

Hidden victims of the Syrian crisis:

disabled, injured and older refugees



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Hidden victims of the Syrian crisis: *disabled, injured and older refugees*

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Executive summary

The Syrian crisis has generated the largest refugee movement since the Rwandan genocide and is described as the defining refugee crisis of our era. According to the United Nations High Commissioner for Refugees, Antonio Guterres, Syrian refugees are about to replace Afghans as the world's largest refugee population.¹ Within this refugee population older, disabled and injured refugees face specific challenges that contribute to their vulnerability, yet, studies of humanitarian programming show that these same groups are often neglected in the assessment, data collection, design and delivery of responses.

Therefore, in October and November 2013, Handicap International and HelpAge International undertook a research project to highlight the number and needs of Syrian refugees in Jordan and Lebanon living with impairment,² injury³ and chronic disease⁴ – for the purposes of this study these groups are referred to as “people with specific needs”. Throughout the report specific consideration is given to the position of older people with specific needs. Due to access and security constraints it was not possible to collect data in Syria itself, however it is recognised that the needs of refugees identified in the following report will be reflected within Syria, and that in this more extreme humanitarian situation the issues outlined below demand further consideration and response.

The findings of this work present a new and critical perspective on the position of the identified groups and the risks and vulnerabilities they face, with far-reaching consequences for the way current humanitarian responses are designed and delivered. As such, the report aims to contribute to the evidence base humanitarians use to design responses, and to support the delivery of inclusive activities which identify and respond to the needs of people with specific needs.

The study shows that of the Syrian refugees surveyed:

- 30 per cent of refugees have specific needs: one in five refugees is affected by physical, sensory or intellectual impairment; one in seven is affected by chronic disease; and one in 20 suffers from injury, with nearly 80 per cent of these injuries resulting directly from the conflict.
- Older people account for 10 per cent of refugees with specific needs, yet they make up 4-5 per cent of the surveyed refugee population meaning they are disproportionately affected; 77 per cent of older refugees surveyed have specific needs.
- Refugees with and without specific needs have the same basic concerns – a lack of income, availability and quality of shelter, and access to basic healthcare, food and essential household items.
- The difficulties faced by those with specific needs in addressing basic concerns and accessing adequate levels of assistance have more severe consequences for their health and living conditions than the general refugee population.

While the psychological impact of the crisis on children has received significant attention, the same is not true for other potentially highly vulnerable population groups. The survey findings paint a bleak picture for refugees with specific needs:

- They are twice as likely as the general refugee population to report signs of psychological distress.
- 65 per cent of older refugees present signs of psychological distress.

1. Reuters (2014), Syrians set to replace Afghans as largest refugee population: U.N. www.reuters.com/article/2014/02/25/us-syria-crisis-un-idUSBREA101MA20140225

2. Impairment is a problem in body function or structure.

3. Injury is the damage to the physical body of a person, resulting from an event (not from a disease or long-term process).

4. Chronic diseases are not passed from person to person. They are long-duration and generally slow-progression diseases that fall into four main types: cardiovascular diseases (such as heart attacks and stroke), cancers, chronic respiratory diseases (such as chronic obstructed pulmonary disease and asthma) and diabetes.

Finally, the study provides an insight into the challenges faced by refugees with specific needs in undertaking basic daily activities. The assessment of challenges faced in conducting such activities forms a crucial part of the evidence base on disability in the refugee population, and suggests a higher level of disability among refugees than assumed to date:

- 45 per cent of surveyed refugees with specific needs have problems in accomplishing simple daily living activities.
- Injury, permanent impairment, chronic disease and older age are all shown to increase the likelihood of refugees facing such challenges.

Supporting refugees with specific needs demands a change in the type of humanitarian assistance available, and the way in which it is delivered. Handicap International and HelpAge International recommend that national and international actors involved in providing assistance to Syrian refugees:

- Collect, analyse and use sex, age and disability disaggregated data (SADDD) to support programme design and implementation.
- Sensitise and build staff capacity to identify and include people with specific needs in service delivery to address both their basic needs (eg income and health care access etc) and specialised needs (eg physiotherapy, provision of prosthetics).
- Ensure all services and assistance are available and accessible by people with specific needs.
- Develop strategies that strengthen existing family and community support mechanisms for people with specific needs.
- Address gaps in the quality of primary healthcare services for those with chronic disease.
- Ensure medical assistance and longer-term rehabilitation is available for post-operative patients (to avoid creating disabilities).
- Ensure projects that address the needs of refugees with specific needs receive the necessary funding support.
- Support central governments and local authorities to adapt strategies, services, infrastructure and regulatory frameworks to ensure accessibility by older, disabled and injured refugees, and support recognition of their rights.



