobility shower seats

Of the 434 children with mobility difficulties, 154 indicated that there was a 'vital' need for mobility shower seats; 52 indicated that they were 'needed but not vital'; 104 indicated that they were not relevant; and 41 indicated that they were 'relevant, but not needed'⁵³. Of the 163 children with a combination of mobility and intellectual and/or psychological difficulties, 69 indicated that mobility shower seats were a 'vital' need; 18 indicated that they were 'needed but not vital'; and 25 that they were not relevant.

Visual and hearing aids/facilities

Among the children who had vision difficulties, 65% (N=78) indicated that visual aids were a 'vital' need. 47% (N=57) of these children expressed a need for Braille books. 47 children indicated that Braille books were a 'vital' need; 10 that they were 'needed but not vital'; and 39 that they were 'not relevant'. 60% (N=75) of children with hearing difficulties expressed a need for hearing facilities. 44 of these children indicated that access to such facilities was a 'vital' need; and 31 that it was 'needed but not vital'.

Educational services

64% (N=511) of children surveyed indicated a need for educational services, such as special needs

schools, early childhood stimulation, and special tutoring. 35% (N=278) of children surveyed indicated that these services were not needed. 81% (N=645) of the children did not have access to educational services. 130 children (17%) indicated there were educational services in their area; while 14 (2%) indicated that they did not know. 85% (N=674) of the children indicated that they had never received educational services. Only 8% (N=58) of children were receiving these services at the time of the survey; and 7% (N=57) had in the past.

Counselling services

61% (N=478) of the surveyed children indicated a need for counselling services, such as psychology, psychiatry, social work, and school counselling. 39% (311) of respondents indicated that counselling services were not needed. 87% (N=685) of the surveyed children indicated that there were no counselling services in their area. 9% (N=74) of the children indicated that these services were available in their area; while 4% (N=30) did not know. 90% (N=712) of the surveyed children had never received counselling services. Only 5% (N=42) were receiving these services at the time of the survey; and 4% (N=35) had in the past.

DUHA • 14 YEARS OLD • HOMS

Duha was born with a disability that has rendered her immobile and mentally disabled. She has lived half her life in war. Duha's condition has deteriorated over time. The lack of medical and rehabilitation services has made things more difficult for her and her family.

While Duha is aware of what is happening around her, she lacks educational and rehabilitative stimulation. Duha's mother reports that there are no services in their area to support them except for a general hospital, which is not equipped to help Duha. A wheelchair and transportation are vital, but they are too costly for her family.



⁵³ See Annex IV, Figure 7. Children with mobility difficulties need for shower seats

Health care services/facilities

80% (N=630) of all children surveyed indicated a need for accessible health care services, such as a primary health care clinic, a hospital, and home health care services. 20% (N=159) of the respondents indicated that they were not needed. 62% (N=487) of children surveyed indicated that there were no health services in their area. 37% (N=294) indicated that these services were available in their area; while 1% (N=8) did not know. 67% (N=531) of children surveyed indicated that they had not received health care services; 19% (N=150), indicated that they had in the past; and 13% (N=108) that they were receiving such services at the time of the survey.

However, among children with mobility difficulties (N=434) more than half of the respondents (64%, N=278) did not believe that home health care was needed. 202 children with mobility difficulties indicated that these services were ‘not relevant’; and 76 indicated that they were ‘relevant but not needed’.

74 respondents indicated that home health care was a ‘vital’ need; and 47 that it was ‘needed but not vital’⁵⁴. Of the 163 children with combined mobility, intellectual, and/or psychological difficulties, 82 indicated that the need for health care services was ‘vital’; 33 indicated that they were ‘needed but not vital’; and 22 that they were ‘relevant but not needed’.

Mental stimulation

56% (N=441) of the children surveyed indicated a need for mental stimulation. 76% (N=289) of children with intellectual and/or psychological difficulties indicated a need for mental stimulation. 63% (N=241) of these children indicated that mental stimulation was a ‘vital’ need; 13% (N=48) indicated that it was ‘needed but not vital’; and 7% (N=25) indicated that it was ‘relevant, but not needed’ (See Figure 8).

77% (N=125) of children with a combination of mobility, intellectual, and/or psychological difficulties indicated a need for mental stimulation. 103 of

BATOOL • 9 YEARS OLD • IDLEB

Batool is currently living with four other children and her one working Uncle, who cannot pay for the expensive special needs equipment and services that she needs. Children with Down syndrome, like Batool, need targeted mental and emotional stimuli to learn and grow. With the difficult economic and violent conditions in Syria today, it is nearly impossible to gain access to such support.



⁵⁴ See Annex IV, Figure 9. Children with mobility difficulties need for home health care services.

⁵⁵ Annex IV, Figure 10. Children with a combination of mobility and psychological and/or intellectual difficulties need for mental stimulation.

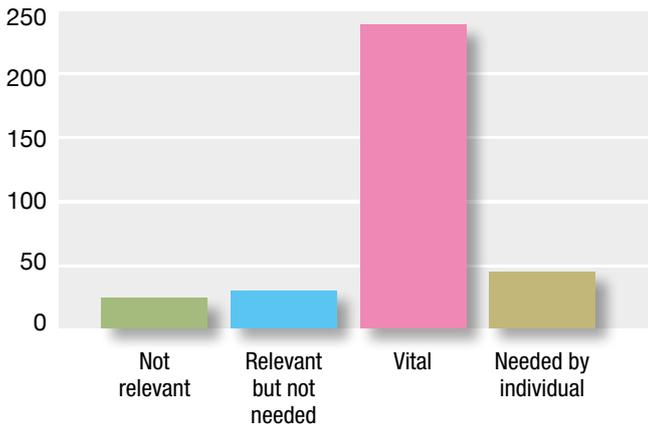


Figure 8. Children with psychological and/or intellectual difficulties who need mental stimulation

these children indicated that it was a ‘vital’ need; 22 indicated it was ‘needed but not vital’; 13 indicated that it was ‘relevant but not needed’; and 12 indicated it was ‘not relevant’⁵⁵. 60% (N=73) of children with hearing difficulties indicated that mental stimulation was needed. 48 of these children indicated that it was a ‘vital’ need; 25 indicated it was ‘needed but not vital’; and 31 indicated that it was not relevant.

“This report is a valuable study into the war’s impact and how we can help those who have been worst affected. All of us in the UK must stand ready to work with partners in Syria and the rest of the international community to help build a positive future for these children.” Rt Hon Stephen Gethins MP

Conclusion

With the conflict in Syria in its seventh year, the humanitarian crisis has become increasingly severe and is reaching new levels of complexity and hardship for millions of displaced and hard-to-reach families, besieged communities, and refugees. Children with disabilities are among the most vulnerable in times of crisis and are often overlooked in humanitarian aid and support programmes. The aim of this report was to identify the types of disabilities children in Syria face, their needs, and their access to services to address the gap in information on this population and improve services and aid for this vulnerable group.

The findings presented in this report reveal that 434 children had mobility difficulties, 380 children had intellectual and/or psychological difficulties, and 163 children had a combination of mobility, intellectual, and/or psychological difficulties.

The report highlights the prevalence of disability from birth as opposed to disabilities resulting from conflict. This suggests that these disabilities are potentially preventable with early medical intervention and warning. Preventable disability prevails outside of the conflict and, as such, will not be resolved without intervention even when the conflict ends. 83% (N=653) of the children surveyed had disabilities from birth; 79% (N=344) of children with mobility difficulties had these difficulties from birth; and 91% (N=149) of children with a combination of mobility, intellectual, and/or psychological difficulties had these difficulties from birth. These findings suggest that there are significant prenatal care and genetic factors, which we suspect may be attributed to consanguineous marriage. In pre-conflict Syria, intermarriage was estimated to account for between 25% and 50% of children with disability and is more common in rural areas⁵⁶. Other risk factors in child disability include a lack of ante-, peri-, and post-natal care; incidents at birth; lack of health education and knowledge; accidents; and inadequate diet/nutrition. Risk factors present in the northern and eastern regions of Syria suggest that these regions may have higher rates of child disability⁵⁷.

The findings presented in this report demonstrate that a large number of children with disabilities in Syria are living without access to some of the most basic necessities. Many of the children surveyed no longer have access to or have never received physical, mental, and psychological support services, including: medical rehabilitation; assistive devices (e.g., wheelchairs, shower seats); educational, counselling, and health care services; and mental stimulation. Results show significant need for these services. The children often require specialised care, which is not available outside major centres. For example, some medical treatments, especially for conditions such as seizures and spasms, require paediatric services with a relatively high degree of expertise. However, some basic treatments can be provided by clinicians in the community (e.g., anti-epileptics); and outreach from a major centre into IDP camps could address these needs. In addition, many of the legal guardians preferred to care for the children on their own, with support from external services, and not receive home health care services. As such, training in occupational or physical therapy could be provided for in-family, self-care for children with disabilities.

Additional desk research revealed the scarcity of services for children with disabilities inside Syria. Table 1.0 provides an overview of the services provided by the UK NGO sector, based on data from 2016–present. Additional research found eight organisations that support or deliver services to children in Syria, including Syria Relief⁵⁸. However, only four of these organisations have offices inside Syria: Syria Relief, Syria Relief and Development, Handicap international⁵⁹, and International Medical Corps. Many of the larger NGOs support smaller local NGOs with offices inside Syria as implementing partners. However, these NGOs have insufficient reach to support many of the children that we have identified as living with disabilities inside Syria. There is vital need to increase awareness regarding the scale of children with disabilities in Syria and the services they need.

⁵⁶ Said Foundation. 2009.

⁵⁷ Said Foundation. 2009.

⁵⁸ Thompson, S. 2017. Disability in Syria. K4D Help Desk Report [PDF]. Brighton, UK: Institute of Development Studies. Available at: <http://www.gsdrc.org/wp-content/uploads/2017/06/056-Disability-in-Syria.pdf>. [Accessed 11 May 2018].

