

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)

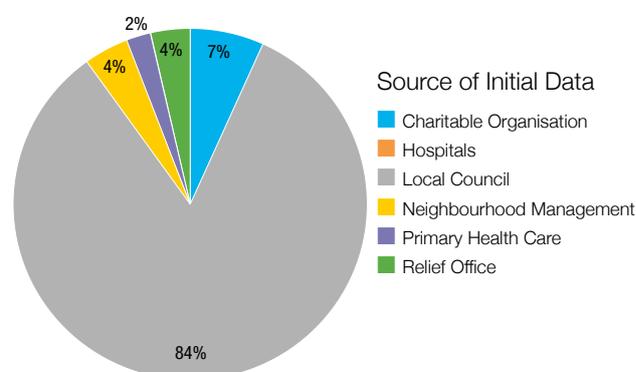
A clearly defined scope was needed to achieve standardised and replicable results. Additionally, clear parameters ensured that Syria Relief staff approached respondents who could provide adequate answers for the survey questions. Children who did not fit within the study parameters and one (or more) 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

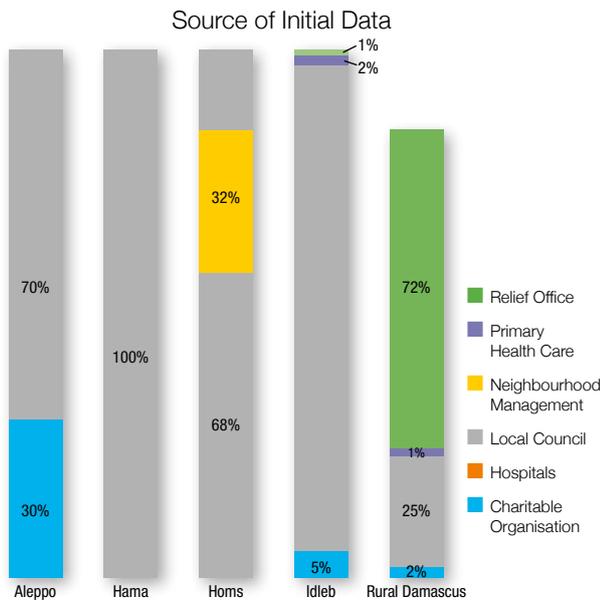
functionality in these areas¹¹. Using a network of staff and pre-existing and established connections with local councils and community leaders enabled Syria Relief staff to access information that would otherwise be unavailable. This network method of data compiling was particularly effective in the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

