

# Disability Data Collection:

A summary review of the use of  
the Washington Group Questions by  
development and humanitarian actors

October 2018



## Acknowledgements

This summary report is the product of a collaboration between Leonard Cheshire and Humanity & Inclusion. Both organisations would like to thank all those who have participated in their respective research projects, and shared experiences and insights about data collection on persons with disabilities and the use of the Washington Group Questions on Disability.

By working together and sharing these insights and learnings, Humanity & Inclusion and Leonard Cheshire hope to contribute to global dialogues about data collection disaggregated by disability. We also hope to ensure that persons with disabilities are meaningfully included in national and global development efforts, poverty alleviation strategies and humanitarian response.

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The Leonard Cheshire team was led by Dr. Ola Abu Alghaib (Director, Global Influencing and Research) and Professor Nora Ellen Groce (Director, Leonard Cheshire Research Centre). The research was undertaken by Nolan Quigley (Consultant).

The Humanity & Inclusion team was led by Pauline Thivillier (Technical Advisor) and three in-country Project Officers: Duaa Shaalan (Jordan), Crispin Bahati (Democratic Republic of Congo) and Emmaleeh Pequit (Philippines), with support from Kate Aykroyd (Data and Learning Analyst), Daniel Mont (Co-President of the Center for Inclusive Policy, and an international expert in disability and development) and Aude Brus (Research Coordinator, Humanity & Inclusion).

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## Foreword

I know that good data can be a game changer in terms of policy and program planning and implementation. My experience over the years, both as an activist and then global advisor, has shown me that without data and evidence, it's extremely hard to advocate for change or track progress. It's my strong belief that for us to achieve real and meaningful inclusion, we need a robust and quality data set about disabled people. This is something that has been severely lacking in the past.

However, strides are being made in filling the gaps in data disaggregated by disability as more and more countries are integrating the Washington Group Questions on Disability into national data collection efforts. This follows decades of concerted efforts to improve data collection on disability. Hopefully this will translate to a more detailed picture of how disabled people are being included in national development and in crisis response, and inform policy development and implementation.

A plethora of organizations outside official government structures contribute to development activities and humanitarian action. And we are starting to see a change by a range of organizations in their programming approach to include disabled people. There is finally a realization that if action is not disability inclusive, it will not deliver change or progress for everyone. We will not meet our collective global commitment to 'leave no one behind'.

These organisations need data collection tools and methodologies to be able to plan effectively, and they need evidence and insight to know which tools to use and when to use them. They also need to be able to train people to implement methodologies. However, it is important to know what the most appropriate data collection methodology for these organisations is.

Many humanitarian and development organisations have opted to use the Washington Group Questions, a methodology designed for national data collection efforts, which is beyond their original purpose.



Until now, we have not known in detail how the Washington Group Questions perform when used by these types of organisations and for different types of activities.

I am delighted that Leonard Cheshire and Humanity & Inclusion have shown leadership in trying to understand how the Washington Group Questions can support data collection on disability by both development and humanitarian actors. This summary report collates and analyses evidence and insight from both development and humanitarian organisations to understand how the Washington Group Questions have been used, and their impact on program design and implementation.

Both organisations have strong foundations in data and insight, especially in support of robust data collection methodologies such as the Washington Group Questions, as well as inclusive development and humanitarian programming. Their new research and combined analysis is an important starting point to shape dialogue and action on the application of the questions in new settings, and any guidance and research that may be needed in the future.

**Judith E. Heumann**

Leonard Cheshire Global Ambassador  
and Trustee of Humanity & Inclusion

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# 1. Executive summary

**The Washington Group Questions on Disability are rapidly emerging as the preferred data collection methodology by the global community for national data collection efforts on disability. However, more and more development and humanitarian actors are now using the methodology in their own data collection efforts. This is beyond the original purpose of the questions, which was to generate usable data for governments.**

Leonard Cheshire and Humanity & Inclusion, two international charities focussed on disability and inclusion, have worked together to share learnings of recent research studies. These studies aim to understand how the Washington Group Questions (WGQ) have been used by development and humanitarian actors and the impact of using the methodology. This summary report outlines the key findings, analysis and conclusions about the application of the Washington Group Questions in a range of contexts. The report concludes with a number of recommendations for different stakeholders.

Leonard Cheshire and Humanity & Inclusion have identified successful examples of using the Washington Group Questions by both development and humanitarian actors in their data collection efforts. However, both sets of research also have shown that it is not always possible to collect data on persons with disabilities in acute humanitarian crises. They also show that the Washington Group Questions are not an appropriate methodology for every situation.

Organisations need to be clear about the needs and objectives for collecting such data and understand the strengths and limitations of the Washington Group Questions. Used alone, they will not give all the information needed to design disability inclusive programming. More research needs to be undertaken to further define the scope in which the Washington Group Questions can be effectively used in development and humanitarian programming.

Going forward, Leonard Cheshire and Humanity & Inclusion will produce a further in-depth report and analysis. We are committed to working together, and with relevant actors and those with an interest in data collection by disability. We will seek to strengthen insight, learning and trainings around data collection processes and the Washington Group Questions for humanitarian and development actors.



Jayakodi, who has been supported by Leonard Cheshire's Livelihoods Project in Cuddalore, India.

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## 2. Introduction

**Many policy and decision makers at national and international level believe that data on persons with disabilities does not exist or is too complicated to collect and use this reason to justify excluding children and adults with disabilities from development efforts and crisis response. To change this misconception, there is an urgent need for good data on persons with disabilities. This will lead to a better understanding and response to the needs of the 1 billion people worldwide who live with a disability.**

Until recently, systematic collection and analysis of disability statistics has been largely overlooked.<sup>1</sup> However, in recent years, there have been considerable efforts to collect and analyse data on persons with disabilities and the situation is starting to change. This has been catalysed by data collection requirements called for in the UN Convention on the Rights of Persons with Disabilities (CRPD)<sup>2</sup> – now ratified by 177 countries – and the inclusion of disability within the 2030 Agenda and Sustainable Development Goals (SDGs)<sup>3</sup> with their call to ‘leave no one behind.’ Consequently, disaggregation of data by disability is now a core principle.

However, more data collection needs to be undertaken. Without viable data, the ability of countries to meaningfully include persons with disabilities in national plans for monitoring and implementation is compromised. The 2030 Agenda and the SDGs are therefore at real risk of not being implemented. Countries may not fulfil their global commitment to ‘leave no one behind’.

A number of global initiatives are pushing for disaggregation of data by disability:

- **Sendai Framework for Disaster Risk Reduction<sup>4</sup>** states that Disaster Risk Reduction (DRR) requires a multi-hazard approach and inclusive risk-informed decision-making based on the open exchange and dissemination of disaggregated data, including sex, age and disability.
- **The Charter on Inclusion of Persons with Disabilities in Humanitarian Action<sup>5</sup>** was launched at the World Humanitarian Summit. It states that data collected on persons with disabilities is to be disaggregated by age and sex, and analysed and used on an ongoing basis to assess and advance accessibility of humanitarian services and assistance, as well as participation in policy and programme design, implementation and evaluation.
- **United Nations Office for the Coordination of Humanitarian Affairs’ (OCHA) Indicator Registry<sup>6</sup>** contains recommendations for disaggregation of some indicators by disability.
- **The Inclusive Data Charter<sup>7</sup>** was launched at the High Level Political Forum 2018 to mobilise political commitments and meaningful actions to deepen disaggregation to understand the needs and experiences of the most marginalised in society.

1 Altman, B. M. (2016). International measurement of disability – Purpose, method and application. Springer International Publishing, Cham.