⁵⁹ On January 24th 2018, Handicap International became Humanity & Inclusion

Table 1. Services provided inside Syria (February 2018)

NGO	Countries active	Interventions
Handicap International (Humanity & Inclusion) ^{60,61}	Syria, Jordan, Iraq and Lebanon	<ul style="list-style-type: none"> • Provides clinical care for the injured and disabled. • Focuses on emergency medicine and rehabilitation. • Improves access to essential services for vulnerable people. • Provides prosthetics and orthotic fittings. • Distributes medical devices. • Provides psychosocial support and physiotherapy.
Christian Aid ⁶²	Lebanon	<ul style="list-style-type: none"> • Supports the Lebanese Physically Handicapped Union (LPHU) to provide physiotherapy, occupational, and speech therapy. • Supports two existing centres for people with disabilities. • Supplies specialist equipment and recruits specialist staff. • Supports education and outreach programmes. • Supplies assistive devices.
Islamic Relief ⁶³	Syria, Lebanon, Jordan and Iraq	<ul style="list-style-type: none"> • Establishes child-friendly learning spaces. • Supports education and health programmes. • Supplies medicine and prostheses. • Rebuilds/rehabilitates hospitals and schools. • Runs psychosocial support programmes.
Syria Relief ⁶⁴	Syria	<ul style="list-style-type: none"> • Works with the National Syrian Project for Prosthetic Limbs (NSPPL). • Sponsors 55 schools and children's centres. • Supports 31 child friendly spaces. • Provides psychosocial support. • Supports teachers in training and specialization.
Syria Relief and Development ⁶⁵	Syria	<ul style="list-style-type: none"> • Supports rehabilitation, physical therapy, and increased mobility. • Works to improve access to health. • Supports outpatient physical therapy and rehabilitation clinics. • Offers rehabilitation and prosthetic limb fitting. • Provides assistance with mobility and gaining functionality.
Mercy Corps ⁶⁶	Jordan	<ul style="list-style-type: none"> • Funded by UNICEF to work towards fully integrating refugees into public school systems. • Provides wheelchairs. • Trains adult refugees with university degrees to provide personal classroom sessions. • Promotes extracurricular activities to reduce stigma.
International Medical Corps ⁶⁷	Syria	<ul style="list-style-type: none"> • Provides mental health and psychosocial support services. • Supports mobile medical services and health care facilities. • Distributes supplies. • Supports hospitals and schools. • Provides emotional support and child-focused mental health care.
Save the Children ⁶⁸	Syria, Jordan, Iraq, Egypt and Lebanon	<ul style="list-style-type: none"> • Supports hospitals and schools. • Provides emotional support and child-focused mental health care.

⁶⁰ Handicap International. 2016. Syria country card [PDF]. Available at: https://www.handicapinternational.org.uk/sites/uk/files/country/files/2016_09_cc_syria_en_ok_0.pdf. [Accessed 25 April 2018].

⁶¹ Handicap International. 2017. Syria [Fact sheet]. Available at: <https://www.handicapinternational.org.uk/country/syria> [Accessed 25 April 2018].

⁶² Christian Aid. 2017. Left out in the cold: Syrian refugees with disabilities in Lebanon. Available at: <https://medium.com/@caglobal/left-out-in-the-cold-syrian-refugees-with-disabilities-in-lebanon-2449e559a2b9> [Accessed 25 April 2018].

⁶³ Islamic Relief. 2017. Syrian Arab Republic. Available at: <http://www.islamic-relief.org/category/where-we-work/syrian-arab-republic/> [Accessed 25 April 2018].

⁶⁴ Syria Relief. Programmes. Available at: <https://www.syriarelieff.org.uk/programmes/> [Accessed 25 April 2018].

⁶⁵ Syria Relief and Development. Our programmes. Available at: <https://srd.ngo/our-programs/> [Accessed 25 April 2018].

⁶⁶ Mercy Corps. 2014. Getting Syria's most vulnerable children to school. Available at: <https://www.mercycorps.org/articles/jordan-syria/getting-syrias-most-vulnerable-children-school> [Accessed 25 April 2018].

⁶⁷ International Medical Corps. 2017. Syria. Available at: <https://internationalmedicalcorps.org/Syria> [Accessed 25 April 2018].

⁶⁸ Save the children. Syria. Available at: <https://www.savethechildren.ca/syria/> [Accessed 25 April 2018].

Recommendations

Key Recommendations for the UK Government

Children have paid the heaviest price in the conflict, and their suffering has increased with the escalation of violence. More than 5.3 million children in Syria are in need of humanitarian assistance, close to half of which have been forced to flee their homes, and many of their families have lost everything.

■ Firmer commitment to the ‘leave no one behind’ agenda is needed through a clearer strategy to support children with disabilities in fragile and conflicted settings pursuant to Sustainable Development Goals⁶⁹.

■ A percentage of UK Syrian aid should be ring-fenced towards investment in needs assessments for children with disabilities in order to enforce the UK Government’s ‘leave no one behind’ strategy. In addition, DfID programming should have disability support mainstreamed throughout all of its programming whether in FCAS, humanitarian response or in post conflict settings. This would help reduce the aid inequality taking place in Syria today and beyond.

■ Disability as a global human rights’ issue must be mainstreamed within all development, health, and educational programmes as well as in humanitarian action intended to improve the lives of children and their families. This should include promoting the development of Inter-Agency Standing Committee (IASC) guidelines⁷⁰.

■ By ratifying the CRPD, the UK must commit to protect and ensure the rights of all persons with disabilities pursuant to Article 11 ‘Situations of risk and humanitarian emergencies’⁷¹.

■ In line with SDG 3, more should be done to provide women with access to maternal healthcare services and to support joint programmes with UNICEF and UNDP that address the issue of prenatal care.

⁶⁹ Overseas Development Institute. Deliver 2030 [Blog. January 2012 to January 2018]. Available at: <https://www.webarchive.org.uk/wayback/archive/20180120120115/http://deliver2030.org> [Accessed 25 April 2018].

⁷⁰ These guidelines provide guidance for the field and focus on mental health and psychosocial support and gender-based violence. Inter-Agency Standing Committee (IASC). <https://interagencystandingcommittee.org/> [Accessed 25 April 2018].

⁷¹ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-11-situations-of-risk-and-humanitarian-emergencies.html>

■ The commitment to the Grand Bargain scheme⁷² should be supported and fulfilled by:

- building alliances with local disability service providers to support the integration of refugees, host communities and IDPs into local disability services;
- encouraging local displaced persons' organisations (DPOs) to integrate disabled refugees and IDPs into their activities; and
- ensuring that services provided to displaced persons with disabilities are also made available to persons with disabilities in the local community.

■ Commitments should be made to ensure that implementing organisations provide adequate, long-term, and coordinated support for children and people with disabilities in the form of earmarked funding. This can be achieved by enforcing rules that ensure implementing organisations develop humanitarian initiatives that include children and people with disabilities among their beneficiaries.

■ Further research and analysis of the needs of displaced persons with disabilities is needed. Further research is needed on the conditions of children with disabilities among IDPs, host communities, and refugees in rural and in urban areas.

⁷² UK Government. 2016. UK leads new approach to prevent and respond to crises at the first-ever World Humanitarian Summit, [News story] May 24, 2016. Available at: <https://www.gov.uk/government/news/uk-leads-new-approach-to-prevent-and-respond-to-crises-at-the-first-ever-world-humanitarian-summit> [Accessed 25 April 2018].



Recommendations

Key Recommendations for all Humanitarian Actors

■ A better understanding of the situation for children with disabilities in fragile and conflicted settings is needed. More focused research should investigate:

- Not only the causes and prevalence of disability but also the support mechanisms needed by people with disabilities.
- The number of children and persons with disabilities and the anticipated increase in this number as the conflict in Syria continues.
- The relationship between consanguinity and disability prevalence in Syria, with research led by UNICEF, WHO, and the World Bank.

■ A ‘twin-track’ approach is needed to improve provisions and services for children with disabilities during periods of conflict:

- Include children with disabilities within general services, such as health, education, water sanitation, and protection, in line with SDG 3, 4, 6, 10, and 16.
- Implement disability-specific efforts for hard-to-reach populations and sub-populations of children with disabilities, such as specialised health care services, medical rehabilitation, and assistive devices.

■ Inclusive and sustainable education for children with disabilities should be advanced, including developing the capacity of all stakeholders within education systems (including provision of technical support) to implement and scale up inclusive education policies for children

with disabilities⁷². Further consultations should be conducted with partners and organisations, such as Syria Relief, to determine the scope for the inclusion of children with disabilities in educational programmes.

■ Existing registration, referral, and case management processes for persons with disabilities need to be strengthened, so that organisations, such as Syria Relief, can support and integrate children with disabilities in its projects. Disability awareness should be integrated into training for registration and protection staff, outreach workers, and case managers.

■ The specific needs of displaced persons with disabilities should be addressed across all clusters (e.g., protection, early recovery, camp management) of the UN Refugee Agency’s cluster approach to non-refugee humanitarian response^{73,74}.

- The needs of persons with disabilities should be addressed at the start of the emergency, during site selection, planning, and design of camp infrastructure and services.
- People with disabilities should be included in camp management structures, community decision-making processes, and at all stages of the programme cycle.
- A centralised database to gather disaggregated data on the number, age, gender, and profile of displaced persons with disabilities is needed to enhance their protection and assistance.

⁷² Forthcoming report by Syria Relief on children with disabilities and their access to services in Syria.

⁷³ UN Refugee Agency (UNHCR) Emergency Handbook. Cluster approach (IASC). Available at: <https://emergency.unhcr.org/entry/61190/cluster-approach-iasc>. [Accessed 25 April 2018].

⁷⁴ Humanity and Inclusion. 2018. Physical rehabilitation needs and services for persons with injuries and disabilities. Issue Brief: Syria [PDF]. Available at: https://hi.org/sn_uploads/content/HI_IssueBrief_Syria_-_REHABILITATION_april2018.pdf. [Accessed 11 May 2018].

Our hope is that the research presented in this report will provide guidance for future research projects in this field and push for more rigorous research on the impact of conflict on civilians. We hope that this research project will support and improve the lives of children with disabilities in Syria and children in other fragile and conflict-affected settings.



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Syria Relief is registered with the
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Wales, and operates within its rules
and regulations, to ensure complete
transparency and accountability



Children living with disabilities inside Syria

ANNEX I

Field Research

About the Authors

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A REPORT BY SYRIA RELIEF



Introduction

Fifteen per cent of the global population has a disability, ranging from moderate to severe. According to the Global Burden of Disease, 95 million children (0–14 years old) are disabled (5% of the global population), of which 13 million have severe disabilities¹. According to the World Health Organisation (WHO), armed conflict generates injuries and trauma that can create disabilities and exacerbate the suffering of those with existing disabilities². 1 in 3 victims of explosive weapons are children, creating an increased likelihood that they will become disabled from their injuries³. By the end of 2016, victims of the conflict in Syria experienced close to 30,000 injuries per-month⁴; 1.5 million were injured with life changing and permanent disabilities⁵, and 86,000 underwent amputations⁶. In addition, 57% of public hospitals are only partially functioning or are completely out of service, and the number of available health care professionals has dropped by approximately 55% compared to 2011. The following is a description of the methodological approaches, research design, and implementation processes employed to conduct the survey study presented in the report, *“Children living with disabilities inside Syria”*. The annex aims to provide information about the processes used to conduct the study and guide organisations in their approach to researching children with disabilities in fragile and conflict-affected states (FCAS).