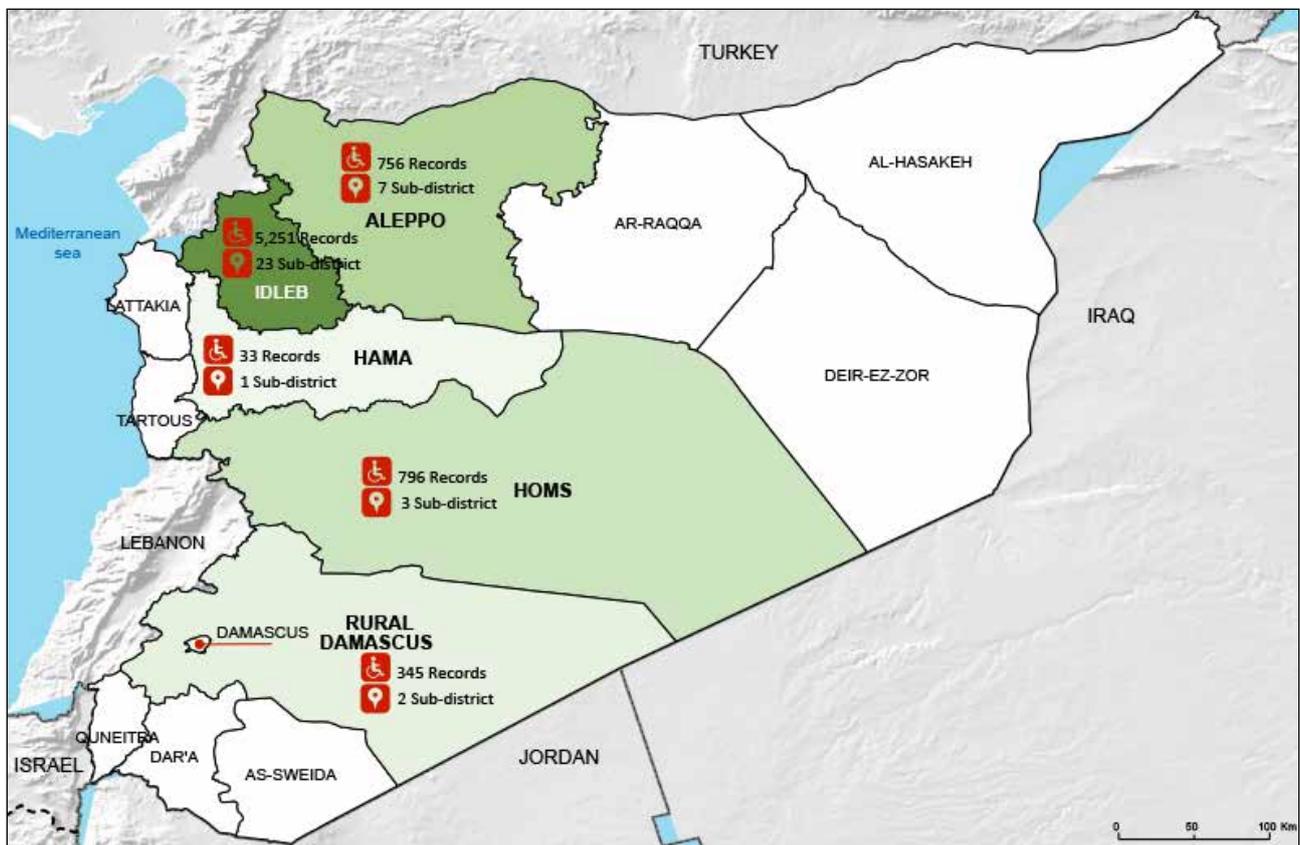


Annex I. Figure 2. Distribution of sources used for the dataset across the five districts in Syria

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	

CF4. Does (name) use a hearing aid?	Yes No	2CF6
CF5. When using his/her hearing aid, does (name) have difficulty hearing sounds like peoples' voices or music? 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	1CF7 2CF7 3CF7 4CF7
CF6. Does (name) have difficulty hearing sounds like peoples' voices or music? 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	
CF7. Does (name) use any equipment or receive assistance for walking?	Yes No	2CF12
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]. Would you say (name) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	Some difficulty A lot of difficulty Cannot do at all	3CF10 4CF10
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]. Would you say (name) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	Some difficulty A lot of difficulty Cannot do at all	
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]. 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	3CF13 4CF14
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]. 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	1CF14

<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.

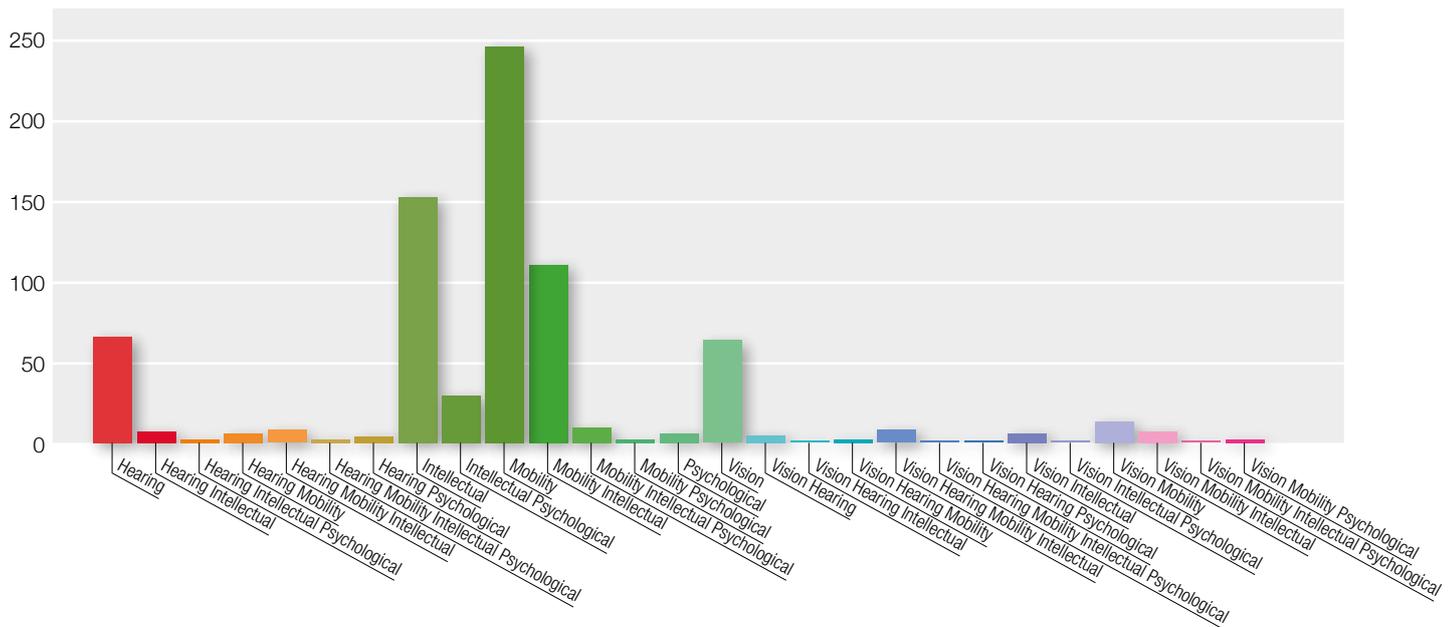
Children living with disabilities inside Syria