2 Article 31 requires States Parties “...to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention”

3 The 2030 Agenda has 17 goals for sustainable development and 169 targets. There are 11 explicit references to persons with disabilities in the 2030 Agenda (in the areas of poverty eradication, education, employment, reducing inequalities, sustainable and inclusive cities, and peaceful and inclusive societies)

4 [www.unisdr.org/files/43291\\_sendaiframeworkfordrren.pdf](http://www.unisdr.org/files/43291_sendaiframeworkfordrren.pdf)

5 [humanitariandisabilitycharter.org/](http://humanitariandisabilitycharter.org/)

6 [www.humanitarianresponse.info/es/applications/ir/indicator/f-output-1](http://www.humanitarianresponse.info/es/applications/ir/indicator/f-output-1)

7 [www.data4sdgs.org/initiatives/inclusive-data-charter](http://www.data4sdgs.org/initiatives/inclusive-data-charter)



14-year-old Tiyan is learning to read and write in Braille. © Molly Feltner / HI

Despite these recommendations and the progress to date, data collection on persons with disabilities is seen as extremely challenging. Disability is understood not only through a spectrum of different health conditions and severity but in interaction with environmental, attitudinal or institutional barriers. Disability is a complex, dynamic and multi-dimensional process which is defined and interpreted differently across societies and nations, making data collection in the international context an even greater challenge.

Until recently there have been no cross-culturally appropriate, accurate and validated data collection instruments on disability. National Statistics Offices and INGOs have used a range of methodologies such as the Model Disability Survey and the Washington Group Questions. In the past the growing body of data has been difficult to find, use and compare because it has been scattered through many national censuses, surveys, studies and reviews. It has not been consistently analysed or widely disseminated and has used a range of different collection instruments.

Furthermore, mainstream humanitarian and development actors often rely on disability-focused organisations to take ownership over the rights of persons with disabilities. Yet these organisations do not always have capacity and experience or expertise in humanitarian response or development programming. They also do not always focus on the full range of disabilities and are therefore not equipped to identify and address the needs of all persons with disabilities affected in a given crisis or development processes.

Beyond national data collection efforts, there are also challenges in data collection by a range of actors, including humanitarian and development organisations. For example, regularly-used humanitarian inter-agency and multi-sectoral assessment tools either do not include questions on disability or use a binary 'yes-no' question to collect data on disability. This does not generate data that is sufficiently comparable or reliable enough to inform humanitarian programming and development efforts.

The Washington Group Questions have emerged through growing global agreement as one of the key methods for identifying persons with disabilities in surveys and censuses. This is why the analysis in this report focuses on their use.

## The Washington Group Questions

In 2001 the United Nations Statistical Commission established The Washington Group on Disability Statistics to develop The Washington Group Questions (WGQ). They were specifically mandated to improve the collection, analysis and use of disability related data. They developed disability measurement tools for use in national censuses and surveys by National Statistics Offices (NSOs).

The WGQ were designed with a functional approach, in line with The World Health Organisation's (WHO) International Classification of Functioning, Disability, and Health (ICF), purposefully avoiding the term 'disability' itself. People can often be reluctant to admit that someone in the household has a disability due to stigma and prejudice that can be attached to this label in many societies. Furthermore, the term disability is often interpreted as resulting from a severe impairment and so people with more moderate impairments, who still might face significant risks of exclusion, are missed. Older people often consider their functional limitations not to be associated with 'disability' but with only age, when age in fact may simply be a cause of their disability.

The first mandate of the Washington Group (WG) was to design questions suitable for census, which by their nature, have very limited space. Therefore the original WG Short Set of Questions was designed to be as short as possible but still accurately capture the large majority of persons with disabilities. The questions were not designed to measure all aspects of difficulty in functioning that people may experience, but rather those domains of functioning that are likely to identify a majority of people at risk of participation restrictions.

While the WGQ by themselves explicitly address only limitations in undertaking basic activities, they are designed for analysis with other information in a way that incorporates the full bio-psychosocial model of disability.<sup>8</sup> For example, by disaggregating outcome indicators (such as employment) by disability as defined by the WGQ, it is possible to find evidence about the existence of environmental barriers that are disabling to people with functional limitations.

The group have developed several tools including:

- Washington Group Short Set (WGSS) (six questions): the most widely used, only six questions (which this report mainly focuses on).
- Washington Group Short Set Enhanced (WG-SSE) includes the short set questions and three questions on upper body functioning, anxiety and depression.
- Washington Group Extended Section Functioning<sup>9</sup> (WGESF) (39 questions): expanding on the short set of six, with the use of assistive devices/aids, functioning with and without the use of devices/aids where applicable and additional domains of functioning such as upper body, anxiety and depression, fatigue and pain.
- Washington Group Child Functioning Module<sup>10</sup> (WGCFM): specific to the needs of children aged 2-4 and 5-17 developed in conjunction with UNICEF.

Additional sets of WG-related questions are currently in development but have yet to be fully validated and implemented. These include questions relating to the environment, education, civic participation and employment. Further work is also being done on questions regarding psychosocial issues.

8 [www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions/](http://www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions/)

9 [www.washingtongroup-disability.com/washington-group-question-sets/extended-set-of-disability-questions/](http://www.washingtongroup-disability.com/washington-group-question-sets/extended-set-of-disability-questions/)

10 [www.washingtongroup-disability.com/washington-group-question-sets/child-disability/](http://www.washingtongroup-disability.com/washington-group-question-sets/child-disability/)

## The Washington Group Short Set of Questions on Disability:

The Washington Group Short Set (WGSS) is a set of questions designed to identify (in a census or survey format) persons with disabilities. Consistent with the purpose of the WGQ, these are people at greater risk than the general population for participation restrictions due to the presence of difficulties in six core functional domains, if appropriate accommodations are not made.

### The Washington Group Short Set of Questions on Disability:

The next questions ask about difficulties you may have doing certain activities because of a health problem:

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?

Answers:

- a. No – no difficulty
- b. Yes – some difficulty
- c. Yes – a lot of difficulty
- d. Cannot do at all



Olanya Sunday and Mesiku Joyce work in tailoring. Leonard Cheshire has supported them through its Livelihoods Project in Uganda. © Leonard Cheshire.

The WGQ have been endorsed as the questions most suitable to disaggregate data by disability by a number of organisations such as the United Nations Development Programme, International Labour Organization, United Nations Children's Fund (UNICEF), World Health Organisation, Office of the High Commissioner for Human Rights, International Disability Alliance and International Disability and Development Consortium.<sup>11</sup> A joint statement was also issued with United Nations Statistics Division in November 2017 to reaffirm the commitment of both groups to collaborate closely and effectively to achieve further improvements in disability statistics. The Economic and Social Commission for Asia and the Pacific (ESCAP) Guide on Disability Indicators for the Incheon Strategy<sup>12</sup> also advocates the use of the WGQ. At the last enumeration exercise in 2017, over 65 countries indicated they had used some form of the WGQ in a national survey or census.

11 Disability disaggregation joint statement by the disability sector: [www.washingtongroupdisability.com/wp-content/uploads/2016/01/Joint-statement-on-disaggregation-of-data-by-disability-Final.pdf](http://www.washingtongroupdisability.com/wp-content/uploads/2016/01/Joint-statement-on-disaggregation-of-data-by-disability-Final.pdf)

12 [www.unescapsdd.org/files/documents/ESCAP%20Guide%20on%20Disability%20Indicators.pdf](http://www.unescapsdd.org/files/documents/ESCAP%20Guide%20on%20Disability%20Indicators.pdf)

## Expanding the use of the WGQ to development and humanitarian programming

The WGQ are now increasingly used beyond their original design purpose. With the 'leave no one behind' agenda gathering momentum, more organisations understand the need for good quality data disaggregated by disability. Development and humanitarian organisations, donors and civil society actors are now using the WGQ to assess/monitor whether their programmes are inclusive of persons with disabilities and and/or mainstream inclusion of persons with disabilities into their programmes. Furthermore, many international funding agencies such as the UK Department for International Development (DFID)<sup>13</sup> and the Australian Department for Foreign Affairs and Trade (DFAT)<sup>14</sup> request that funded projects explore how to use the WGQ in data collection and analysis efforts. As such, many organisations are now facing the task of translating a question set designed for large scale national questionnaires into small scale programming and research programmes.

## About the summary report

Leonard Cheshire and Humanity & Inclusion have collaborated together to share learnings from recent studies to analyse, compare and contrast the use of the WGQ in both the development and humanitarian contexts. The synthesized studies aim to provide insight on how the questions have been used, the quality data generated by using the questions beyond their original purpose, and whether they are the appropriate methodology to be used by development and humanitarian actors in their disability inclusion work. The studies aimed to also generate learnings, which have been translated into recommendations for the purposes of this report.