The study survey is based on the Washington Group’s (WG) Children with Disabilities Survey (long version) for children between the ages of 5 and 17 years⁷.

The WG survey was designed to help measure child functioning and identify aspects of child development. The Child Functioning Module used in this study was developed in partnership with UNICEF and comprises a set of survey questions for identifying children with disabilities. Working in conjunction with WG, the original survey was adapted to capture the types of disabilities that children in Syria experience and their needs and access to services.

The Washington Group defines disability as difficulty undertaking basic activities. In this study, the term ‘disability’ was replaced with ‘reduced functionality’. Use of the term ‘reduced functionality’ was meant to prevent harm to survey respondents, who may have felt stigmatised by the term ‘disability’. For the purposes of this study, ‘reduced functionality’ was defined as physical or mental impairment that has a substantial and long-term adverse effect on a child’s ability to carry out normal day-to-day activities. The study explores the reduced functionality of children in Syria, using the following parameters, based on Washington Group’s categories of functionality⁸.

Physical and mental impairments

Physical impairments include impairments affecting the senses, such as sight and hearing; and impairments affecting mobility, such as heart disease, polio, and epilepsy. Mental impairments include impairments, such as learning disabilities and mental health issues.

¹ The Global Burden of Disease (GBD) provides a tool to quantify health loss from hundreds of diseases, injuries, and risk factors, so that health systems can be improved and disparities can be eliminated. Available at: <http://www.healthdata.org/gbd>. [Accessed 25 April 2018].

² World Health Organisation (WHO), 2011. World report on disability [PDF]. Available at: http://www.who.int/disabilities/world_report/2011/report.pdf. [Accessed 25 April 2018].

³ WHO and Humanity & Inclusion (HI). Project Update: WHO and HI draw attention to the needs of people inside Syria living with injuries and disabilities. Available at: http://www.hi-us.org/news_a_the_who_and_hi_draw_attention_to_the_needs_of_people_inside_syria_living_with_injuries_and_disabilities. [Accessed 25 April 2018].

⁴ WHO and HI. Project Update.

⁵ WHO, 2016. Syrian Arab Republic: Annual Report 2016 [PDF]. Available at: http://www.who.int/hac/crises/syr/sitreps/syria_annual-report-2016.pdf. [Accessed 25 April 2018].

⁶ WHO and HI. Project Update.

⁷ Washington Group on Disability Statistics, 2016. MICS questionnaire form for vaccination records at health facilities, Child functioning (Ages 5–7) [PDF]. Available at: http://www.washingtongroup-disability.com/wp-content/uploads/2016/01/Child_Functioning_for_Children_Age_5_to-17_-Oct-2016_FINAL.pdf. [Accessed 25 April 2018].

⁸ Washington Group on Disability Statistics, Methodology. <http://www.washingtongroup-disability.com/methodology-and-research/>. [Accessed 25 May 2018]

Substantial adverse effects

The following are examples of substantial adverse effects:

- Inability to see moving traffic clearly enough to cross a road safely
- Inability to walk unassisted
- Inability to turn taps or knobs
- Inability to remember and relay a simple message correctly

Long-term adverse effects

Long-term effects include those that are likely to recur at least once beyond the 12-month period following the first occurrence and include effects that:

- have lasted at least 12 months
- are likely to last at least 12 months
- are likely to last for the rest of the life of the person affected

Day-to-day activities

Day-to-day activities are normal activities carried out by most people on a regular basis and involve one of the following broad categories:

- Mobility (i.e., moving from place to place)
- Manual dexterity (e.g., use of the hands, wrists, or fingers)
- Physical coordination
- Continence
- Lifting, carrying, or moving ordinary objects
- Speech, hearing, or eyesight
- Memory, concentration, learning, or understanding
- Recognising physical danger

In addition, the study examines the children's social participation, educational attainments, transportability, and daily challenges and the availability and quality of services for children with reduced functionality.

The main objectives of this research are to:

- inform practitioners, NGOs, policy makers, and governments regarding the lives of children with reduced functionality and their families (from the host community, internally displaced, or refugees) in fragile and conflict affected states (FCAS).
- increase practitioners', policy makers', and governments' understanding of the barriers to access basic and specialised services for children with reduced functionality, including inclusive education.
- assist organisations, policy makers, and governments in the review of their policies and programmes to provide more equitable opportunities and tailored responses for children with reduced functionality in conflict settings, such as in Syria.
- provide policy recommendations for governments, NGOs, and donors to support the agendas of Sustainable Development Goals 3, 4, 10, and 16 for children with reduced functionality⁹.

Research questions:

- What types of disabilities do children identified with reduced functionality inside Syria (especially amongst host and IDP communities) have?
- What level of access to services do these children have (if any); and what are the differences between children with reduced functionality?
- What are the major barriers and facilitators for children with reduced functionality to access inclusive education (from the caregivers' point of view)?

The study was conducted in two phases: Phase I: Initial data collection to identify the study sample; and Phase II: The main survey, including pre-test and survey implementation.

⁹ SDG 3: 'Good Health and Well-being'; SDG 4: 'Quality Education'; SDG 10: 'Reduced Inequalities'; SDG 16: 'Peace, Justice and Strong Institutions'. United Nations, 2017. The Sustainable Development Goals Report 2017 [PDF]. Available at: <https://unstats.un.org/sdgs/files/report/2017/TheSustainableDevelopmentGoalsReport2017.pdf>. [Accessed 11 May 2018].

Phase 1: initial data collection

The first phase of the research was conducted between April and July 2017 and involved the collection of data on children with reduced functionality from established community and health networks and existing local databases across five Syrian provinces in which Syria Relief operated at the time of the survey (Aleppo, Idlib, Hama, Homs, and Damascus [Rural]). A list of 10,059 children aged 0–18 years was compiled based on the parameters of different types of disabilities. The data was collected through six of Syria Relief's offices in Syria and reviewed by Syria Relief's Monitoring, Evaluation, And Learning team (MEAL) in Turkey. Our MEAL coordinators in Turkey ensured that the data was accurate, relevant, and non-repetitive. They omitted children who did not meet the study criteria for reduced functionality and the age limit of the survey (5–17 years). The identified children were then grouped into four main categories:

- Hearing reduced functionality
- Visual reduced functionality
- Mobility reduced functionality
- General awareness reduced functionality (intellectually and psychological difficulties)

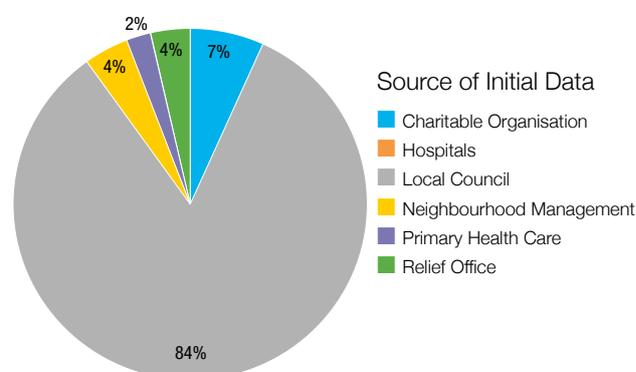
A clearly defined scope was needed to achieve standardised and replicable results. Additionally, clear parameters ensured that Syria Relief staff approached respondents who could provide adequate answers for the survey questions. Children who did not fit within the study parameters and one (or more) of the four main categories and were not between the ages of 5–17 were eliminated from the study. Of the initial list of 10,059 children, a total of 2,878 were excluded. The final list of respondents comprised 7,181 children who could be randomly sampled for data collection in the second phase.

PHASE I Data Gathering

Our teams in Syria contacted the relevant medical service teams; aid and local council groups; and local leaders in Aleppo, Idlib, Hama, Homs, and Rural Damascus where Syria Relief operates to gather information on children with reduced

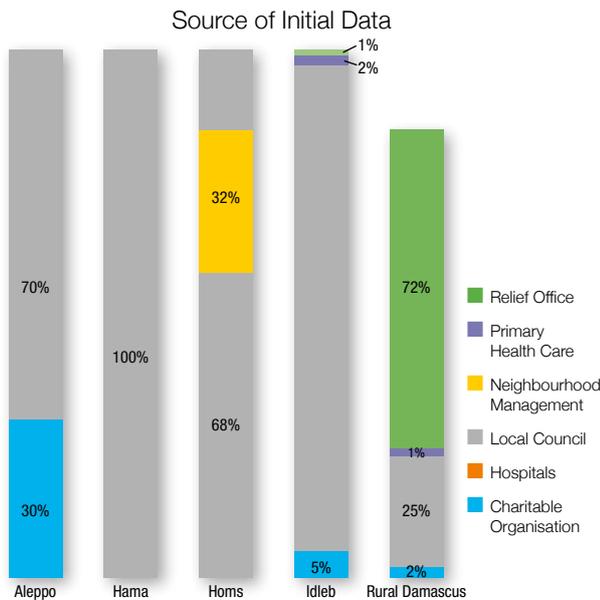
functionality in these areas¹¹. Using a network of staff and pre-existing and established connections with local councils and community leaders enabled Syria Relief staff to access information that would otherwise be unavailable. This network method of data compiling was particularly effective in the Syrian context due to its social constructs within the various communities.

Consent for compiling the initial database was obtained through agreements between the local groups and Syria Relief for the purposes of humanitarian aid and information sharing. Individual consent for each child was not needed at this stage as this information had already been compiled by community leaders and health staff. Research assistants then approached health, community, and aid workers and local leaders to collect data from the records of children with reduced functionality. The data were individually sorted and compiled in the Syria Relief offices in Syria before being sent on to Turkey for final compilation in a database of 10,059 children. The initial data on children with reduced functionality was gathered from existing databases from known civil society groups and medical facilities that are in regular contact with the listed families. Sources used to compile the database of 10,059 children with reduced functionalities included, in descending order, local councils, charitable organisations, relief offices, neighbourhood management, and primary healthcare facilities (See Annex I. Figure 1).



Annex I. Figure 1. Proportion of data from sources used to compile the database

¹¹ These provinces and areas of operation are not controlled by the government; they were often controlled by civilian groups and organisations that were willing to collaborate with us.