Gwenn Dubourthoumieu/Handicap International

Summary of survey findings

Syrian refugees with an impairment

- 22 per cent of surveyed Syrian refugees have an impairment; 6 per cent have a severe impairment.
- Of those 22 per cent, half experience difficulties in daily living activities.
- 44.2 per cent of impairments recorded in this survey were physical, 42.5 per cent sensory and 13.4 per cent intellectual.
- Just 1.4 per cent of UNHCR-registered refugees in Lebanon are recorded as having a disability.
- 20 per cent of refugees with impairment are affected by more than one.
- The survey highlighted a higher prevalence of impairment in Jordan (26 per cent) compared with Lebanon (20 per cent).
- 7 per cent of surveyed refugees suffering from non-communicable diseases also have an impairment.

Syrian refugees with chronic diseases

- 15.6 per cent of the surveyed Syrian refugees have a chronic disease.
- 54 per cent of older surveyed refugees have a chronic disease.
- 7 per cent of interviewed refugees suffer from both impairment and chronic disease.
- 10 per cent of those aged 0-30 are affected by chronic disease.
- 30 per cent of those aged 30-50 are affected by chronic disease.
- Half of those aged 50+ are affected by chronic disease.
- In Jordan 19.6 per cent of surveyed refugees have a chronic disease and 13 per cent in Lebanon.

Injured Syrian refugees

- 5.7 per cent of surveyed Syrian refugees in Jordan and Lebanon have a significant injury.
- 80 per cent of injuries were sustained as a direct consequence of war in Syria.
- In Jordan, one in 15 Syrian refugees has been injured. The highest percentage of people with injuries are found in Zaatari camp (8.9 per cent).
- In Lebanon, 1 in 30 Syrian refugees has been injured because of war. The highest percentage of people with injuries is found in North Lebanon (10 per cent).
- Men account for 72 per cent of injured people and women for 28 per cent, while the levels of injury among children is the lowest of all the age groups.
- 55 per cent of injured people have difficulties in performing daily living activities without support.

Older Syrian refugees

- 5 per cent of surveyed refugees are older people, but they make up 10 per cent of those with specific needs.
- 77 per cent of older people have specific needs.
- 54 per cent of older people have a chronic disease.
- 66 per cent of older people have an impairment.
- 33 per cent of older people have a severe impairment.
- 60 per cent of older people have problems in daily living activities.
- 65 per cent of older people present signs of psychological distress.
- 13 per cent of heads of households are older people.
- Where an older person is present in a family they are head of the household in 6 out of 10 cases.

Objectives and methods

Objectives

The data collection and analysis is designed to provide robust evidence of the numbers and needs of older people, and people with impairments, injuries and chronic disease. The data collection methodology was designed to enable comparison between these groups and refugees who do not present these specific conditions. The findings are intended to contribute to the evidence base that humanitarian partners use to design and deliver assistance and advocacy, to ensure the needs of the identified groups are more effectively addressed by the ongoing response in Jordan and Lebanon.

Study design

The survey was undertaken in seven areas of Jordan and Lebanon; specifically North Lebanon, Bekaa, Beirut City and Mount Lebanon governorates in Lebanon; and Irbid and Amman governorates and Zaatari Camp in Jordan. These locations host high concentrations of refugees and provide a perspective on the different contexts refugees are living in – rural, peri-urban, urban and camp based.

The refugee population in Jordan and Lebanon is made up of three groups: United Nations High Commissioner for Refugees (UNHCR) registered and unregistered refugees, including those pending registration. To ensure the perspectives of these three groups were included in the study, two sampling methods were used:

- A main random cluster sampling was used to identify registered refugees. Clusters were selected based on the population density of registered refugees (source: Cadastral registration data in Lebanon and UNHCR registration data in Jordan).
- An additional random sampling was planned using the databases of humanitarian partners to identify non-registered refugees. The objective was to apply the currently accepted ratio of registered to non-registered refugees to define the two samples sizes. Unfortunately partner databases were not available and hence a word-of-mouth 'snowball' sampling approach was used to identify and interview non-registered refugees.

Sampling

A total of 3,202 registered and non-registered refugees, including those pending registration, were interviewed. Thirty random clusters out of 100 were selected in each governorate and in Zaatari camp. Each group of 30 clusters was designed to contain at least 410 Syrian refugees in order to produce a maximum of 5 per cent of margin of error, for a prevalence of 20 per cent (the estimated percentage of people with specific needs in the population), a confidence interval of 95 per cent, and a design effect of 1.5 and 10 per cent non-response. Final data collection resulted in clusters of 429 people in Jordan and 478 people in Lebanon on average.

Study population and inclusion criteria

All members of households were enumerated, interviewed and screened. Older people were identified as those aged 60 years and above. People with impairment were identified through a specific questionnaire evaluating five categories: their ability to move around and/or reach and use objects; sight; hearing; speech; ability to learn and understand. People with injury and people with chronic diseases were screened by self-declaration and observation.