Both organisations are well placed to conduct these studies. Leonard Cheshire hosts the Washington Group Secretariat and has built up extensive knowledge of how the questions are used across different contexts. Humanity & Inclusion is working to improve the availability of quality data on persons with disabilities and increase its use by humanitarian and development organisations. It has also collaborated with the Washington Group on Disability Statistics on a set of six videos<sup>15</sup> and one learning module.<sup>16</sup>

This summary will be followed by a more in-depth report about both sets of research.

13 The UK Department for International Development (DFID) states that all partners should explore the WG Short Set of Questions on Disability to disaggregate programme data by disability status. It also developed a data disaggregation action plan to build the culture within DFID to systematically collect and report data which has been disaggregated, and to work with others to change the international development system on disaggregated data: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/554802/DFID-Disability-Framework-2015.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/554802/DFID-Disability-Framework-2015.pdf)  
[www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/582315/Data-disaggregation-action-plan-Jan-2017.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/582315/Data-disaggregation-action-plan-Jan-2017.pdf)

14 The Australian Department of Foreign Affairs and Trade's disability-inclusive development initiatives includes various commitments on disability data including UNICEF Partnership on Disability-Inclusive Data Collection, Strengthening disability statistics for the post-2015 development agenda, Supporting the institutional capacity of the Washington Group on Disability Statistics: [dfat.gov.au/aid/topics/development-issues/disability-inclusive-development/Pages/disability-initiatives.aspx](http://dfat.gov.au/aid/topics/development-issues/disability-inclusive-development/Pages/disability-initiatives.aspx)

15 [www.washingtongroup-disability.com/wp-content/uploads/2016/02/2016\\_HI\\_WG\\_Disability-Data-Videos.pdf](http://www.washingtongroup-disability.com/wp-content/uploads/2016/02/2016_HI_WG_Disability-Data-Videos.pdf)

16 [hilearngo.handicap-international.org/workspaces/176/open/tool/home#/tab/-1](http://hilearngo.handicap-international.org/workspaces/176/open/tool/home#/tab/-1)

## About Leonard Cheshire

Leonard Cheshire is a leading inclusive development agency, working to improve the lives of persons with disabilities in developing countries across the globe. It has a strong focus on supporting the generation and collation of quality data disaggregated by disability. The Leonard Cheshire Research Centre,<sup>17</sup> based at University College London, provides the academic home base for the Secretariat of the Washington Group on Disability Statistics. The Centre also undertakes research which gives unique insights into disability and inclusive development. Leonard Cheshire has also collated disability data under education, economic empowerment, technology and innovation, and stigma and discrimination indicators for over 40 countries on the Disability Data Portal ([www.disabilitydataportal.com](http://www.disabilitydataportal.com)) which was launched at the Global Disability Summit in July 2018.

Leonard Cheshire focusses on inclusion and participation, working to achieve this in a number of ways in 16 countries across Asia and Africa. It partners with Disabled People's Organisations (DPOs) to strengthen their involvement in policy and implementation processes. Its programmatic work focuses on developing models of inclusion in education, economic empowerment and overall participation in society. Leonard Cheshire also works at a global level to ensure that inclusive development remains high on the international agenda.

## About Humanity & Inclusion

Humanity & Inclusion is an independent charity working in situations of poverty and exclusion, conflict and disaster. Humanity & Inclusion works tirelessly alongside persons with disabilities and vulnerable people to help meet their basic needs, improve their living conditions and promote respect for their dignity and fundamental rights. Humanity & Inclusion supports persons with disabilities and vulnerable people in around 60 countries affected by conflict, disaster and poverty.

From July 2016 to March 2019, Humanity & Inclusion is implementing a DFID funded project<sup>18</sup> (in collaboration with the Washington Group on Disability Statistics and the International Disability Alliance) to improve data collection on persons with disabilities in humanitarian crises. Through an action-research, the project aims to test and assess the WGQ for use in humanitarian contexts, and use the learning to develop guidance on the use of the WGQ specifically designed for humanitarian actors.



Chan Chi, a beneficiary from HI's inclusive education project in Cambodia. ©Anthony Jacopucci/HI

<sup>17</sup> [www.ucl.ac.uk/iehc/research/epidemiology-public-health/research/leonard-cheshire-research](http://www.ucl.ac.uk/iehc/research/epidemiology-public-health/research/leonard-cheshire-research)

<sup>18</sup> More information on the project can be found here: [humanity-inclusion.org.uk/en/disability-statistics-in-humanitarian-action](http://humanity-inclusion.org.uk/en/disability-statistics-in-humanitarian-action)

## 3. The studies

### Leonard Cheshire's research into the use of the Washington Group Short Set Questions by development actors

The objectives of Leonard Cheshire's study were to:

- Understand contemporary use of the WGQ by NGOs and DPOs.
- Identify and analyse the strengths and limitations of their use in development and other contexts.
- Make recommendations for their use, particularly by NGOs and DPOs.

The study was conducted between January and March 2018.

#### Methodology

1. In-depth interviews with interviewees who were recruited either from the Washington Group INGO Working Group in London, or from donor agencies. Inclusion criteria for interviewees included:
  - Well informed in the use of the WGQ in the development setting.
  - Holding a position of employment that ensured an organisational strategic perspective on the current and future use of the Washington Group tools.
  - Either a disability or statistics expert.
2. An in-depth set of interview questions was designed to allow interviewees to discuss their knowledge, experience and attitudes towards the WGQ, and were subsequently reviewed by additional members of the Working Group. The three key questions were:
  - What motivated the interviewee's organisation to use the WGQ?
  - How has the organisation used the WGQ and what were the results?
  - What has the learning been, and what are the recommendations to other INGOs considering using the WGQ?

Over 20 individuals from 12 organisations were interviewed in early 2018. Participants were from Camfed, CBM, Christian Aid, DFAT, DFID, Equal International, Humanity & Inclusion, Leonard Cheshire, Leonard Cheshire Research Centre, LEPROA, Sightsavers, SSD, WaterAid (UK, Australia and Timor Leste). Four respondents were at field level.

All live interviews were recorded and transcribed. Two interviewees were questioned through email correspondence as they were unable to conduct live interviews due to busy travel schedules.

The data was analysed using thematic content analysis.

## Humanity & Inclusion's action-research into the use of the WGQ in humanitarian action

The objectives of Humanity & Inclusion action-research were to:

- Understand how the WGQ perform in different humanitarian settings / sectors of intervention to identify persons with disabilities.
- Determine the necessary process for humanitarian actors to collect useful and quality data using the WG questions.

The action-research took place between March 2017 and June 2018.

### Methodology

The study employed a mixed methods approach using different data collection tools:

1. In-depth interviews (34) with decision-makers to understand the motivation for collecting data on persons with disabilities, their views on the WGQ and use of the data for inclusive programming.
2. Focus group discussions (29) and training evaluation with enumerators after they were trained on the WGQ and after they administered the WGQ to understand the process of administering the questions and training requirements.
3. Two sets of quantitative surveys were carried out with affected populations, including an exit interview survey to understand their perception and understanding of the WGQ and a follow-up survey to ask more detailed questions on disability and compare the results to the WGQ.
4. Observation surveys of enumerators administering the questions were performed to identify challenges and good practices.
5. Anonymised sets of data collected by humanitarian actors were shared with Humanity & Inclusion to support with the analysis.

Over 30 organisations of different types (UN, INGOs, local NGOs, government, DPOs) working in different sectors participated in the research in the three pilot countries: the Democratic Republic of Congo (DRC), Jordan and the Philippines.

All interviews and focus group discussions were recorded, transcribed and when relevant translated to English. Qualitative data was analysed using thematic content analysis and inductive coding. Quantitative data was explored and analysed in excel using descriptive statistics and, when relevant, further exploratory techniques in SPSS.

## 4. Analysis of key findings

**Humanity & Inclusion and Leonard Cheshire have compared the key findings of their research and have identified common outcomes and experiences of development and humanitarian organisations using the WGQ.**

### 4.1 Opting to use the WGQ

Both organisations recognised that the decision to use, and the introduction of the WGQ, needs to be implemented as an organisation-wide movement. Organisational commitment and adoption were affected by a range of factors.