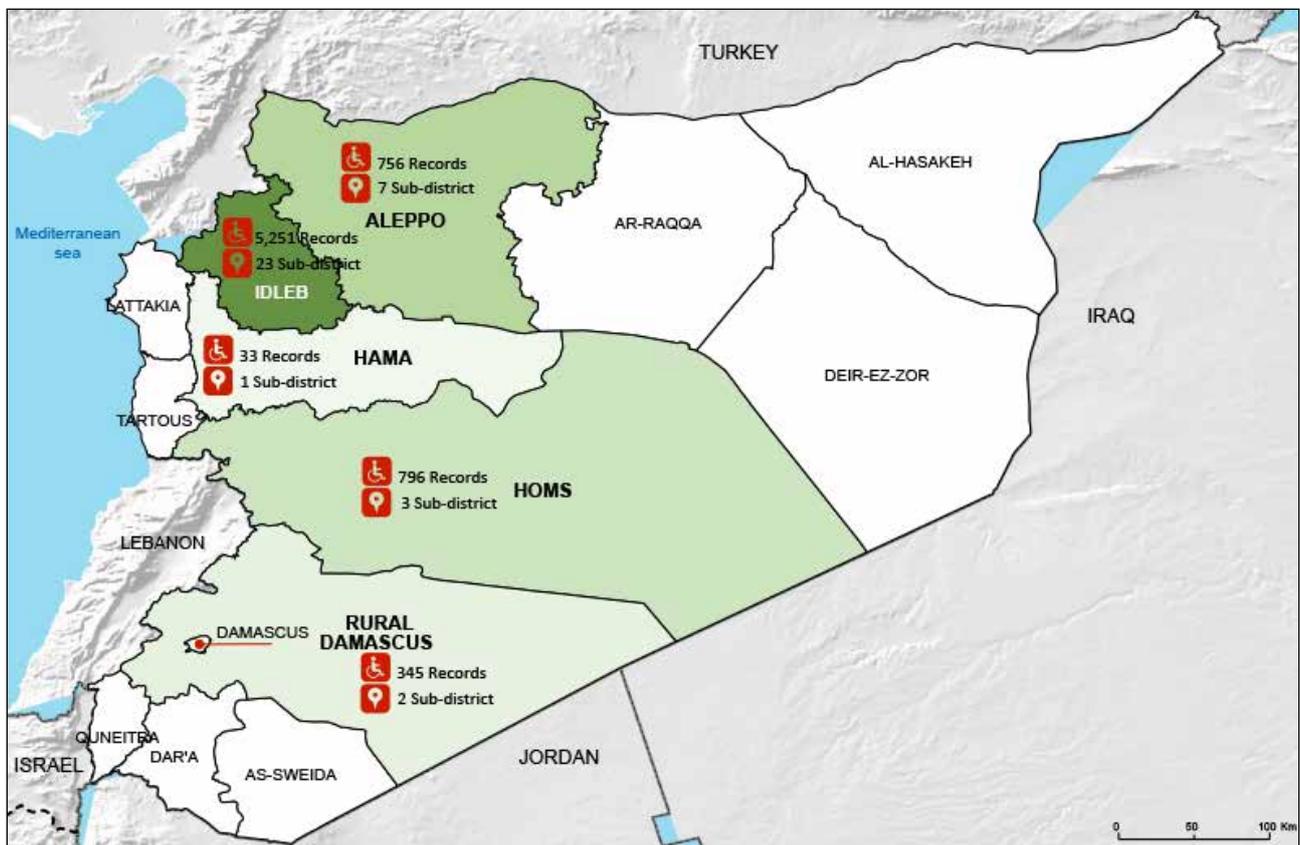


Annex I. Figure 2. Distribution of sources used for the dataset across the five districts in Syria

In Aleppo, 70% of the data was collected from local councils and 30% came from charitable organisations. In Hama, all of the data was collected from local councils; while in Homs, 68% of the data was collected from local councils and

32% from neighbourhood management. In Idleb, 92% of the data was collected from local councils, 5% from charitable organisations, 2% from primary health care providers, and 1% from the Syria Relief office. In Rural Damascus, 72% of the data was collected from the Syria Relief office, 25% from local councils, 2% from charitable organisations, and 1% from primary health care providers.

The information collected included the child's name, age, contact information and address, caregiver/ guardian information, number of family members, description of reduced functionality, and type and cause of reduced functionality. This raw descriptive data was regularly evaluated by the field staff and MEAL coordinators in Turkey to ensure the information was accurate and complete. The coordinators in Turkey followed up on missing information with the local teams and filtered the information to include supplementary information on the reduced functionality of each respondent. They verified the data by cross referencing it with the local communities and registration offices.



Annex I. Figure 3. Distribution of respondents by location (based on 7,181 records)

Phase I: Results:

Of the 10,059 children identified with reduced functionality, 60% were male and 40% were female. 33% of the children were between the ages of 14–17 years, 25% were between the ages of 8–10 years, 21% were between the ages of 5–7 years, and 21% were between the ages of 11–13 years. 74% of the respondents were from Idleb, 11% were from Aleppo, 10% were from Homs, 4% were from rural Damascus, and 1% were from Hama. In the five areas in which Syria relief operates, 87% of the children identified with some form of reduced functionality were from host communities and 13% were from IDP communities. Mobility ranked the most prevalent form of reduced functionality (54%), followed by general awareness difficulties (30%). For most children (82%), reduced functionality occurred at childbirth. 8% of the children incurred reduced functionality during the conflict, 8% in an accident, and 2% after childbirth. It is likely that children whose reduced functionality began at childbirth will require long-term care and support. This suggests the need to find better ways to support and integrate these children into society.

Findings of the initial data collection reflect the population in the areas in which Syria Relief operates and are not necessarily representative of the overall population. During data collection, Syria Relief operated in five of the 14 provinces in Syria; however, its access was limited due to the dynamics of the conflict and the number of potential respondents it could reach in each district. Within each of the districts there are sub-districts (which are further divided into communities and geographic distribution): 23 in Idleb, 12 in Aleppo, 4 in Hama, 4 in Homs, and 2 Rural in Damascus. Access to the sub-offices in each governing area influenced our ability to collect data.

Of the 10,059 children identified with reduced functionality, a total of 2,878 were omitted due to their incompatibility with the study parameters, WG's definition of reduced functionality, and the age limitation of the survey (ages 5–17 years). The remaining 7,181 constituted a list of potential respondents for the main survey. The following figure (Annex I. Figure 3) portrays the distribution of the 7,181 children in each governing area and sub-district in Aleppo, Idleb, Hama, Homs, and Rural Damascus.

Sample size

Issues of selection bias often pervade in studies. Despite their ubiquity, considerable confusion surrounds approaches to sample selection. The size of the sample is perhaps the most important parameter of sample selection as it affects the accuracy, cost, and duration of the study more than any other factor. To calculate the sample size, in addition to the use of mathematical formulas, it is necessary to consider both the available budget and the requirements for precision. The latter must be further considered in terms of requirements for national versus sub-national estimates. Moreover, the overall sample size cannot be considered independently of the number of sample areas (i.e., primary sampling units or PSUs) and the size of the ultimate clusters. In general, the more PSUs selected, the better the survey; however, the number of PSUs is affected by cost considerations. If the distances between PSUs are great, and the research staff must travel from place to place, then decreasing the number of PSUs will significantly decrease the overall costs. In contrast, if requirements call for sub-national estimates, there will be pressure to select more, rather than fewer, PSUs.

In the Syrian context, consideration for the security of the research staff and the logistical restrictions of working in a conflict setting had significant impact on sample selection in this study. As a result, we chose a large number of PSUs in the areas in which Syria Relief operates. Factors considered in determining the sample size in this study were:

- Precision, or relative sampling error, required
- Level of confidence desired
- Estimated (or known) proportion of the disabilities and population in the specified target area
- Predicted or anticipated coverage rate, or prevalence, for the specified indicator
- Adjustment for potential loss of sample households due to non-response

Sample selection

The selection process in this study reflected a proportionate number of respondents in terms of the prevalence of reduced functionality within each of the five regions in which Syria Relief operates

(Aleppo, Idlib, Hama, Homs, and Rural Damascus). This was achieved using a formula that provided a random sample selection. Using this formula, the researchers could randomly select respondents from the list of 7,181 potential respondents and sample a proportionate number of respondents from each province. This allowed the researchers to collect a fair sample of the distribution of children with reduced functionality across the different localities. The formula was used multiple times for random selection of respondents for this purpose. Each potential respondent received a unique number and rank, selected at random, using the following formula for unique number assignment from the 'Names' column. We used the following mathematical equation to calculate the sample size from each district:

$=\text{RANDBETWEEN}(1, \text{COUNTA}([\text{Names}])) + \text{ROW}() / 100^{12}$

We determined that the study required a sample of 718 children or more. The names in this list were then

given a unique 'ranking', using the following formula:

$=\text{RANK}([\text{Unique}], [\text{Unique}])$

Finally, a final list was arranged, using the outputs of the two equations:

$=\text{IF}(\text{COLUMNS}(\$G\$1:G1) > \$E\$2, "", \text{COLUMNS}(\$G\$1:G1))$

This method was used multiple times and can continue to generate randomly selected samples based on available names.

The ideal sample size was estimated as 10% of the final list of 7181 children, with an additional marginal error of 1% to account for respondents who may be missing or left their homes at the time of the survey; thus, a total of 11% of the final list was sampled, meaning a total of 789 children. The sample reflects 11% of the potential respondents in each district and their distribution across sub-districts.

Phase 2: the main survey

The survey questionnaire was originally designed by the Washington Group in collaboration with UNICEF and is available for use online¹³. The survey was adapted by Syria Relief researchers in the UK, in collaboration with MEAL coordinators in Turkey, to fit the cultural and conflict-related context of Syria and to include questions about the need for and access to services. Once modified, the Washington Group reviewed the changes and made several adjustments until a final version was agreed upon. The survey underwent 28 revisions before reaching the final version in English. Once complete, the survey was translated into Arabic by staff in Turkey, with input from field research assistants in Syria and the UK. A Syrian translator made additional adjustments in Arabic. The survey was then further refined following pre-testing in the field. The final survey was composed of 24 closed-ended questions, with restricted response options, and was designed to capture the dynamics of children with reduced functionality in Syria. The survey aimed to: understand the difficulties that children

with reduced functionality face daily and how they adjust to life in the conflict in Syria; understand the needs of these children; and explore what can be done to improve their lives.

Phase II: Field Staff

Twenty-nine field research assistants were selected in Syria to conduct data collection for the study. The research assistants were predominately female to address cultural and conflict-specific factors. Women in Syria have become, in many cases, the sole caregivers of their families. Male members of the household, who were often not present in the home before, have been more absent in the context of the war. Male research assistants, in many cases, would not be permitted into the homes of female respondents to conduct interviews or ask questions of a sensitive nature. Employing female field research assistants facilitated data collection and ensured respondents were comfortable to respond openly. A male research assistant was also part of the field research team in each of the study areas,

¹² Trump Excel. Group Generator Template. Available at: <https://trumpexcel.com/random-group-generator-template/>. [Accessed 25 April 2018].