Data collection

The questionnaire formats were designed using a range of recognised tools and approaches. The HESPER scale⁵ was used to understand the expressed needs and problems of the Syrian refugee population. To identify people facing functional and activity limitations, and evaluate the degree of difficulties they experienced, a specific questionnaire and analysis of challenges in activities of daily living (ADL)⁶ were used.

5. WHO and King's College London (2011). The Humanitarian Emergency Settings Perceived Needs Scale (HESPER) provides a quick and scientific method of assessing the perceived needs of people affected by large-scale humanitarian emergencies, such as war, conflict or major natural disaster. www.who.int/mental_health/publications/hesper_manual/en (accessed 28 March 2014).

6. www.investopedia.com/terms/a/adl.asp



Gwenn Dubourthoumieu/Handicap International

All survey teams received a two-day training session covering the roles and mandates of HelpAge International and Handicap International, survey objectives and methodology, key concepts and themes, communication techniques, evidence-collection protocols and research ethics.

To complement, triangulate and validate primary data, the study involved an additional review of secondary information and key informant interviews with specialised staff from local organisations, international NGOs and agencies, as well as observational evidence collected during interviews with refugees.

The data was collected in Jordan in early October 2013 and in Lebanon in late October 2013.

Ethics

The study design did not present any risk of potential harm to participants resulting from the data collection process. During primary data collection, teams explained the purpose of the survey to participants using an information sheet in Arabic. Prior to completing the questionnaire, verbal consent was given by participating family members. For young people or those with intellectual impairment, consent was sought from a family member who was present during all interviews. All people with specific needs requiring further support were either informed or referred as necessary, with the agreement of UNHCR. In addition, the aims and objectives of the survey were discussed and agreed with UNHCR in Lebanon and Jordan, and national authorities (camp managers, heads of communities). Information about the survey was disseminated before the survey began through the usual humanitarian channels (working groups, coordination meetings). For the purposes of data collection and storage all responses were anonymised.

Data analysis

Descriptive analyses using multivariate analysis statistical hypothesis tests (chi² for variance, independence, etc) were used in order to describe and compare the various groups considered by the study and validate the statistical relevance of the findings.

All major statistical results in this report present restricted standard deviations:

- For findings covering both countries: the margin of error is ± 1.7 per cent.
- For findings at country level: the margin of error is ± 2.2 per cent for Syrian refugees in Lebanon and ± 2.7 per cent in Jordan.
- For findings at governorate level: the margin of error for Syrian refugees in Lebanon is ± 4.4 per cent and ± 4.6 per cent in Jordan.

Limitations

During the data collection phase, challenges were encountered that affected the make-up of the study sample. Firstly, access constraints caused by insecurity meant survey teams were not able to reach several areas in the North governorate of Lebanon (North East Akkar), and had limited time in several areas of Bekaa valley (Baalbek, Aarsal and Hermel). Secondly, as data collection was undertaken during the day, some family members (mostly adult and older men) were not at home as they were working, or searching for work. Finally, some of the youngest children (under the age of two) were not accounted for in the study. Consequently, in comparison, men, young children and older people form a slightly lower percentage of the interview sample. No corrections have been applied to the presented findings because this slight under-representation does not impair the validity of the findings.

The lack of trained mental health experts meant it was not possible to undertake a detailed evaluation of the situation of refugees affected by mental disability;⁷ this component is therefore not included in this study.

The survey design allows for the findings presented to be extrapolated from the sample of surveyed refugees to the wider refugee population at governorate and country level, with the necessary precautions. Such extrapolated estimations are not included in this report.

7. For mental disability definition, see Annex 2.

Analysing the vulnerabilities of Syrian refugees

Evaluating the vulnerability of a person or group in a humanitarian emergency is highly challenging, mainly because vulnerability encompasses a variety of interconnected conditions and situations at personal, family and community levels.

For the purposes of this study we have used the following definition of vulnerability: *“The characteristics of a person or group and their situation that influence their capacities to anticipate, cope with, resist and recover from the impact of a... hazard (an extreme... event or process). It involves a combination of factors that determine the degree to which someone’s life, livelihood, property and other assets are put at risk by a discrete and identifiable event (or series or cascade of such events) in nature and in society.”*⁸

To better understand the complex individual and family-level vulnerability of the Syrian refugee population, the study looks at specific conditions and how they affect this particular population’s capacity to cope with their refugee situation.

These conditions are:

- an impairment⁹
- a chronic disease¹⁰ (excluding injury)
- an injury.¹¹

Within the context of this study, and throughout this report, people affected by one or more of the conditions above are termed ‘people with specific needs’.