#### External factors

Both research projects identified similar reasons for organisations seeking to collect data disaggregated by disability using the WGQ. On a local level, data was collected to improve programme design; on a funding level it was collected to meet donor requirements; and on a global level to contribute to the implementation of the SDGs or other global initiatives oriented around inclusion.

Both studies reflect on the important influence of external funders, many of which call for the inclusion of the WGQ in upcoming grant proposals. DFID and DFAT in particular are putting plans in place to require the use of the WGQ for programmes such as Water, Sanitation and Hygiene (WASH) and Sexual and Reproductive Health, and not just those specifically targeted at persons with disabilities.

WaterAid (a Leonard Cheshire interviewee) noted both internal and external factors which led to the organisational decision to use the WGQ. This included a push from staff internally towards disability inclusion as well as the external influence of DFID's growing commitment to disability and data.

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**“Decisions internally will come from partners and donors. If the donors are involved it makes decision-making within the organisation very easy.”**

INTERNATIONAL MEDICAL CORPS UK [HUMANITY & INCLUSION INTERVIEWEE]

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#### Internal factors

Overall Humanity & Inclusion found during key informant interviews with decision-makers at organisational level that 75% of them were very positive about using the WGQ.

Leonard Cheshire found that some organisations had internal disagreement, confusion and hesitancy amongst some staff regarding some of the questions, particularly in those organisations that were less disability focused. Humanity & Inclusion's action-research showed that a wide range of stakeholders had to be involved in the decision to use the WGQ, with different organisations taking different approaches. In general, it was observed that having an inclusion adviser at headquarters or a person in the field with an interest in disability was a facilitating factor. Some organisations took a top-down approach and requested field teams to collect data on disability to fulfil donor requirements or global policies. Leonard Cheshire also identified a motivation gap between the head office and the field, with head office often demonstrating more commitment to the questions. By contrast, Humanity & Inclusion found that in other agencies, especially smaller INGOs or local NGOs, the drive had really come from the field.

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**“To start the decision makers – who were executive directors, country directors and programme directors. Then, once engaged, it would be technical staff, M&E staff and programme managers.”**

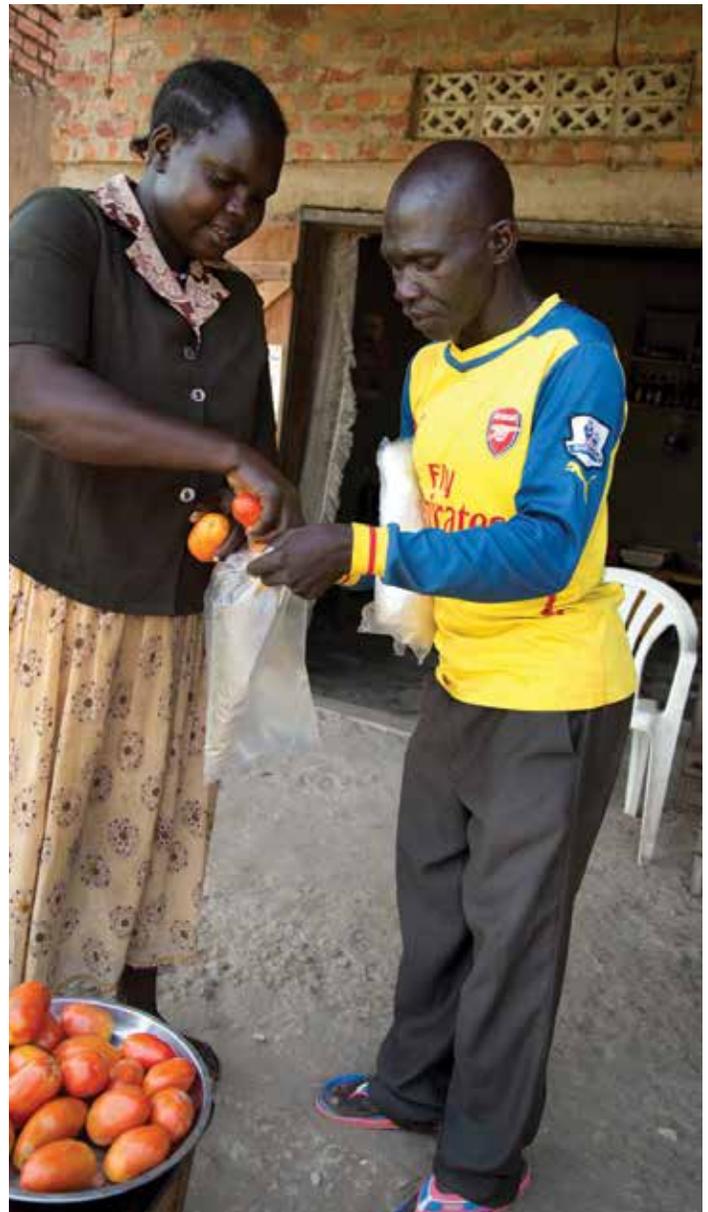
HUMANITY & INCLUSION, JORDAN [HUMANITY & INCLUSION INTERVIEWEE]

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Both organisations found that training was required at all levels of usage. Many interviewees from both sets of research highlighted that they would benefit from further training on disability and inclusion as well as how to ask the questions in the field. The research also identified that training requirements are different for the different levels of programming; in the field, at programme level, and at policy and donor level.

A short survey with humanitarian actors carried out by Humanity & Inclusion highlighted that content should be available to all learners. However, additional details on the WGQ are needed for technical advisers, programme staff, M&E staff and enumerators. Plans to train staff need to reflect those involved in the data collection processes, including those in involved in data collection, planning, implementation and analysis.

CBM (a Leonard Cheshire interviewee) noted the vast difference in experience of using the WGQ when a team in Papua New Guinea implemented the questions without going through the WGQ training or any disability sensitisation. The data results were not useful.



Guma Patrick, right, works in retail. Leonard Cheshire has supported Guma through its Livelihoods Project in Uganda.  
© Leonard Cheshire

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**“Usually the programme manager takes this decision (inclusion of persons with disabilities) and he is based in the field.”**

INTERNATIONAL MEDICAL CORPS JORDAN  
[HUMANITY & INCLUSION INTERVIEWEE]

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## 4.2 The impact of the WGQ

Both sets of research identified that the use of the WGQ by humanitarian and development actors led to additional benefits, beyond the generation of data. This included a better understanding of disability by staff and resulted in a cultural change in the organisations.

### Understanding of disability

Both Leonard Cheshire and Humanity & Inclusion found that prior to using the questions, there was often an organisational lack of understanding around disability. Many viewed disability as a medical issue based on the medical model.<sup>19</sup> Many initially exhibited a lack of understanding regarding the functional approach taken by the WGQ and the human rights based model. However, when supported with training, organisations developed an improved understanding of disability.

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**“The social model will help in covering major basic functions of a human being that should be performed by all individuals on daily basis.”**

REACH, JORDAN [HUMANITY & INCLUSION INTERVIEWEE]

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**[The way] “the questions are framed is an education about what disability is – understanding functionality makes it easier for people in our country teams to make the connection between disability and their project and to think creatively about how to improve inclusiveness. [than the simple do you have a disability question we had used previously]”**

CHRISTIAN AID [LEONARD CHESHIRE INTERVIEWEE]

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### Culture change as a result of training and using the questions

Both studies found that a beneficial cultural change was triggered by asking the WGQ. Leonard Cheshire’s research identified that this occurred even before the questions were actually asked. Using the WGQ generated a change in culture and/or attitudes towards persons with disabilities by the enumerators. During Humanity & Inclusion’s action-research, all the enumerators trained on the WGQ reported that their perception of persons with disabilities had changed.

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**“When we use the questions it makes it easier to start to talk to persons with disabilities in the field. It also teaches us all how to be more respectful of them. It helps us use the right language and frames our relationships. It makes people much more open and receptive to talk to us about their family members who have disabilities. It even helps us in our own personal lives to reframe how we talk about persons with disabilities.”**

WATERAID TIMOR LESTE [LEONARD CHESHIRE INTERVIEWEE]

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**[Translated from French] “Thanks to the training organised by Handicap International [Humanity & Inclusion], these six questions have been well explained and been understood by the enumerators and help us to understand the types of difficulties [...] and how to address them in our programmes.”**

OXFAM, DRC [HUMANITY & INCLUSION INTERVIEWEE]

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19 The medical model focuses on impairments or bodily functions and managing or curing an illness or disability.