ANNEX IV

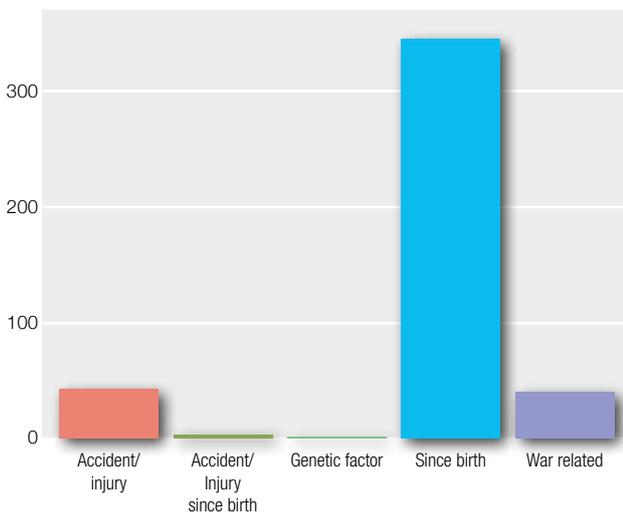
Study results figures

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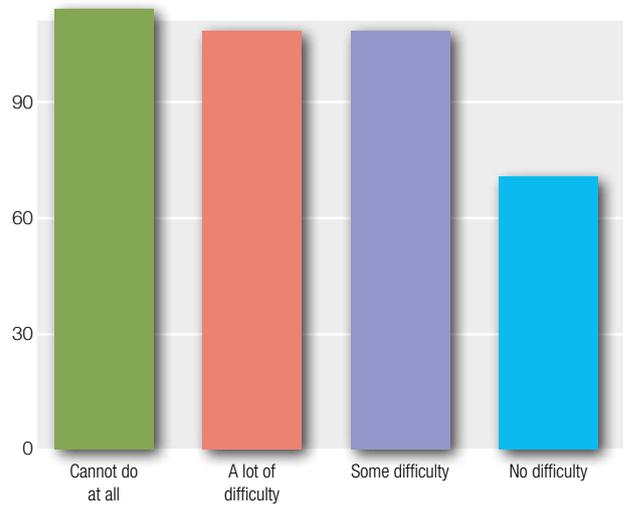




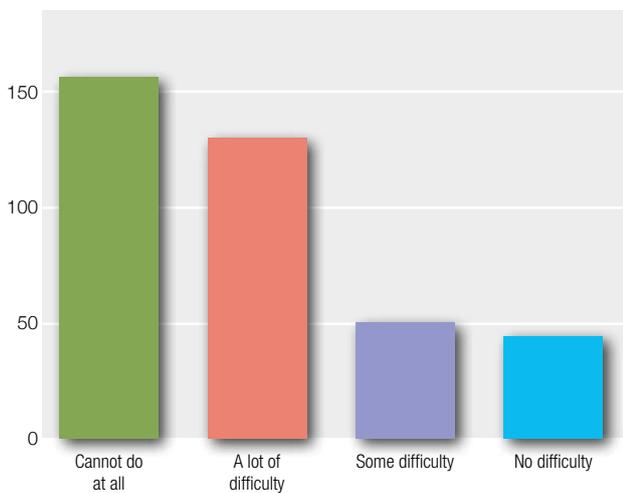
Annex IV. Figure 1. Types of difficulties and their combinations among surveyed children



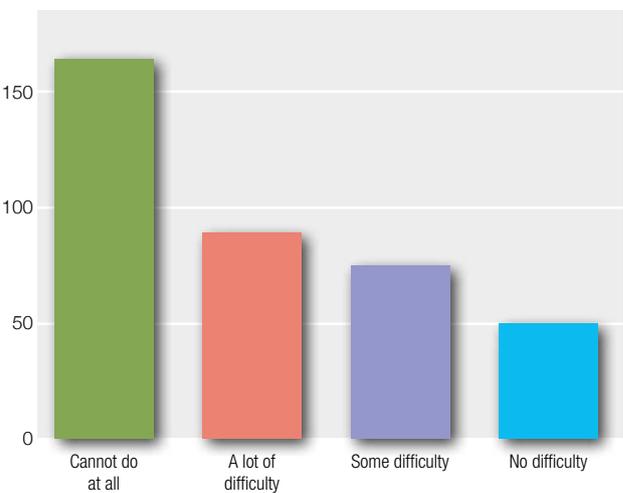
Annex IV. Figure 2. Reasons for mobility difficulties