The data collected for this study is fully disaggregated by age and gender, enabling a systematic age and gender analysis of ‘people with specific needs’. Such analysis is critical as it recognises that the roles individuals play in the family, the community and in society at large are defined and established largely on the basis of gender and age. These ‘universal determinants’ of an individual’s position will play an equally important role in how they cope with emergencies, for example, how possible it is for them to access services, or the likelihood that they will be affected by injury.

A note on ‘vulnerability’

It is important to recognise that the decision to analyse these specific conditions and how they impact on vulnerability is based on the detailed and extensive operational experience of HelpAge International and Handicap International in displacement contexts,¹² and ongoing joint operations in Jordan and Lebanon. It is not assumed that all those with impairment, chronic disease or injury are vulnerable, or that age and gender have a systematic impact on vulnerability.

The objective of this study is to provide humanitarian partners with a better understanding of how such conditions affect people’s experience of the current crisis, and contribute to a more nuanced picture of vulnerability in support of more effective programming.

Report structure

The report has three main sections. The first presents an overview of the complex picture of people with specific needs in Jordan and Lebanon, taking into account interconnections of the conditions above, their registration status and levels of family support. The second section presents an in-depth analysis of the prevalence of the selected individual conditions above, providing additional cross-analysis with age, gender and refugees’ locations. Finally, the report examines the negative impacts of displacement on the chosen population sub-group, as compared with the wider Syrian refugee population. In this section, specific attention is given to analysis of difficulties in addressing basic needs, in performing activities of daily living (ADL) and in signs of psychological distress. Assessment of challenges in undertaking daily living activities forms a crucial part of the evidence base on the number of people affected by disability moving away from a simple focus on visible conditions.

8. Wisner B, Blaikie P, Cannon T, Davis I (2005). *At Risk: Natural hazards, people’s vulnerability and disasters*. New York: Routledge

9, 10 and 11. See definition in Annex 2.

12. This study builds on an existing body of documented experience on displacement. In 2012, HelpAge published *The neglected generation: the impact of displacement on older people*. The study examined the situation of older internally displaced people, and identified the specific risks and challenges they face in such contexts, and the capacities and strategies developed to address their needs.

The Syrian conflict and the situation of refugees

The conflict in Syria was triggered by protests in mid-March 2011. Three years later (at the time of writing) it has evolved into a complex and protracted humanitarian crisis, spilling into neighbouring countries and the wider Middle East region, with an estimated 9.3 million people now in need of humanitarian assistance.

Within Syria, 6.5 million people have been internally displaced¹³ – a level of displacement unprecedented in the Middle East. In 2013 alone an estimated 1.4 million people fled the conflict, and in January 2014 UNHCR estimated that a staggering 2.37 million people were displaced outside the country, primarily in Jordan, Lebanon, Turkey, Iraq and Iraqi Kurdistan. Thousands more fled to the Caucasus, the Persian Gulf and North Africa.

The reasons for leaving Syria are clear – the severity of the conflict, fear of atrocities committed against civilians by both sides, and declining resources inside the country have made it impossible for millions of Syrians to stay. Those who leave, and particularly those with older, disabled or injured people in their families, often face difficult journeys to reach the safety of neighbouring countries. At the same time, the sheer number of Syrian refugees and the duration of their displacement in countries such as Jordan and Lebanon has put a huge strain on the resources and capacity of host governments and communities.

Employment opportunities in both countries – limited even before the crisis – are being eroded further both by the economic burden of the conflict (resulting in part from reduced trade with Syria), and by the growing supply of cheap refugee labour. The World Bank estimates the total financial impact of the Syrian crisis on the Lebanese economy to be US\$2.6 billion (as at September 2013). Between 2012 and 2014, Lebanese gross domestic product (GDP) fell to 2.9 per cent, pushing 170,000 Lebanese into poverty (in addition to the 1 million currently living below the poverty line), and doubling the unemployment rate to over 20 per cent.¹⁴ It is no surprise, therefore, that in Jordan (now host to over half a million refugees) and in Lebanon (now hosting close to a million refugees), the pressure on services such as health, water supply, basic commodities and shelter is pushing national capacity to breaking point and creating tensions with local communities.

Since 2012, Handicap International and HelpAge International have been working in partnership in Jordan and Lebanon to support and address the needs of Syrian refugees – specifically those who are older and those living with a disability or who are injured. While these refugees share the same difficult living conditions as the general refugee population, they face increased challenges in accessing basic services and meeting basic and specific needs because these services are rarely made inclusive and accessible for these groups. The situation is compounded by a lack of reliable and disaggregated data on the prevalence and numbers of these population groups, making the design of programmes to address their needs highly challenging. This report is designed to address this gap, and promote awareness and understanding among humanitarian actors of the plight of these refugees to ensure their needs can be met through the delivery of impartial, accountable and inclusive humanitarian assistance.