¹³ Washington Group on Disability Statistics, 2016. MICS questionnaire form for vaccination records at health facilities, Child functioning (Ages 5–7) [PDF]. Available at: http://www.washingtongroup-disability.com/wp-content/uploads/2016/01/Child_Functioning_for_Children_Age_5_to_17_-Oct-2016_FINAL.pdf [Accessed 25 April 2018].

in case respondents preferred to communicate with a male interviewer or the situation posed a significant risk to the female research assistant's life.

Due to the sensitive nature of the study subject, it was important to follow strict research procedures. The following criteria were used to select field research assistants:

- Experience in healthcare, education, or medical or social sciences research.
- Experience with data collection (interviews and surveys) and/or Syria Relief's methodology and research procedures.
- Experience studying patient and/or professional populations in conflict zones.
- Ability to work independently and be flexible.
- Ability to communicate with people from different backgrounds and to be sympathetic to children with reduced functionality and their families.
- Ability to communicate well verbally, non-verbally, and in writing.

Field research staff training

The field research team participated in a three-day training workshop prior to data collection to reduce bias¹⁴ and ensure that respondents participating in the study would not be harmed. The training was conducted remotely via Skype by the lead Syria Relief researcher, a research assistant, and a MEAL coordinator in Turkey and included a session with a researcher from the Washington Group, who explained the survey and how to collect data using the survey in the field.

The training covered the following areas, among others: research design, questions, and methods; data collection procedures; data life cycle, anonymity, and security; data evaluation and limitations; research ethics and bias; researcher safety; participant recruitment and consent; and interview methods. The training also included practical and applied exercises on conducting interviews and how to work with children with reduced functionality using the Washington Group's standards. Simulated interviews were conducted to provide opportunity for practice and evaluate the field research assistants' behaviour and ethical conduct. These exercises increased the research

assistants' awareness to potentially sensitive issues on the ground and potential harms based on the local culture. The training provided by the Washington Group included:

- Dealing with and awareness of reduced functionality from a social perspective
- Working with children to complete the survey questions
- Dealing with children with reduced functionality
- Understanding the concept of reduced functionality (disability)
- Understanding factors that influence attitudes towards a reduced functionality person

Field research assistants were required to sign a code of conduct form that highlighted their responsibilities and ethical obligations throughout the study. They were required to know all items in the survey questionnaire, the purpose of the research project, the code of conduct, and the consent form and to be able to provide respondents with relevant information and answer their questions.

Phase II: Pre-test

The survey questions were closed-ended with restricted response options, which made quantifying results possible yet limited the scope/detail of data collected, since each child with reduced functionality has a unique experience. To address this limitation, we pre-tested the survey, further refined the questions, and adjusted data collection procedures in the field. The pre-test was conducted by the field research assistants with 60 randomly sampled children (30 children with reduced functionality from our list and 30 children without) across the study locations in Syria. The pre-test aimed to:

- test the usability of the survey questions in Syria
- test whether the survey accurately reflects the circumstances of children with reduced functionality in Syria
- examine the distribution of individuals with reduced functionality within the various districts
- determine whether the survey confirms the initial data collected
- test the field research assistants approach to and perceptions of the survey

¹⁴ We acknowledge that bias cannot be completely eliminated or avoided, particularly in the context of war.

The pre-test allowed the researchers to assess whether the survey questionnaire was completed correctly and in full, the questions were understood by the respondents, and the questions were appropriate. The pre-test also helped assess whether respondents were able and willing to provide the information that the study aimed to gather.

30 respondents with reduced functionality were randomly selected from the 7,181 children in the database, and 30 respondents without were randomly selected from the population of civilians in each of the governorates included in the study. Over a 48-hour period in the field, the field research assistants conducted two interviews each to complete the survey with one child with reduced functionality and one child without. This ensured that the field research assistants could successfully conduct the interviews for the main survey and allowed the researchers to assess the data collection process. During the pre-test sessions, respondents were encouraged to complete the questionnaire and share their views on the survey itself. The field research assistants in Syria were also encouraged to provide the researchers with feedback about any issues, difficulties, positive aspects, and general events that took place in the field. Once the surveys were complete, the research assistants scanned and uploaded the data to Google drive daily. This allowed the researchers in the UK and MEAL coordinators in Turkey to monitor each field research assistant's work and provide recommendations if there were any errors detected.

Pre-test results

Overall, local councils and communities responded positively to the aims of the research project and were highly engaged and cooperative. They were enthusiastic about the research project and the initiative to understand the needs and experiences of children with reduced functionalities. Based on the feedback provided by the pre-test respondents and the field research assistants, adjustments were made to the survey questions in consultation with the UK researcher. Modifications included:

- The single-selection response was changed to a multiple-choice option, when it came to the questions on the types of reduced functionality. This was done to reflect the multiple difficulties that the children have and the multiple causes for their difficulties.

- The category 'genetic causes' was added to the possible responses to the question on the causes of reduced functionalities. According to field research assistants, a genetic cause of reduced functionality manifested over time. Thus, 'genetic' was only selected if medical confirmation had been previously provided to the respondent/guardian by a medical doctor.
- In the section on access to and need for services, researchers clarified the services listed and added examples relevant to the Syrian context because respondents did not understand some of the terminology used.

The consent form was also altered to allow for both the child and their guardian to provide consent. This change was made because, in some cases, consent was given for photographs by the guardian in writing. However, when it was time to take the photographs, the child was unwilling. This required their consent.

In addition, a few of the randomly selected children had already passed the age of 17 years. Thus, their names were omitted and randomly replaced from the database of 7,181 children. As well, a few of the selected children were siblings from the same household. To address such situations, amendments were made to the respondent coding system within each office, and a standardised format was agreed on for the main data collection¹⁵. The original coding formula was as follows:

CHA-IDL-SAROF-XXXX

(project code-district code-office code-household code)

This formula was then altered to add a unique child code following the household code:

CHA-IDL-SAROF-XXXX-XX

Pre-test survey results

61% of the children sampled were male and 39% were female. 84% of the children were from host communities and 15% were from IDP communities. 64% of the children with reduced functionalities were between the age of 5–12 years and 36% were between the ages of 12–17 years. Many children with reduced functionality (84%) experienced these difficulties from infancy (less than one years old); 7%

¹⁵ Each code consisted of a combination of family, locality, and child codes and was structured for one child per-household. For multiple children to be interviewed in the same of the household required amendments to the system.

indicated that the difficulties started between the ages of 1–6 years; 5% between the age of 6–11 years; and 4% between the ages of 11–16 years. These results indicate that reduced functionality often occurred during the child's early years of development and that their reduced functionality may have long-term or lifelong effect. 83% of respondents indicated that the child's reduced functionality occurred at birth, 10% stated their reduced functionality was the result of an accident or an injury, 6% indicated that it was because of the war, and 1% that it was due to a genetic factor. More than half of the respondents (55%) with reduced functionality indicated that they had some form of mobility difficulties, 46% had some form of learning difficulty, 15% had hearing difficulties, 15% had vision difficulties, and 9% had psychological difficulties. As previously noted, some children had multiple difficulties.

Phase II: Main Survey Implementation

The main survey was implemented between August and October 2017 across the provinces in which Syria Relief operates: Azaz (Aleppo); Al-Ghouta (Rural Damascus); Talbeeseh (Homs); Idleb City (Idleb); Sarmada (Idleb); and Ein El-Beida (Lattakia but gathered data for Idleb). Governorates sampled included Homs, Idleb, Rural Damascus, and Aleppo¹⁶. It was extremely risky and difficult for staff to move from one location to another. This presented safety concerns for staff on the ground and the data collection process. Due to budgetary constraints and limited accessibility, the report captures a total sample of 789 children with reduced functionality (11% of the 7181 children in our database), which were selected to preserve the distribution of the four categories of reduced functionality across each sub-region (mobility, general awareness, vision, and hearing). The 11% ratio was maintained on two levels: the distribution of reduced functionalities across each sub-district and prevalence of the reduced functionality category within each sub-district. Figures were rounded up rather than down.

Respondents

789 respondents participated in the main survey. Survey respondents were recruited from four governorates (Aleppo, Idleb, Rural Damascus, and Homs); 36 sub-governances; and 270

communities. The largest number of respondents was from Idleb (N=526); followed by Sarmada (N=96); Homs (N=88); Rural Damascus (N= 40); Azaz (N=25); and Lattakia (N=14). A total of 160 potential respondents chose to opt-out. The field research assistants discovered that in some of the locations, a number of interviews were being conducted by other organisations at same the time, which may have influenced respondents' decision to opt out. To compensate for those who refused to participate, the researchers randomly selected additional respondents in the same area from the database. Some of those who had initially opted-out later returned to complete the survey. The overall random selection of respondents was maintained, with minimal changes in the original sample selection. Annex 1. Table 1 presents the distribution of the study sample across the four governorates.

Syria Relief Office	Study Sample (N)	Refused to participate (N)	Returned (N)
Azaz (Aleppo)	25	4	3
Damascus (Rural)	40	0	0
Homs	88	7	16
Idleb	526	112	63
Lattakia (Idleb)	14	6	2
Sarmada (Idleb)	96	31	8
Total	789	160	92

Informed Consent

The field research assistants, trained in the process of obtaining informed consent and its importance, provided respondents with printed consent forms¹⁷ prior to conducting the main survey. The consent form highlights the aims and objectives of the research project and seeks the respondent's and their legal guardian's consent for participation in the study. A separate section includes consent to photograph the respondent and use their portrait in the final report. Respondents were given time to read the aims of the research project, ask questions, and make an informed decision about participating in the study. The field research assistants explained the survey process and that the survey results would be stored on a secure cloud server. Further explanation was required for

¹⁶ Initial data from Phase I included the district of Hama, but the final data collected was from those listed due to changing access issues. Interviews continued as planned with our office still in operation, but with those interviews taking place along the Idleb/Hama meeting point.

¹⁷ Please see Annex II for a copy of the consent form in English. Respondents received a translated version of the consent form in Arabic.

some respondents, in remote parts of Syria, on what a cloud server is. The field research assistants ensured that respondents understood that they would not receive any form of aid or remuneration for their participation and they could withdraw from the study at any point. The field research assistants read the entire form when respondents were unable to; this ensured that the respondents understood the consent forms' contents before they agreed to participate in the research. Once respondents signed the consent form, they were given a unique field number that was recorded on the survey to ensure the anonymity of their responses. All signed consent forms were scanned and electronically sent to the MEAL coordinators in Turkey and the researcher in the UK.