Both organisations identified that using the WGQ improved organisational communication on issues around disabilities as it became underpinned by improved insight and understanding around disability. Staff felt they could communicate more respectfully and meaningfully with persons with disabilities. Furthermore both organisations identified that the questions supported an improved understanding of disability for programmers as well as enumerators.

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“Our salesforce database has a record for each girl we support – we had a tick box on there where we recorded if they had self-selected as having a disability – with a free text space for further detail if wanted. Now we are adding extra space where we can record if they have registered at least some difficulty in at least one domain when asked the WGQ. This reflects our transition as an organisation – moving away from a tick box approach to disability to incorporating the WGQ and the nuances of severity and different impairments into our database.”

CAMFED [LEONARD CHESHIRE INTERVIEWEE]

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Vulnerability assessments of a camp to be evacuated in Haiti 2014.

© Corentin Fohlen / HI

### 4.3 Understanding the scope of the WGQ

Both studies found that to ensure quality and relevant data on persons with disabilities is collected by humanitarian and development actors, it is important to be clear on the objectives of the data collection to determine whether the WGQ are the right methodology to use.

#### Prevalence vs diagnosis

Frequently the WGQ were misinterpreted as a diagnostic tool, as opposed to their intended purpose to identify the prevalence of disability in order to measure the inclusion of programming. As a consequence, there was often a lack of clarity within organisations around the use of the data for inclusive programming purposes, given the incorrect expectation that the methodology would yield diagnostic data.

The WGQ were also criticised for not identifying people with mental health issues. However this is in part a problem relating to understanding how they are intended to be used, as they are not a diagnostic tool. Research shows that about half of people with psychosocial disabilities are captured by the WGQ, although their psychosocial conditions are not identified. If both identifying more people with psychosocial disabilities and identifying them as such is important, it would be necessary to add the four questions on anxiety and depression that are included in the WG Extended Set. This approach was tested during Humanity & Inclusion's action-research in a project focussing on mental health and psychosocial support.

In a Mental Health and Psychosocial Support (MHPSS) project implemented by International Medical Corps in Jordan, of all persons with disabilities identified, only 51% were identified by the WGQSS. The remaining 49% were identified by the questions on anxiety and depression.



Madra Julius, left, is a men's hairdresser. Leonard Cheshire has supported Madra through its Livelihoods Project in Uganda.  
© Leonard Cheshire



Aishta Adam Bouloumi, an 11 year old Chadian girl with a hearing impairment, who is receiving an education in one of HI's inclusive education programmes in Chad. © Benoit Almeras / HI

The issue of diagnosis versus using the WGQ for statistical purposes is an important one. The questions are designed to identify as many people with a disability as possible with a short set of questions where the number of false positives and false negatives is not highly significant. This allows analysts to analyse prevalence and outcomes for statistical purposes that are important for monitoring, evaluation and policy planning. The questions are not detailed enough for use in diagnosing an individual or determining eligibility for disability programmes in a highly accurate way.

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**“Just knowing that people have difficulty remembering something does not necessarily provide a clear picture of what the problem behind it is. Without having the proper medical and mental data behind this I don’t know how we can provide adequate and appropriate action.”**

INTERNATIONAL MEDICAL CORPS, JORDAN  
[HUMANITY & INCLUSION INTERVIEWEE]

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In the case of services such as rehabilitation or mental health and psychosocial support (MHPSS), as the WGQ are not a diagnostic tool, referrals cannot be done accurately. In health programming, Humanity & Inclusion found that it is important to make the distinction between using the WGQ to understand the level of access persons with disabilities have to the health facility, and asking questions to diagnose medical conditions and identify impairments.

International Medical Corps, Jordan decided to use the WGQ as a pilot in its MHPSS project to understand if persons with disabilities were accessing their service. They then added their own specific questions about mental health, psychosocial and protection concerns to collect the information that they required for their programming.

## Using the WGQ in humanitarian action

Humanity & Inclusion found that amongst the concerns of humanitarian actors was the use of the WGQ in areas of conflict like the Syria crisis. This can lead to the identification of a high number of persons with disabilities due to explainable high incidence of injury and Post Traumatic Stress Disorder (PTSD); both of which could lead to disability.

In the report *Removing Barriers: The Path Towards Inclusive Access*,<sup>20</sup> it was found that one in three Syrians with disabilities living in Jordan reported having a disability as a result of illness or disease. During its action-research Humanity & Inclusion also found that around 10% of persons with disabilities reported an injury as the cause of their disability.

During Humanity & Inclusion's action-research, persons with disabilities were also asked when their difficulties started.

Analysis showed that on average, in Jordan, 40% of Syrian refugees with disabilities reported experiencing difficulties as a result of the humanitarian situation.

Questions on anxiety and depression were also asked by two organisations participating in the research to try to understand the impact of PTSD and psychosocial disability in humanitarian action.

In a MHPSS project implemented by International Medical Corp in Jordan almost half of persons with disabilities identified reported difficulties related to anxiety and depression. The high prevalence can be explained by the nature of the project. As part of the data collection for the *Removing Barriers: The Path Towards Inclusive Access* report, around 10% of adults and children reported anxiety.

Some organisations have argued that there could be an over-identification of psychosocial issues in a humanitarian setting and that some of these issues would resolve after the crisis. The purpose of the data collection in humanitarian action is to help plan the response to the crisis, and at that time these people are in need of support. As such the data has to be interpreted relative to the purpose. The long term rate of mental health problems might be lower than that measured in the humanitarian setting, but the needs at that time could be that high.

Identification of the cause or age of onset can be relevant in some cases. However if the objective for collecting data is to understand whether services are accessible these two factors are irrelevant. A person with a temporary or recent disability is still at risk of restricted social participation, and therefore a distinction does not need to be made.

## Using the WGQ in already identified groups of persons with disabilities

Leonard Cheshire's Girls' Education Challenge Transition (GECT) project in Kenya also raised questions about the use of the WGQ among groups of already identified girls with disabilities. Girls with disabilities were automatically enrolled in the project following on from the previous four-year Girls' Education Challenge 1 (GEC 1) project. They had already been identified as having a disability against criteria established by the Kenyan Institute of Special Education (KISE).

However, applying the WGQ in an existing disability cohort did not reveal any prevalence information, as the girls had already been identified as having a disability against the KISE criteria.

20 Removing Barriers: The Path towards Inclusive Access: <https://data2.unhcr.org/en/documents/details/65892>

## 4.4 Understanding the entry points for using the WGQ

Humanitarian actors also highlighted the importance of when to use the WGQ in existing projects and the impact of using the questions at different entry points. Humanity & Inclusion's research revealed that when to collect data on persons with disabilities in a humanitarian or development context is influenced by a wide range of factors.

### Entry points of the WGQ in humanitarian contexts

Humanitarian actors often insisted on the fact that it is important to have the correct data at the start of an emergency to ensure an inclusive response to disability. However, in sudden onset emergencies it can be hard to collect detailed individual data early in the response, and so efforts should be made during emergency preparedness. In addition, at the initial stage of a humanitarian response, existing data can sometimes be irrelevant after an emergency has hit.

In displacement and refugee emergencies, data can usually be collected during the registration activities. In protracted emergencies, data can be collected frequently and used to monitor performance.

### Entry points of the WGQ depending on the sector of intervention

The sector that is making the intervention is also something that needs to be considered in humanitarian action when using the WGQ. For example, different objectives/concerns regarding the use of the WGQ were observed in the food security/livelihoods sectors around the targeting of vulnerable people (including persons with disabilities), and in the health sector around the use of the question for referrals to health facilities. The WGQ were not designed for targeting or referrals which led to challenges in the implementation of the pilot. Overall protection mainstreaming<sup>21</sup> was found to be a good entry point for data collection on persons with disabilities.