13. www.internal-displacement.org/countries/syria (accessed 28 March 2014)

14. World Bank, 'Lebanon: Economic and Social Impact Assessment of the Syria Crisis', www.worldbank.org/en/news/feature/2013/09/24/lebanon-bears-the-brunt-of-the-economic-and-social-spillovers-of-the-syrian-conflict (accessed 14 March 2014)



Lydia de Leeuw/Handicap International

Section 1

Overview: people with specific needs

Overview: people with specific needs

In Jordan and Lebanon, more than 30 per cent¹⁵ of the Syrian refugees surveyed have specific needs.

Among the reviewed conditions (impairment, injury or chronic disease), impairment is the most frequently reported, with 22.4 per cent¹⁶ of the people interviewed for this study presenting with some functional limitations to physical mobility, vision, hearing or intellectual ability. For 6 per cent¹⁷ of the surveyed population the impairment is severe.¹⁸ The second most reported conditions are chronic diseases, which affect 15.6 per cent¹⁹ of those surveyed. Finally, 5.7 per cent²⁰ of the surveyed Syrian refugee population are affected by injury.

The study results further show the complex interaction between the different conditions identified by the study, with **one third of people with specific needs experiencing more than one condition**. Chart 1 represents more precisely the interconnection of individual conditions within the Syrian refugee population with notable overlaps between those with chronic disease and those with impairment. Further analysis of these findings is presented in Section 2.

15. n=997; 31.1 ± 1.94%

16. n=716; 22.4 ± 1.76%

17. n=193; 6.03 ± 1.01%

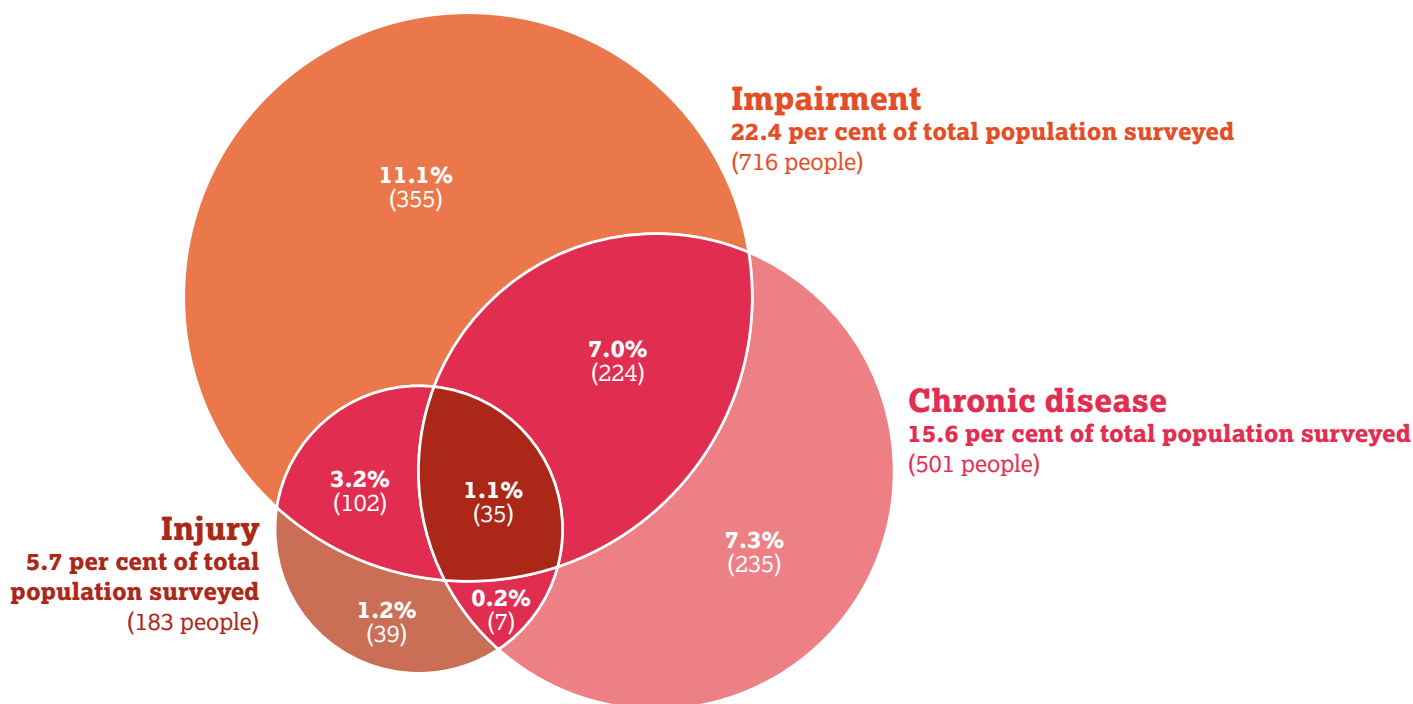
18. By serious limitations or impairments, we mean those that completely, or almost completely, affect one or more bodily functions.