Data collection

Following informed consent, the survey was conducted on a one-to-one basis, using a self-administered method with the children and their guardians. Surveys were completed using the traditional paper and pen format. The field research assistants encouraged the children to participate; however, their guardians were asked questions if they were beyond the child's capacity to answer. For respondents who were illiterate or unable to read or write, the field research assistants conducted the survey verbally and provided support and guidance to the respondents. Survey interview sessions were a maximum of 90 minutes in length, although the time varied depending on the child, their caregiver, and their level of education. The length of the sessions allowed for respondents to take short breaks if needed, especially given the sensitivity of the subject matter.

The completed surveys were immediately returned to the base offices of Syria Relief, where the handwritten responses were compiled, scanned, and uploaded to a secure server at the next available opportunity. Kobo Toolbox¹⁸ software was used to

gather and securely store the data. Once uploaded, the paper documents were destroyed. The field research assistants then sent the data via Google Drive to the MEAL coordinators in Turkey and the researcher in the UK, who analysed and compiled the data in a database¹⁹.

Security concerns and limitations in the field

This study involved children with reduced functionality in non-government areas during the conflict in Syria. As such, the safety of the respondents, their guardians, and the research team was a top priority. To avoid disrupting the local community and placing increased risks on the children, their guardians, and the research assistants, the research team ensured that respondents from the same areas were interviewed on the same day. Each neighbourhood was visited once, and all respondents in the area were interviewed in a single visit by a research assistant local to the community.

Due to both security concerns and limitations in the field in Syria, data was gathered on paper rather than electronically. In certain besieged or opposition-held areas in which Syria Relief is present, the population is often wary of organisations and/or researchers using electronic devices. They are often suspicious that those using electronic devices are trying to pinpoint the geographic positions of warring actors or record sensitive information. The use of electronic survey devices could have jeopardised the safety of our staff and the civilians surveyed. Once the surveys were completed, the written responses were compiled and uploaded to our secure server, and the original paper documentation was destroyed. Throughout the final report any identifying information was replaced with codes to protect the anonymity of the children, their families, and the staff who conducted the survey in the field.

¹⁸ Kobo Toolbox is used by the United Nations (UN), The UN Office for the Coordination of Humanitarian Affairs (OCHA), and other humanitarian groups for data collection purposes.

¹⁹ The full dataset of children with reduced functionality is available on the Syria Relief website. [add the URL]

Children living with disabilities inside Syria

ANNEX II

Study Questionnaire on Child Functioning, Needs and Services

A REPORT BY SYRIA RELIEF



Study Questionnaire on Child Functioning, Needs, and Services

Identification of household		
Name of (sub)district		<input type="checkbox"/>
Name of community		
Communication address		
Telephone number		
Household number	<input type="checkbox"/>	<input type="checkbox"/>
Name of household head		
Respondent name		
Respondent's relationship to household head		
Respondent age (years)	<input type="checkbox"/>	<input type="checkbox"/>
Respondent gender: 1= male 2= female		<input type="checkbox"/>
Enumerator name		
Date of interview		
Was this household screened as having a child with disability: 1 = yes 2 = no		<input type="checkbox"/>

¹Types of difficulty	²Reasons for difficulty
Vision	Accident/injury
Hearing	War-related
Mobility	Since birth
Intellectual	
Psychological	

Child functioning (age 5-17) CF		
CF1. I would like to ask you some questions about difficulties your child may have. Does (name) wear glasses or contact lenses?	Yes No	2CF3
CF2. When wearing his/her glasses or contact lenses, does (name) have difficulty seeing? Would you say (name) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	No difficulty Some difficulty A lot of difficulty Cannot do at all	1CF4 2CF4 3CF4 4CF4
CF3. Does (name) have difficulty seeing? Would you say (name) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	No difficulty Some difficulty A lot of difficulty Cannot do at all	

<p>CF4. Does (name) use a hearing aid?</p>	<p>Yes No</p>	<p>2CF6</p>
<p>CF5. When using his/her hearing aid, does (name) have difficulty hearing sounds like peoples' voices or music?</p> <p>Would you say (name) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</p>	<p>No difficulty Some difficulty A lot of difficulty Cannot do at all</p>	<p>1CF7 2CF7 3CF7 4CF7</p>
<p>CF6. Does (name) have difficulty hearing sounds like peoples' voices or music?</p> <p>Would you say (name) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</p>	<p>No difficulty Some difficulty A lot of difficulty Cannot do at all</p>	
<p>CF7. Does (name) use any equipment or receive assistance for walking?</p>	<p>Yes No</p>	<p>2CF12</p>
<p>CF8. Without his/her equipment or assistance, does (name) have difficulty walking 100 meters on level ground? That would be about the length of 1 football field. [Or insert country specific example].</p> <p>Would you say (name) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</p>	<p>Some difficulty A lot of difficulty Cannot do at all</p>	<p>3CF10 4CF10</p>
<p>CF9. Without his/her equipment or assistance, does (name) have difficulty walking 500 meters on level ground? That would be about the length of 5 football fields. [Or insert country specific example].</p> <p>Would you say (name) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</p>	<p>Some difficulty A lot of difficulty Cannot do at all</p>	
<p>CF10. With his/her equipment or assistance, does (name) have difficulty walking 100 meters on level ground? That would be about the length of 1 football field. [Or insert country specific example].</p> <p>Would you say (name) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</p>	<p>No difficulty Some difficulty A lot of difficulty Cannot do at all</p>	<p>3CF13 4CF14</p>
<p>CF11. Without his/her equipment or assistance, does (name) have difficulty walking 500 meters on level ground? That would be about the length of 5 football fields. [Or insert country specific example].</p> <p>Would you say (name) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</p>	<p>No difficulty Some difficulty A lot of difficulty Cannot do at all</p>	<p>1CF14</p>

<p>CF12. Compared with children of the same age, does (name) have difficulty walking 100 meters on level ground? That would be about the length of 1 football field. [Or insert country specific example].</p> <p>Would you say (name) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</p>	<p>No difficulty Some difficulty A lot of difficulty Cannot do at all</p>	<p>3CF14 4CF14</p>
<p>CF13. Compared with children of the same age, does (name) have difficulty walking 500 meters on level ground? That would be about the length of 5 football fields. [Or insert country specific example].</p> <p>Would you say (name) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</p>	<p>No difficulty Some difficulty A lot of difficulty Cannot do at all</p>	
<p>CF14. Does (name) have difficulty with self-care such as feeding or dressing him/herself?</p> <p>Would you say (name) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</p>	<p>No difficulty Some difficulty A lot of difficulty Cannot do at all</p>	
<p>CF15. When (name) speaks, does he/she have difficulty being understood by people inside of this household?</p> <p>Would you say (name) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</p>	<p>No difficulty Some difficulty A lot of difficulty Cannot do at all</p>	
<p>CF16. When (name) speaks, does he/she have difficulty being understood by people outside of this household?</p> <p>Would you say (name) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</p>	<p>No difficulty Some difficulty A lot of difficulty Cannot do at all</p>	
<p>CF17. Compared with children of the same age, does (name) have difficulty learning things?</p> <p>Would you say (name) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</p>	<p>No difficulty Some difficulty A lot of difficulty Cannot do at all</p>	<p>4CF14</p>
<p>CF18. Compared with children of the same age, does (name) have difficulty remembering things?</p> <p>Would you say (name) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</p>	<p>No difficulty Some difficulty A lot of difficulty Cannot do at all</p>	

<p>CF19. Does (name) have difficulty concentrating on an activity that he/she enjoys doing?</p> <p>Would you say (name) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</p>	<p>No difficulty Some difficulty A lot of difficulty Cannot do at all</p>	
<p>CF20. Does (name) have difficulty accepting changes in his/her routine?</p> <p>Would you say (name) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</p>	<p>No difficulty Some difficulty A lot of difficulty Cannot do at all</p>	
<p>CF21. Compared with children of the same age, does (name) have difficulty controlling his/her behaviour?</p> <p>Would you say (name) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</p>	<p>No difficulty Some difficulty A lot of difficulty Cannot do at all</p>	
<p>CF22. Does (name) have difficulty making friends?</p> <p>Would you say (name) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</p>	<p>No difficulty Some difficulty A lot of difficulty Cannot do at all</p>	
<p>CF23. How often does (name) seem very anxious, nervous or worried?</p> <p>Would you say: daily, weekly, monthly, a few times a year, or never?</p>	<p>Daily Weekly Monthly A few times a year Never</p>	
<p>CF24. How often does (name) seem very sad or depressed?</p> <p>Would you say: daily, weekly, monthly, a few times a year, or never?</p>	<p>Daily Weekly Monthly A few times a year Never</p>	

Services for children with difficulties			
(9i) For each service listed below, indicate whether you are aware of the service, if your child needs the service, if your child has received the service, or if your child is still receiving it.			
	Service offered in your area? 1=Yes 2=No 3=Don't know	Ever received this service? 1=Yes in the past 2=Yes still receiving 3=No	Need the service? 1=Yes 2=No
	(1)	(2)	(3)
Medical rehabilitation (e.g., physiotherapy, occupational therapy, speech and hearing therapy)			
Assistive devices service (e.g., Sign language interpreter, wheelchair, hearing/visual aids, Braille)			
Educational services (e.g., remedial therapist, special school, early childhood stimulation, special tutoring)			
Vocational training (e.g., employment skills training)			
Counselling for child with disability (e.g. psychologist, psychiatrist, social worker, school counsellor)			
Counselling for parent/family (e.g., psychologist visiting the family, groups sessions)			
Welfare services (e.g., social worker, disability grant)			
Health services (e.g. at a primary health care clinic, hospital, home health care services)			
(9ii) If you received the service in the past (1 in Column 2 above) but you are no longer receiving the service, why did you stop?			
	Reason stopped Code 1-8	Coding	
a. Medical rehabilitation		1. It was too expensive 2. It was too far or you had no transport 3. It was not helping you anymore 4. I reached the level of functioning I set as goal 5. The services were no longer available 6. I was not satisfied with services 7. There was a communication/language barrier 8. The staff was not properly trained to deal with children with disabilities 9. The child was uncomfortable being among other children	
b. Assistive devices service			
c. Educational services			
d. Vocational training			
e. Counselling for child with disability			
f. Counselling for parent/family			
g. Welfare services			
h. Health services			