Saritha, who has been supported through Leonard Cheshire's international work in Bangalore, India. © Leonard Cheshire

21 [www.globalprotectioncluster.org/en/areas-of-responsibility/protection-mainstreaming.html](http://www.globalprotectioncluster.org/en/areas-of-responsibility/protection-mainstreaming.html)

## 4.5 Administration of the WGQ in the field

The Humanity & Inclusion study showed that enumerators were often more sceptical about the use of the WGQ before administering the questions. When asked to rate the use of the WGQ on a scale of 1 to 10 (10 being very easy), they gave it the average mark of 7.5 (somewhat easy). After having some experience of administering the questions in the field, the reported ease with which they were able to administer these questions increased. Leonard Cheshire also found that enumerators had difficulty using, understanding and accepting the questions. However, during observation of data collection by Humanity & Inclusion, enumerators did not face major difficulties when administering the questions.

Of the 100 enumerators observed during the action-research, the WGQ were read accurately in 80.1% of cases and answers to the WGQ were recorded accurately in 95% of cases overall.

Observation checklist [Humanity & Inclusion]

Humanity & Inclusion also investigated the impact of the WGQ on affected populations during an exit interview. Analysis of the data in the Philippines and Jordan (this activity did not take place in DRC for security reasons) shows that most people felt comfortable with the WGQ.

Overall, 97% of people felt comfortable when asked the WGQ. It is interesting to note that 100% of persons with disabilities interviewed felt comfortable against 94% of persons without disabilities.

Exit interview of 50 interviewees [Humanity & Inclusion]

In cases where the WGQ were not administered properly, the challenges identified were around language used, contextual understanding and translation.



Meralia Simon, a 90 year old in Haiti, survivor of hurricane Matthew. © Benoit Almeras / HI

## Language around disability

The use of the term disability in the questionnaire or in interaction between the interviewer/enumerator and the respondent will reintroduce variability in how the term is understood. It may introduce stigma and can reduce or eliminate the validity of the questions set.<sup>22</sup>

In Humanity & Inclusion action-research, enumerators were observed to use the word 'disability' in 5.9% of interviews and refer to 'medical conditions' in 6.1% of cases of the 100 observations carried out. The Leonard Cheshire Research Centre highlighted one example from the field which stated that survey questions were prefaced with "God forbid somebody in your household would have a disability but..."



Mazapkwe Lawrenzina, left, is a baker. Leonard Cheshire has supported her through its Livelihoods Project in Uganda.

© Leonard Cheshire

## Translation

Both studies found problems with translation and language around disability. For example the word 'concentration' was frequently misinterpreted as meaning memory. Both also identified more general problems with translation affecting the accuracy of question interpretation. Interviewees from the Leonard Cheshire Research Centre highlighted an example of a translation challenge in Uganda, where the word 'child' can mean anybody with a living parent. In some instances Humanity & Inclusion observed in the Philippines that questions were not translated in local languages, and enumerators had to do it 'on the fly'. WaterAid (a Leonard Cheshire interviewee) stated that it often translated the questions locally and had some concerns about this. They believed that the WG should do more to signpost organisations towards approved translations or encourage organisations to share different versions (however, the WG does have a translation protocol on its website).

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**"When doing the observation we noticed that almost 1 time out of 2 the questions were not asked accurately with the enumerators either paraphrased or examples were provided. The questionnaire being in Tagalog and English enumerators had to translate the questionnaire in local language."**

HUMANITY & INCLUSION IN-COUNTRY PROJECT  
OFFICER, PHILIPPINES [HUMANITY & INCLUSION  
INTERVIEWEE]

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22 [www.washingtongroup-disability.com/wp-content/uploads/2016/12/WG-Document-2-The-Washington-Group-Short-Set-on-Functioning.pdf](http://www.washingtongroup-disability.com/wp-content/uploads/2016/12/WG-Document-2-The-Washington-Group-Short-Set-on-Functioning.pdf)

## Contextual understanding of the WGQ

Both studies found that context affected how questions were understood and answered. For example for the questions “Do you have difficulty seeing, even if wearing glasses?”; and “Do you have any difficulty hearing, even if using a hearing aid?” Humanity & Inclusion found that in some parts of the DRC many interviewees had no access to glasses or hearing aids.

Christian Aid (a Leonard Cheshire interviewee) highlighted that the self care questions were perceived as intrusive in certain contexts. The same feedback was gathered by Humanity & Inclusion when training UNHCR staff in Jordan. Christian Aid also highlighted that the question about ‘difficulty remembering’ was problematic in the humanitarian context given the issue of post-traumatic stress (which is normal and can last for six months after the traumatic incident/disaster).

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**“Some questions are complicated to ask and explain to respondents such as the communication, remembering and concentrating questions.”**

INTERNATIONAL MEDICAL CORPS JORDAN  
[HUMANITY & INCLUSION INTERVIEWEE]

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## Raising expectations of beneficiaries

Both Humanity & Inclusion and Leonard Cheshire found that organisations felt asking the WGQ raised expectations of beneficiaries for support; often without there being programme capacity to meet these expectations. This was particularly evident around the issue of glasses and hearing aids.

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**“People with disabilities identified wanted to know what actions will be available for them.”**

SYNERGIE DES ASSOCIATION DES PERSONNES HANDICAPÉES (DPO), DRC [HUMANITY & INCLUSION INTERVIEWEE]

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Asking the WGQ without capacity to offer support was a shared concern across both studies. Several organisations felt that it was important to be clear with beneficiaries how the data collected would be used and also to manage expectations of their capacity to adapt their programmes based on the results.

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**“We don’t yet have a clear idea of what will be next. [...] Screening a population about these issues raises an ethical issue as we are not set up to do anything to respond to these difficulties that people have reported to us through the Washington Group Questions. We should have a back up project for those identified.”**

LEPRA [LEONARD CHESHIRE INTERVIEWEE]

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**“Enumerators need to be aware of the services provided to people with disabilities and what are the agencies that provide those services.”**

REACH JORDAN, [HUMANITY & INCLUSION INTERVIEWEE]

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Humanity & Inclusion identified the following good practices: inserting the WGQ in the demographic section of the questionnaire (and not health as often seen); providing a clear introduction to the questionnaire and its aim; and providing some information about services available.

Humanity & Inclusion found that humanitarian actors who did not have a protection mandate were especially concerned as they reported that it was not in the scope of their work to provide assistive devices.

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**“[Actors] Didn’t see the urgency or the importance. I would look at their vision and mission and try to find the links for them in order to push them forward. I would take for example the mission value of empowerment and ask them how they were doing this in practice. Then they would see perhaps there was a gap.”**

HUMANITY & INCLUSION PROJECT OFFICER,  
PHILIPPINES [HUMANITY & INCLUSION INTERVIEWEE]

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Leonard Cheshire learnt that one organisation, Sightsavers, had developed a referral pathway where unmet needs were identified. However it is important to stress that this can only be done in a relatively small scheme focused on eye health, and it would be impossible to provide a referral pathway to meet all needs given that the questions are not a diagnostic tool.

However, it is unclear whether the rise in expectation was generated by the specific questions being asked, or whether it was the fact that an INGO was engaging with participants, which led to an expectation of support or further interaction.



Emelda Akinyi (left) with Vivian. Leonard Cheshire has supported Emelda via its Girls’ Education Challenge project in Kenya. © Leonard Cheshire

## Asking the WGQ at household level

Both studies found that organisations used the questions in a household survey format where the head of the household answers for everyone in the home. This could impact the data collected. For instance, the Leonard Cheshire Research Centre noted some bias towards men in Liberia – because of a tendency for male household heads to answer the questions which led to potential underreporting of women with disabilities. WaterAid (a Leonard Cheshire interviewee) shared that the questions were slightly changed when used in a household survey context. For example, they stated that they may need to insert “for those who would ‘normally’ be able” to the questions to avoid an answer such as a baby has difficulty walking. (However it is important to note that the WGQ should not be applied to children under the age of 5.)

Humanity & Inclusion observed different ways of using the questions at household level during its action-research, depending on the level of details required for the project and the unit of measurement used for monitoring exercises.

In *Removing Barriers: The Path Towards Inclusive Access* survey in Jordan, the WGQ were asked to all members of the household. Data shows that 22.3% of people interviewed have a disability and about 60% of households have at least one family member with disabilities. Collecting data from each member of the household was important for this study, as the aim was to understand the barriers faced by persons with disabilities and the survey was designed to ensure individual level data could be collected.