19. n=501; 15.6 ± 1.55%

20. n=183; 5.72 ± 0.98%

Chart 1: Number and percentage of people with specific needs in the surveyed Syrian refugee population

Handicap International and HelpAge International, 2013



Age analysis

Among surveyed refugees, older people account for almost 5 per cent²¹ of the total sample, compared with current UNHCR refugee registration data that shows on average (in Jordan and Lebanon) the older refugee population accounts for just 3 per cent of the total population.²² The difference between the two data sets is explained in part by the challenges faced by older refugees in reaching registration points – these factors are explained in more detail on page 16.

Within the population with specific needs, older people are over-represented, accounting for 10 per cent of the sample – a finding that contrasts with the total proportion of older people in the population. Further analysis of the situation of older refugees shows that of those surveyed, a massive 77 per cent have specific needs as defined by this study, suggesting they will face increased risks and challenges in accessing services and meeting basic needs.

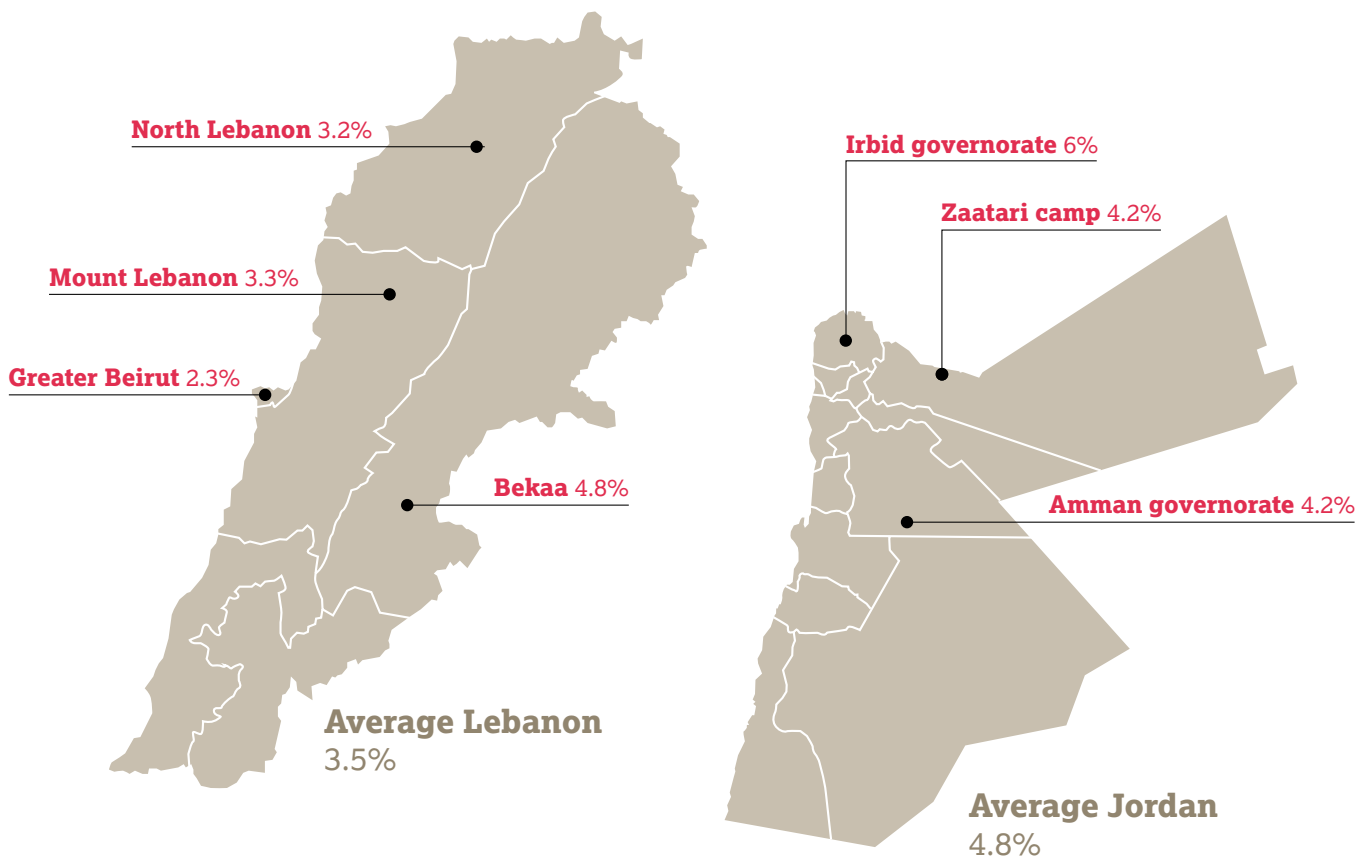
Map 1 shows the differing distribution of the older refugees surveyed for this study.