(9iii) If you are still receiving the service now (2 in Column 2 above) what do you think should be improved?		
	Reason stopped Code 1-8	Coding
a. Medical rehabilitation		1. Staff dealing with children with disability need more training 2. Lack of staff specialised in dealing with children with disabilities 3. Equipment for disable people in the premises are not satisfying (wheel chairs, hearing aid, walking aid, visual aid, recreational activities) 4. The facility is not accessible for disables (ramps, toilets, elevators, etc...) 5. Special transports should be organised for people with disabilities and their families to reach the premises 6. Integration with other children should be improved 7. Flexibility in terms of timing should improve 8. Distributions of assistive devices should happen at home and not at collection points 9. The child feels uncomfortable in dealing with other children
b. Assistive devices service		
c. Educational services		
d. Vocational training		
e. Counselling for child with disability		
f. Counselling for parent/family		
g. Welfare services		
h. Health services		
(9iv) For each service listed below, indicate whether your child needs the service and to what degree		
Medical rehabilitation / Health Service		Not relevant Relevant but not needed Needed but not vital Vital
Physiotherapy		
Occupational therapy		
Speech therapy		
Hearing therapy		
Mental stimulation		
Transport to the rehab facility / clinic		
Facility accessible for disable children		
Home service		
Assistive devices service		Not relevant Relevant but not needed Needed but not vital Vital
Sign language interpreter		
Vital		
Wheelchair		
Prosthetic Limbs		
Hearing Aid		
Visual Aid		
Special mattresses		
Shower seat / bath seat		
Braille books		
Education / Vocational training		Not relevant Relevant but not needed Needed but not vital Vital
Transport to the school / centre		
Rump to access the school / centre		
Accessible toilets		
Class for children with special needs		
One-to-One Teachers for children with special needs		
Accessible Gym facilities		
Counselling service		
Home teaching		
Counselling for the child or for the family		Not relevant Relevant but not needed Needed but not vital Vital
One to one psychological support for the child		
Group counselling for the child		
Psycho-social support centre		
One to one psychological support for the family		
Group sessions with other families		
Welfare services		Not relevant Relevant but not needed Needed but not vital Vital
Disability grant		
Social worker to support the family in feeding-washing-moving-dressing the disabled child		
Social workers to look after the disable child while the parents are at work		

Consent Form for Participation in Research on Children with Reduced Functionality

Project title

The research project aim is to understand the needs of participants but also to understand how children with reduced functionality can be better supported in conflict setting. The research project aims to produce a report to inform a better humanitarian response. The research focuses solely on children between the ages of 5–17 and will cover areas, like hearing, mobility, reduced functionality, and seeing.

What will happen

In this study, you will be asked to take part in a questionnaire, which has questions on children with reduced functionality. The questions will ask you to remember the child in question and what the everyday life is for that child. Participants will also be given the opportunity to contact the team at a later date, if they have any further concerns. Especially if they subsequently become fearful for their well-being and their lives. The interview will last approximately 55 minutes. Notes will be written during the interview, and photos will be taken. From this point onwards, you will be given a unique number that identifies the responses you give as part of the research.

Invitation

By participating in the research project by Syria Relief, a humanitarian charity working with local populations, I _____ understand that the research project is designed to collect information regarding children with reduced functionality in Syria. I understand that my participation in this project is on a voluntary basis, and no monetary gifts or exchanges will be given. I also understand that I will not be paid for my participation. I am also aware that the information I provide will be kept confidential on the organisation's database in a secure location. The use of data will be subject to standard data use policies, which protect the anonymity of individuals and institutions. I also understand that the organisation has the right to use the data I provide in this survey however it sees fit.

I have read and understand the information provided above. I have had all my questions answered to my satisfaction, and I voluntarily agree to participate in this study. I have been given a copy of this consent form.

Participants' rights

- You may decide to stop being a part of the research study at any time without explanation. You have the right to ask at any point that any data you have supplied to be withdrawn and destroyed.
- You will not be paid for your contribution.
- You have the right to omit or refuse to answer or respond to any question that is asked of you.
- You have the right to have your questions about the procedures answered (unless answering these questions would interfere with the study's outcome). If you have any questions as a result of reading this information sheet, you should ask the researcher before the study begins.

Benefits and risks

- There are no known benefits or risks for you in this study.
- Participation in this study involves completing some standardised questionnaires that are routinely used as preliminary screens in qualitative interviews.
- Results of the questionnaire will be coded later on.
- Participants will be asked to complete a questionnaire followed by an in-depth interview.
- Though it is not possible to provide feedback for all individual results, the team may be able to refer an individual if there are deep-rooted issues that the individual may want to discuss with an appropriate professional.

Confidentiality/anonymity

- The data we collect will not contain any personal information about you except your name, your contact details, and associated organisation.
- For all interviews, we have developed a system of coding information so no one can determine who has shared the information with us. After you have consented to being interviewed, the coding will begin immediately, and your name will no longer be linked to the information you share.

For further information

If you want to find out about the final results of this study, please email me at: _____

Please check the appropriate boxes:

TAKING PART:

I have read and understood the project information sheet dated _____ Yes No

I have been given the opportunity to ask questions about the project. Yes No

I agree to take part in the project. Taking part in the project will include being interviewed via a survey document. Yes No

I understand that my taking part is voluntary; I can withdraw from the study at any time and I do not have to give any reasons for why I no longer want to take part. Yes No

Use of the information I provide for this project only. Yes No

I understand my personal details such as phone number and address will not be revealed to people outside the project. Yes No

I understand that my words may be quoted in publications, reports, web pages, and other research outputs. Yes No

Please choose one of the following two options:

1. I would like my real name used in the above.
2. I would not like my real name to be used in the above.

USE OF THE INFORMATION I PROVIDE BEYOND THIS PROJECT:

I agree for the data I provide to be archived at Syria Relief UK Data. Yes No

I understand that other researchers may use my words in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form. Yes No

So we can use the information you provide legally:

I agree to assign the copyright I hold in any materials related to this project to [name of researcher]. Yes No

I understand that if I don't want to be photographed or I don't want my child to be photographed, I can inform the interviewer and I can still take part in the survey. Yes No

Name of participant [printed] _____ Signature _____ Date _____

Researcher [printed] _____ Signature _____ Date _____

Children living with disabilities inside Syria

ANNEX III

Analysis of five sub-districts

A REPORT BY SYRIA RELIEF



In this annex, we examine results from sub-districts, with samples of 40 respondents or more, from the overall data analysed and presented in the report. The sub-districts include (in descending order of sample size) Ma'arrat An Nu'man (N=65); Idleb (N=61); Saraqab (N=57); Ehsem (N=56); and Kafr Nobol (N=54). We examined the survey results in these sub-districts to verify the overall findings and provide a more comprehensive understanding of children living with disabilities in Syria. In some sub-districts in the overall sample, the number of respondents surveyed was as little as four, which could skew the study findings. Therefore, we focussed on sub-districts with a threshold of 40 respondents and above. The findings of this analysis do not reflect the sum population of respondents with reduced functionalities in this study but the respondents across the sampled sub-districts.

Results of this analysis demonstrate similar patterns at the sub-district level to those found in the overall data analysis:

Ehsem. Results from the sub-district of Ehsem reflect the findings of the overall sample of 789. Mobility difficulties were the most prevalent difficulty identified among children in this sub-district, followed by intellectual difficulties, vision difficulties, and a combination of both mobility and intellectual difficulties. 11 different types of difficulties or combinations of difficulties were found in this sub-district.

Kafr Nobol. Results from the sub-district of Kafr Nobol similarly demonstrate that mobility was the most prevalent difficulty among the children. This was closely followed by intellectual difficulties, vision difficulties, and a combination of mobility and intellectual difficulties. 12 types of difficulties or combinations of difficulties were identified among respondents in this sub-district.

Idleb. Results from the sub-district of Idleb demonstrate similar trends to the overall results and the sub-districts above. Mobility ranked the most prevalent difficulty, followed (with a wide gap) by intellectual difficulties, a combination of mobility and intellectual difficulties, and vision difficulties. 8 types of difficulties or combinations of difficulties were identified in this sub-district.

Ma'arrat An Nu'man. Results from the sub district of Ma'arrat An Nu'man again demonstrate that mobility difficulties were the most prevalent among respondents. Mobility difficulties were followed (with a larger gap than in other sub districts) by intellectual difficulties, a combination of mobility and intellectual difficulties, and hearing difficulties. 15 different types of difficulties or combinations of difficulties were identified in this sub-district, the largest number amongst the sub-districts.

Saraqab. Results from the sub-district of Saraqab reveal that mobility difficulties were the most prevalent among the children. This was followed (with a large gap) by intellectual difficulties and a combination of intellectual and mobility difficulties. There were twice as many children with mobility difficulties as children with intellectual difficulties and children with a combination of intellectual and mobility difficulties. A combination of vision and mobility difficulties was the fourth most prevalent. 10 types of difficulties or combinations of difficulties were identified in this sub-district.

Results from the five sub-districts (with 40 respondents or more) reveal similar patterns to those found in the analysis of the overall data collected. In all five sub-districts, mobility difficulties were the most prevalent among respondents. This was followed by intellectual difficulties in all five sub-districts. A combination of intellectual and mobility difficulties was the third most prevalent in all sub-districts but Ehsem. In Ehsem, vision difficulties were the third most prevalent.

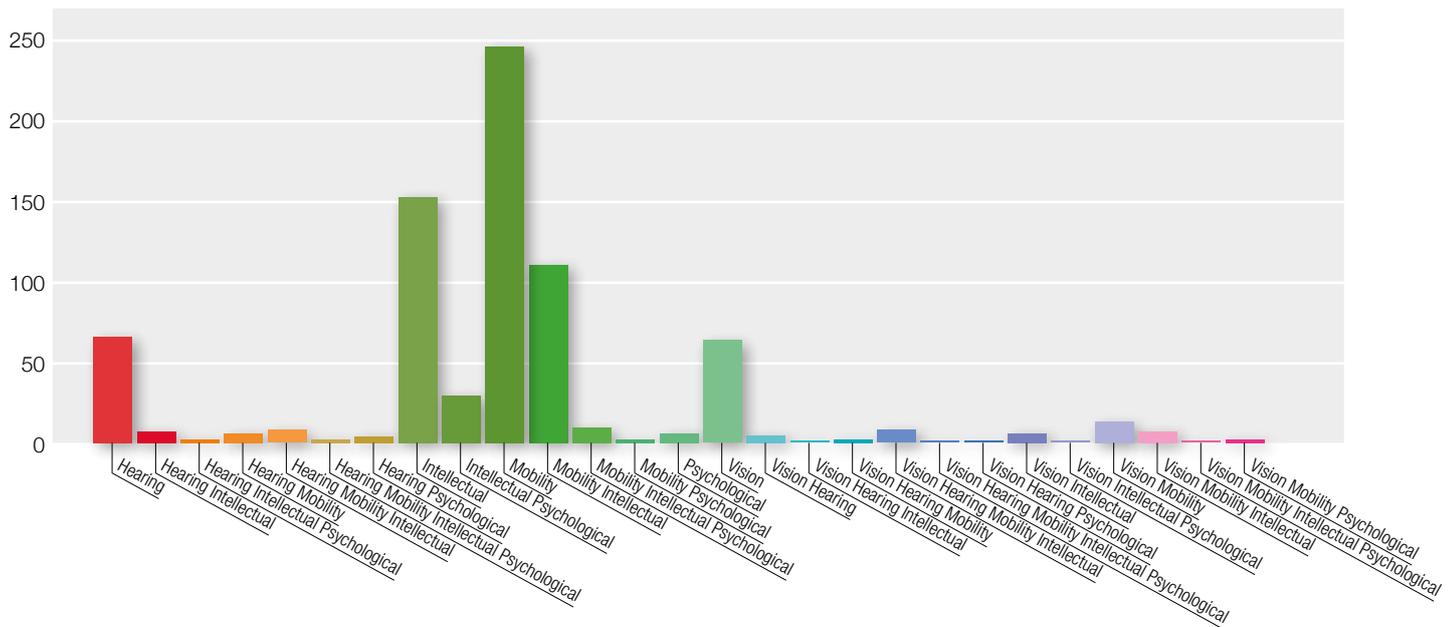
Children living with disabilities inside Syria