UNHCR during its Vulnerability Assessment Framework (VAF)<sup>23</sup> collected data from the head of household only. However, as identification of persons with disabilities was necessary for all household members (but time was limited), the head of household was asked to answer the WGQ for them (do you/or any member of your household have difficulties...).. If the head of household reported that someone had a lot of difficulties, the name, age and sex of the individual were recorded so follow-up could be ensured. Data shows that 13% of individuals have a disability, which amounts to 40% of households.

In the DRC, OXFAM integrated the WGQ into the baseline of their WASH project, which was asked to head of households only as data is used to review which households are included in their current service, and tools were not designed for individual data collection. The baseline findings identified 28% of persons with disabilities. Members of the household with disabilities cannot be identified during these exercises.

23 Report available here: <https://data2.unhcr.org/en/documents/details/65404>

## 4.6 Flexibility

### Removing questions to save time

Both studies identified time as an issue in asking the WGQ. Humanity & Inclusion found that there is a big difference between perceived time to ask the questions (seven minutes) and actual time (three minutes). Enumerators also raised concerns about the cumulative time taken to ask every member of the household. It may be that the different acute time-pressured context of the humanitarian setting meant that a greater burden of time was perceived in this context than in the development context.

For reasons of time or space where it is not possible to ask all six questions, there is a degree of flexibility in the WGQ. At a minimum, humanitarian and development actors can use four questions (seeing, hearing, walking/climbing steps, and remembering/concentrating). Also, for reasons related to culture it is possible to omit the question relating to self-care; however this means that some persons with disabilities may be missed.



Participants at a women participation workshop in Sri Lanka, in the context of a project funded by the US Department of State, which aims to strengthen women's participation in peace processes in the country, especially women with disabilities. ©HI

Using a screening question<sup>24</sup> invalidates the tool. Whilst the tool stipulates not to use a screening question, both studies found that some organisations felt that using a screening question could save time. Camfed (a Leonard Cheshire interviewee) spoke of the temptation to put a screening question in when they are part of a larger data collection tool and to remove answer options to “make them easier”. Camfed realised the need not to insert a screening question but had to manage internal requests and suggestions to do so.

In the DRC, to ask the WGQ at the household level, the Norwegian Refugee Council (NRC) integrated the WGQ into their post food distribution monitoring activities and asked the head of household whether there were persons with disabilities living in the household. 18% of people responded yes. However when these people were asked the WGQ directly, the prevalence of persons with disabilities fell to 3%. This shows that the introduction of a filter question, whilst saving time, returns a high level of error. As a result of these findings, NRC reviewed their use of the WGQ.

### Adding questions from other WGQ sets to collect more information on difficulties

Some organisations found it difficult to decide which questions to leave out and which questions to add (which does not follow the WGQ implementation guidelines).<sup>25</sup> Lepra found that the ability to include questions from the Washington Group Extended Set on Functioning (which includes questions on depression and anxiety) allowed a better understanding of the people they worked with and the challenges they face. Likewise, CBM and WaterAid found benefits in using WGQSS questions specifically to their programme needs. However, further training is needed to ensure that the correct questions are asked at a minimum.

24 Screening questions are placed at the beginning of a survey in order to determine whether respondents or households have certain characteristics that would make them eligible to answer further questions

25 [www.washingtongroup-disability.com/wp-content/uploads/2016/12/WG-Document-2-The-Washington-Group-Short-Set-on-Functioning.pdf](http://www.washingtongroup-disability.com/wp-content/uploads/2016/12/WG-Document-2-The-Washington-Group-Short-Set-on-Functioning.pdf)

## 4.7 Data analysis

Both studies found challenges in the analysis phase. Despite the fact that guidance on using the WGQ and SPSS (a statistical analysis software) is available on the WG website,<sup>26</sup> both development and humanitarian organisations identified limited data analysis skills in-country, and that in certain cases some organisations were not performing data analysis at all. Humanity & Inclusion identified difficulty in analysing data, and that management information systems needed to be adapted. However, they were unsure at the action-research stage of how to do it.

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**“Let me be honest with you, since this is the first time we are using these questions, we give the analysis and the quality of this data for you Handicap [International], to analyse it and to learn from you how can we analyse such questions.”**

DANISH REFUGEE COUNCIL, JORDAN [HUMANITY & INCLUSION INTERVIEWEE]

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Leonard Cheshire’s research identified that organisations found the time required for data analysis overreached capacity. Christian Aid (a Leonard Cheshire interviewee) reported that time spent on data analysis increased by 30 per cent with the inclusion of the WG questions. Humanity & Inclusion found that issues were partially experienced due to low data literacy. Actors expected to manipulate the data often struggled to correctly determine and apply the relevant WGQ cut off points<sup>27</sup> and to successfully disaggregate further data by disability. Humanity & Inclusion often witnessed organisations trying to link the WGQ to impairment types. Some organisations recognised internal skills gaps, whereas others did not and proceeded to make errors in their analysis and interpretation of data. Notably, most practical difficulties raised were not unique to the WG data but could be seen to align to the disaggregation of data more generally.

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**“They have tried to analyse the data in their own way. Some of them have analysed this domain by domain. And this has led to double counting. Those that needed support were sent a help sheet. But for the others, M&E teams would tend to think they could do it without anything to learn. Or couldn’t ask for the help as they were meant to be the experts.”**

HUMANITY & INCLUSION OFFICER, DRC [HUMANITY & INCLUSION INTERVIEWEE]

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26 [www.washingtongroup-disability.com/wp-content/uploads/2016/12/WG-Document-5-Analytic-Guidelines-for-the-Washington-Group-Short-Set.pdf](http://www.washingtongroup-disability.com/wp-content/uploads/2016/12/WG-Document-5-Analytic-Guidelines-for-the-Washington-Group-Short-Set.pdf)

27 Disability is best understood as a continuum. In terms of difficulty functioning, the ‘difficulty’ can be operationalised through a range of descriptors from no difficulty at all, through some difficulty and a lot of difficulty to completely unable to carry out the action. Each of these descriptors represents a cut-off or threshold in the determination of a final disability identifier; for example, to define those with and without disability. These levels of functioning are also represented in the response categories to the WG Short Set on Functioning (WG-SS). A ‘lot of difficulty’ or ‘cannot do at all’ is the cut-off recommended by the WG. [www.washingtongroup-disability.com/wp-content/uploads/2016/12/WG-Document-5-Analytic-Guidelines-for-the-Washington-Group-Short-Set.pdf](http://www.washingtongroup-disability.com/wp-content/uploads/2016/12/WG-Document-5-Analytic-Guidelines-for-the-Washington-Group-Short-Set.pdf)

## 4.8 Use of data for inclusive programme design and implementation

Both Leonard Cheshire and Humanity & Inclusion found that using the WGQ had implications for programme planning and design.

### Increase in the number of persons with disabilities identified

Both sets of research identified that organisations using the WGQ experienced an increase in numbers of persons with disabilities identified, which had an immediate impact on programming.

For example, Christian Aid found that their results immediately changed programming. Using the WGQ increased reporting of disability from 1-3 per cent, to 10-15 per cent. Therefore increased internal capacity was necessary to ensure that programming responded effectively. Similarly, Humanity & Inclusion found that results from the Norwegian Refugee Council changed from 3 per cent to 25 per cent when using the WGQ in their post distribution monitoring surveys.

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“The WGQ have been most helpful in providing quality control and helping us identify research participants. The data could be really useful to help us understand how different functional difficulties impact on people’s access to WASH. They lend themselves to developing more nuanced programmes responding to different people’s impairments and needs.”

WATERAID [LEONARD CHESHIRE INTERVIEWEE]

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[Translated from French] “We want to use them [the WGQ] to increase our experience and knowledge about persons with disabilities specifically but also to have specific plans.”

ANALYSE DATA FOR FIGHTING INDIGENCE (ADAFI), DRC [HUMANITY & INCLUSION INTERVIEWEE]

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HI staff conducting an assessment of extremely vulnerable individuals during the Rohingyas refugees crisis.