21. 4% among interviewed people, 5% according to interview with refugee families (n= 218; 4.97 ± 0.92%)

22. UNHCR Syrian regional refugee response. Jordan: 3.4%, Lebanon: 2.7% (data accessed 21 January 2014)

Map 1: Proportion of older surveyed refugees in Lebanon and Jordan

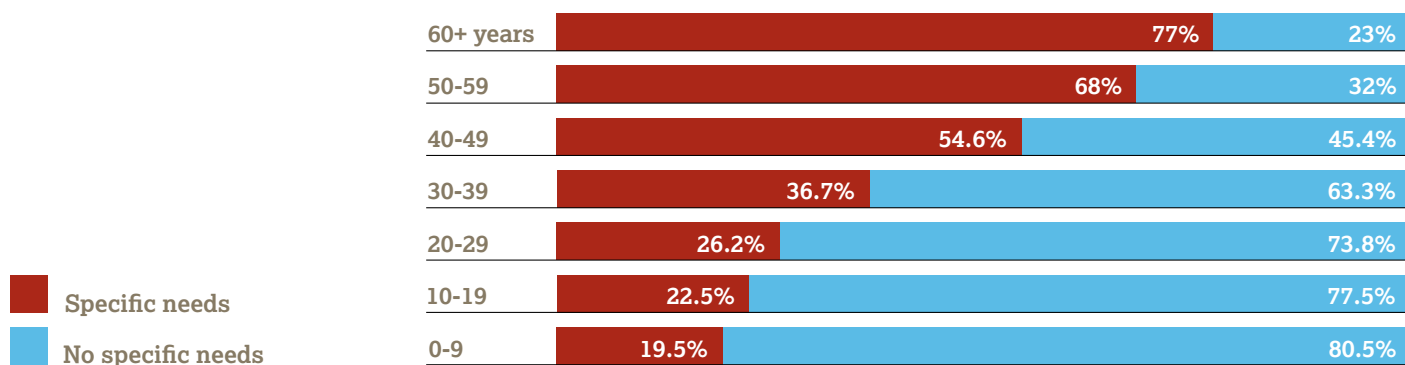
Handicap International and HelpAge International, 2013



Broadening our age analysis from a focus on older people we can identify a clear trend in the relationship between specific needs and age, as illustrated in Chart 2. For those aged 40 and above, **more than half have specific needs** as defined by this study.

Chart 2: Percentage of survey refugees with specific needs per age category

Handicap International and HelpAge International, 2013



Gender analysis

The survey findings identified no significant differences in the overall proportion of men and women in the population of people with specific needs, compared with the general population (ie the surveyed population unaffected by any of the identified conditions). However, within sub-populations (injured for example), clear discrepancies appear. These trends are analysed in more detail in Section 2.

Family support structures

The findings of the analysis provide important insights into family structures. Specifically, families in which one member has specific needs are considerably smaller than families in the wider refugee population – 2.4 family members on average, compared with close to six in the general population.

The finding is of particular importance to humanitarian actors as it is commonly assumed that care and the necessary support to access services for those with specific needs will be provided by the family. In cases where the family support structure is small, both individuals and families are likely to experience drastically reduced levels of support, particularly in cases where family members are often working away from the home, or searching for employment. Interestingly however, older people continue to live in family units of comparable size to the general population ie close to six people.

While the study did not investigate in detail the reasons for this difference, two explanations were identified based on discussions with data collection teams, and HelpAge International and Handicap International staff:

- In many cases, families reported that only the family members with specific needs and their caregivers were able to leave Syria.
- In some other cases, the teams noted that families with members who had specific needs were dividing themselves into smaller family units when registering with UNHCR or the authorities in order to access additional assistance.

Geographical distribution of refugees with specific needs

While surveyed areas in Jordan are essentially urban areas (Amman, Irbid and their suburbs) and camps (Zaatari), the refugee population in Lebanon is more dispersed throughout the country. In Lebanon, the study found that people with specific needs are more commonly living in rural areas (33.8 per cent²³ of the refugee population) and less commonly in urban areas (23.5 per cent).²⁴ In addition, the study highlights that in Lebanon, people with specific needs are not equally represented in the various governorates. In fact, they represent more than 40 per cent of Syrian refugees in North Lebanon governorate and 30 per cent in Bekaa governorate, but only 25 per cent in Mount Lebanon and 18 per cent in Beirut.