ANNEX IV

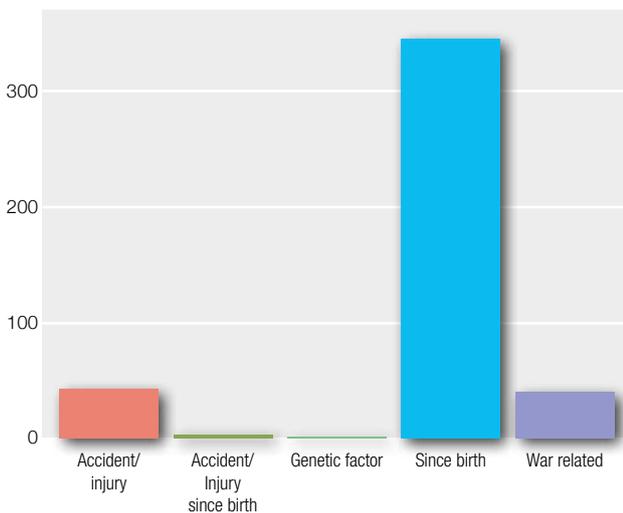
Study results figures

A REPORT BY SYRIA RELIEF

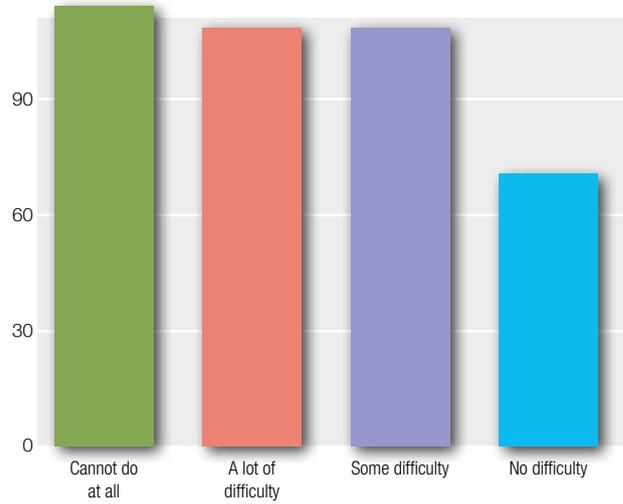




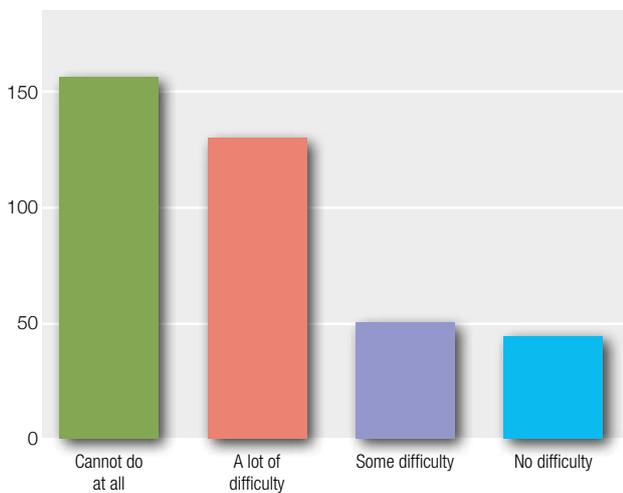
Annex IV. Figure 1. Types of difficulties and their combinations among surveyed children



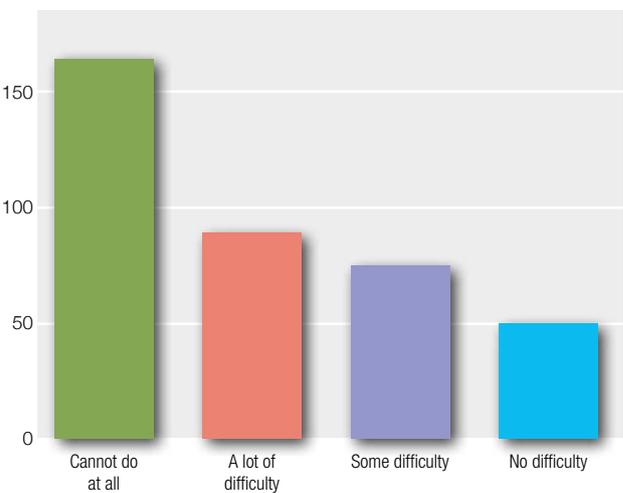
Annex IV. Figure 2. Reasons for mobility difficulties



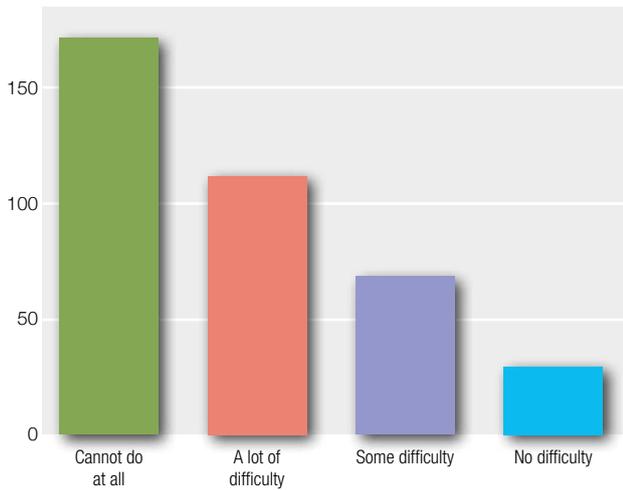
Annex IV. Figure 3. Children with psychological/intellectual difficulties: Difficulties when spoken to inside the home



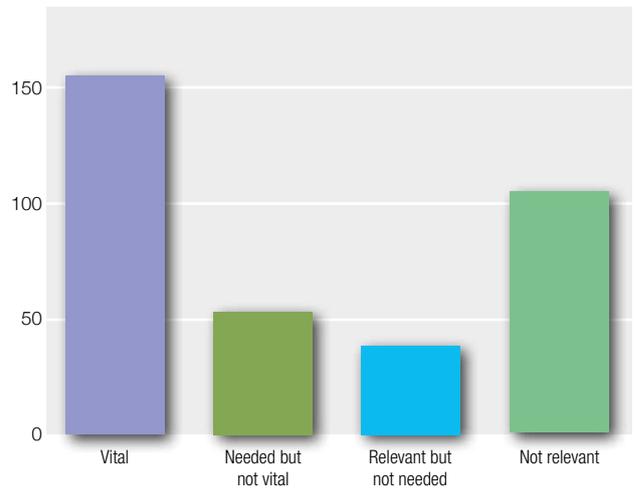
Annex IV. Figure 4. Children with psychological/intellectual difficulties: Difficulties when spoken to outside the home



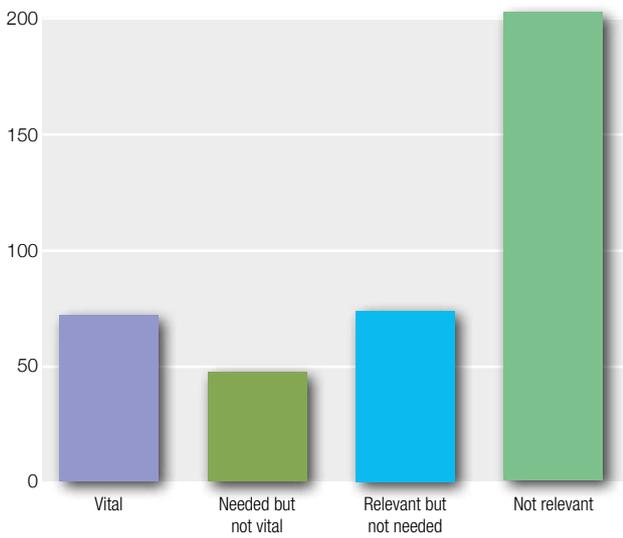
Annex IV. Figure 5. Children with psychological/intellectual difficulties: Difficulties with concentration



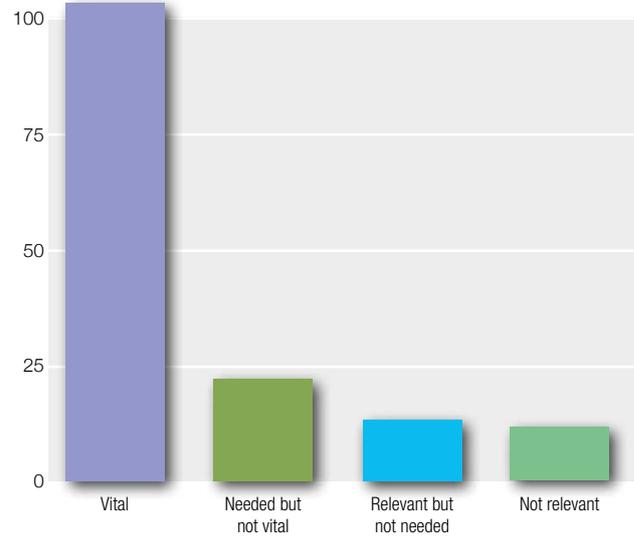
Annex IV. Figure 6. Children with psychological/ intellectual difficulties: Difficulties with memory



Annex IV. Figure 7. Children with mobility difficulties, need for shower seats



Annex IV. Figure 8. Children with mobility difficulties, need for home health care services



Annex IV. Figure 9. Children with a combination of mobility and psychological/ intellectual difficulties need for mental stimulation

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