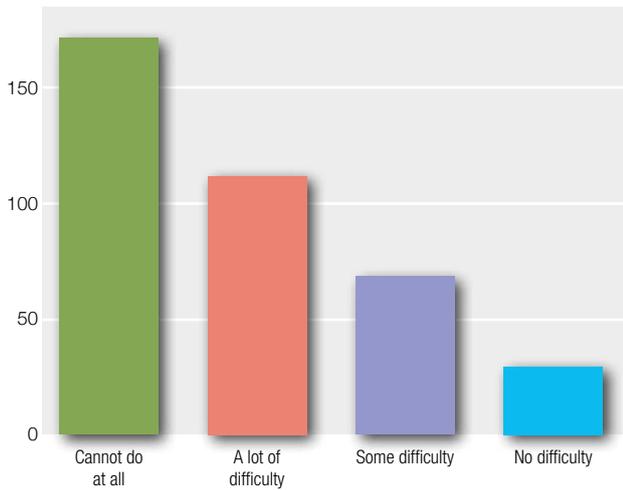
Annex IV. Figure 3. Children with psychological/intellectual difficulties: Difficulties when spoken to inside the home



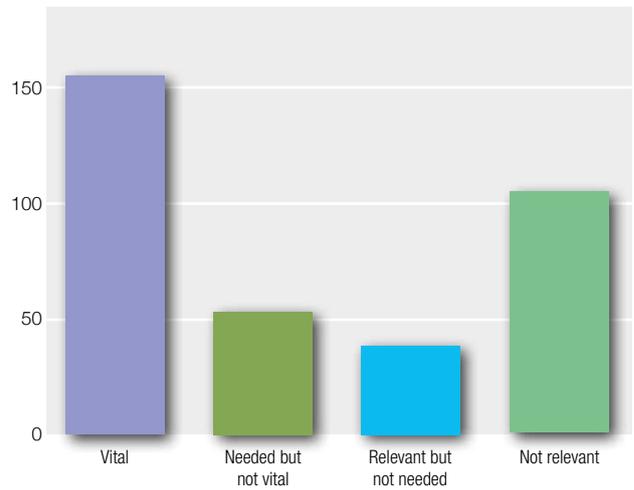
Annex IV. Figure 4. Children with psychological/intellectual difficulties: Difficulties when spoken to outside the home



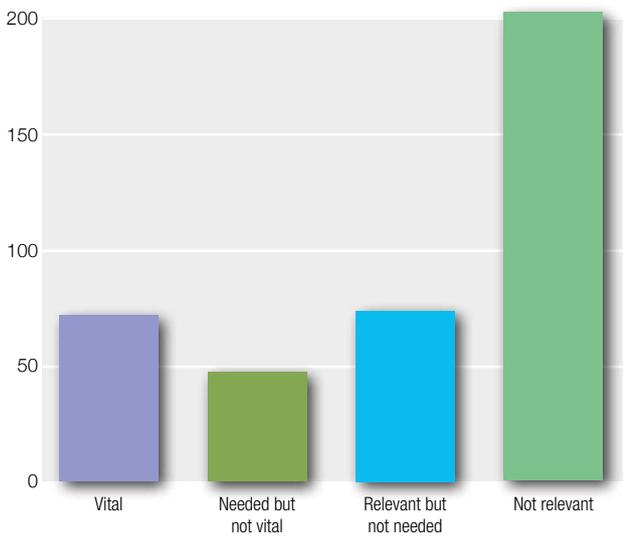
Annex IV. Figure 5. Children with psychological/intellectual difficulties: Difficulties with concentration



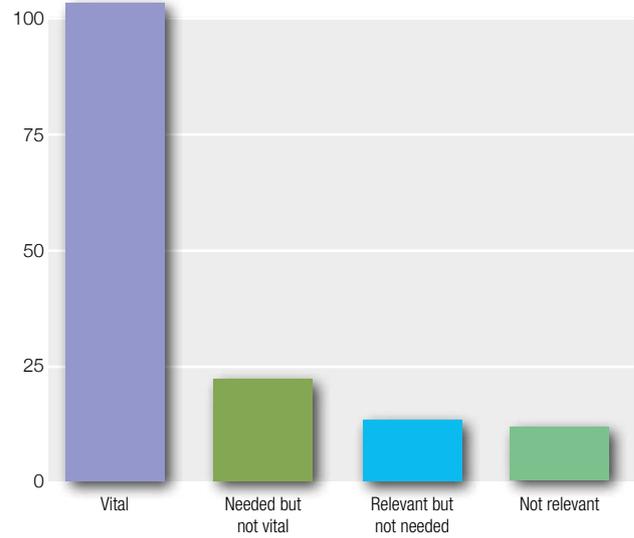
Annex IV. Figure 6. Children with psychological/ intellectual difficulties: Difficulties with memory



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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