© M. A. Islam / HI

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## Challenges

Some of the data collected led organisations to question what to do next – next steps were not immediately apparent. The identification of high percentages of persons with disabilities felt overwhelming to some organisations and made them question their role in supporting these constituents.

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**“My concern is that I am being left with data that provides a huge prevalence [...] for example that 60% of the population has a disability and I don’t have funding to do anything about it.”**

INTERNATIONAL MEDICAL CORPS UK [HUMANITY & INCLUSION INTERVIEWEE]

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Humanity & Inclusion found that many actors felt they required supplementary/additional questions to measure inclusion (risks, barriers & facilitators) and/or to gather data around disability to usefully inform their activities.

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**“As a kind of rapid assessment it could be good but for long term programming it might not be sufficient.”**

ACTION AGAINST HUNGER, PHILIPPINES [HUMANITY & INCLUSION INTERVIEWEE]

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Inclusion was identified as a key aspect organisations need to learn about and address, as this principle *should* directly impact programme planning and implementation. If organisations are collecting data around disability but have an incomplete understanding of inclusion, the effective connection of the data and programme implementation is limited.

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**“Large numbers of humanitarian aid workers; they don’t know what is the meaning of inclusive. They don’t know actually how to make services inclusive. How to create an inclusive environment, and what tactics you need to be followed in order to create and have a welcoming and proactive environment.”**

HUMANITY & INCLUSION OFFICER, JORDAN – KII [HUMANITY & INCLUSION INTERVIEWEE]

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## Best practices

By integrating questions into existing surveys, organisations were able to cross reference other key factors, such as gender or location, to better understand the target population and/or measure access of persons with disabilities in the different project activities. In other words, the data could be disaggregated.

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**“The questions have given us a better understanding of the people we work with and the challenges that they face – broadening our outlook on their lives – not just the disease.”**

LEPRA [LEONARD CHESHIRE INTERVIEWEE]

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**“In Jordan, the World Food Programme (WFP) conducted a Food Security Outcome Monitoring (FSOM) by adding the WGQ. WFP were able to disaggregate these key outcomes indicators by disability to understand whether their services were reaching persons with disabilities.”**

[SHORT CASE STUDIES FROM HUMANITY & INCLUSION]

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## 5. Conclusion

**When used correctly, the WGQ can identify the prevalence of disability within a programme. And more often than not, the use of the WGQ by humanitarian and development actors resulted in positive culture changes in approaches towards disability and inclusion.**

The WGQ can be used by development and humanitarian actors in their data collection efforts. However they are not for every situation or context. Organisations need to be clear about the needs and objectives of collecting data on persons with disabilities and understand the strengths and limitations of the WGQ.

Used alone, they will not give all the information needed to design disability inclusive programming. They are not designed to be used in isolation, but built into a pre-existing data collection. By including the questions in a larger survey, disability status can be disaggregated against other indicators to assess and monitor how individuals with disabilities compare to their peers without disabilities.

In both the Leonard Cheshire and Humanity & Inclusion studies, where training had been administered, the majority of participants stated that it was well received, with a considerable and immediate impact on how persons with disabilities were perceived. The research identified that training was administered in different ways. Some organisations used broad schemes bringing in members of the WG Secretariat team, or key members attending training through Leonard Cheshire, UNICEF, UNSD, IDA or other groups. Many reported using the growing material on the WGQ website but requested more guidance on how to use the questions.

Humanity & Inclusion both administered training to partners taking part in the research and included a sensitisation session on disability. A number of other organisations surveyed reported the same. Training for data collectors and programme staff to ensure that the questions are translated and asked correctly was especially important.

Whilst the 'Leave no one behind' agenda is gaining pace and organisations are recognising the need to include persons with disabilities, organisations need to be mindful of how to and when to use the questions. Understandably, nearly all organisations identified the need for more training and guidance to ensure that they have the capacity and understanding of how to use the questions for inclusive programming. Adopting and embedding the WGQ is a process and it would be advisable for organisations to start with a small pilot project and scale up over time.

Furthermore, donors need to be realistic about the capacity and interest of INGOs to conduct the in-depth analysis of data envisaged by the design of the WGQ. If a donor is requiring the use of the questions, organisations who are unfamiliar with the Washington Group should seek support and resources and be connected with other organisations using the questions. Rushing too quickly to use the questions without appropriate training can lead to problems in terms of quality of the data collected and the ability to use that data to improve programmes.

These studies are the start of a process to understand better how the WGQ are used beyond their original purpose. Clearly, more needs to be done to understand how the WGQ perform in programming when used at scale. There is a need for more research and analysis of how the questions can be used by INGOs and NGOs for programme monitoring and evaluation and to monitor change and impact. More research is also needed to see how the WGQ affect programme design and implementation and the understanding of disability and inclusion in the future amongst mainstream humanitarian and development actors.

Leonard Cheshire and Humanity & Inclusion will continue to work together to prepare a more in-depth report of their research, analysis and findings.

## Top tips for INGOs and NGOs

1. Be clear about the purpose of the WGQ – they cannot be used as a diagnostic tool.
2. If your target population is children, use the the Child Functioning Module, as the WG Short Set is not appropriate for children under 5, and for older children many with developmental disabilities will be missed.
3. Use the questions exactly as they are written (never skip a question or guess the answers); never use a screening question and/or refer to ‘disability’ or ‘medical condition’.
4. Use translations of the questions verified by the WG. Consult the translation protocol on the WG website for guidance.
5. Ensure that your data collection tools and management information system can be adapted to use the WGQ.
6. Make training available to staff involved in the data collection and analysis and integrate training around disability awareness and inclusion.
7. Ensure that enumerators are trained to ask questions sensitively and manage expectations when asking questions.
8. Ensure that the data analysis phase is planned and adequately supported.
9. Work with other INGOs to share knowledge, data and best practice.
10. Promote the participation of and accountability towards persons with disabilities and disabled people’s organisations (DPOs) in efforts related to data collection and decision-making processes.

## Considerations for humanitarian coordination mechanisms

1. Advocate for the incorporation of the WGQ in survey processes such as Demographic Health Surveys and Multiple Indicator Cluster Surveys, as well as national censuses in high humanitarian risk countries.
2. Identify other entry points in humanitarian data collection processes where the use of the WGQ is appropriate.
3. Modify standard data collection tools and databases used in humanitarian action to include the WGQ.
4. Improve the Inter-Agency Standing Committee (IASC) registry of humanitarian indicators by proposing the development of new indicators on inclusion of persons with disabilities and reviewing/promoting existing ones.
5. Use inter-agency and sectoral mechanisms as well as open platforms to share data on persons with disabilities.

## Considerations for donors

1. Strengthen the demand for data on persons with disabilities in humanitarian action through donor reporting requirements.
2. Advocate for the use of the WGQ in programme design and monitoring activities and highlight its endorsement by persons with disabilities.
3. Where organisations are mandated to use the WGQ in grants, donors should also support grantees to build technical expertise and capacity to use the questions – especially at planning, implementation and analysis stages.
4. Provide financial and technical support for the development of further WG resources for INGOs, with practical examples of how the questions have been used by different types of NGOs (and other organisations) in a range of settings.

## Advice for the Washington Group on Disability Statistics

1. Share training resources with more practical examples of how the questions have been used by different types of NGOs (and other organisations) in a range of settings.
2. Continue to facilitate the sharing of best practice and examples of how the WGQ have been used successfully and establish/strengthen links with INGOs of all kinds that are using or interested in using the questions.
3. Make validated translation documents available, and create more where indicated.

## Next steps for Leonard Cheshire and Humanity & Inclusion

1. Publish the full findings of respective research studies.
2. Work with donors and interested partners to develop training and tools to support organisations mandated to use the WGQ in grants to build technical expertise and capacity in organisations.
3. Collaborate with the WG and interested partners to investigate what complementary information is needed for disability inclusive programming to understand barriers and facilitators towards inclusive programming in more depth.
4. Develop guidance on disability inclusive programming (data collection, analysis and use).
5. Support the development of open source resources such as the Disability Data Portal and develop partnerships to support greater data disaggregation by disability and data visualisation.
6. Raise awareness of the importance of collecting and using data to promote and strengthen the rights of persons with disabilities in humanitarian contexts in line with the State obligations under CRPD Articles 11 and 31.

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