Families identified a number of factors that influenced their decision about where to settle. Among them, the most frequently reported (in order of prevalence) are:

- **Ethnicity and religion** Northern Lebanon is mainly Sunni, while Bekaa and Mount Lebanon are religiously mixed (most Syrian refugees come from a Sunni background).
- **Proximity to families originating from the same area** Families from the same villages tend to resettle together, if possible. In addition, family or traditional links between contiguous areas either side of the border are a strong consideration when deciding where to settle.
- **Socio-economic factors** For some refugees (including those from urban areas), life in rural areas poses fewer financial challenges and offers a better quality of life. Furthermore, in Lebanon, support from the local community is perceived as stronger in rural areas than urban areas.
- **Availability of services and possibility of access to such services** This is perceived as being better in certain areas, such as Bekaa and North Lebanon.
- **Affinity with the environment** Refugees from rural origins tend to settle in rural areas and those from urban origins in urban areas. In addition, the rural population in Syria is largely older compared with urban areas. Given that the population of refugees with specific needs is also proportionally older than the general refugee population, it is more likely these groups will settle in rural areas.
- **Low mobility** Families travelling with one or more people with limited mobility face challenges during resettlement and are more likely to settle in areas nearer the border such as Bekaa and North Lebanon.

In Jordan, the reasons refugees gave for choosing where to settle are similar to those in Lebanon. Newcomers try to reunite with families and friends who left Syria earlier and tend to stay with other families from the same area. The other considerations are socio-economic factors and availability of services (health, education etc). However, teams did not note reasons related to mobility or religion.

Registration

It was not possible to ensure the desired representation of non-registered refugees in Lebanon and Jordan.²⁵ (See the study design description on page 7 for more details.)

While the survey findings indicate differences in the degree of registration among the surveyed population in Jordan and Lebanon, and in different governorates of these countries, on first examination the results of the surveyed population do not show significant differences between the levels of registration among those with specific needs and the general population (those without specific needs).

In Lebanon, our findings show 77 per cent of refugee surveyed were registered and 14.5 per cent unregistered. The remainder were pending registration or did not answer the question during the interview.²⁶

23. n=647; 33.80 ± 2.59%

24. n=450; 23.51 ± 2.32%

25. The research team was unable to obtain lists of identified, but non-registered, refugees from partners to interview for the study. Consequently, the sample of non-registered refugees was reached by collecting data through door-to-door surveys, and based on guidance from registered refugees. As such, the sample does not reach the expected rate of registered and non-registered refugees.

26. 2.9% of people were pending registration. In 5.7% of the cases, the question on registration status was not answered.

In Jordan, the results show a higher level of registration, with 94.6 per cent registered and 3.6 per cent²⁷ unregistered. In Zaatari camp, all families involved in the survey were registered or in the process of being registered. The higher rates of registration in Jordan are explained by the fact that the registration process is much simpler and trusted by most refugees, and that most refugees enter via official border crossings to camps where they are all registered.

However, a closer examination of the survey findings shows that among surveyed registered refugees:

- People with impairment are under-represented – they may be registered but their impairment is often not recognised or recorded.
- Older people are significantly under-registered compared with other groups.

As an illustration, in Lebanon 16 per cent of people with severe impairment and 25.8 per cent of older people were not registered compared to 16.2 per cent and 12.6 per cent respectively for other adults and children.²⁸

Non-registration can have a serious impact on access to basic services such as healthcare and cash assistance. Last year, a survey among Syrian refugees and Lebanese people who had been living in Syria but were driven out by the war showed that 63 per cent of them did not receive any form of assistance from any NGO.²⁹ The precarious position of non-registered refugees is supported by evidence from UNHCR's own assessments in Lebanon which show that 17 per cent of the refugees they surveyed were unregistered and that unregistered refugee households were often living in substandard accommodation compared with registered households (meaning a factory, warehouse, worksite, garage, unfinished shelter or tent).³⁰

The main reasons for non-registration are:

In Lebanon

- Difficulties are faced in reaching registration points because of the distance, lack of transport or cost of travel, or difficulties in bringing all family members to registration points.
- There is a lack of information about the registration process.
- Families and individuals expect no improvement in their living conditions following registration.
- A large number of registered refugees reported they had been removed from UNHCR 'service lists' as part of UNHCR's rationalisation of beneficiary lists in response to the underfunding of the Regional Response Plan (currently 73 per cent funded).³¹ Surveyed refugees who have been excluded from assistance report advising new arrivals against registration as they do not see the benefits.

In both Lebanon and Jordan

- Some people fear possible consequences of registration – they do not want to see their names recorded on official documents.
- Some families think they lack the necessary documentation – they left their homes in a hurry, leaving their documents behind, or lost their document on the way.

27. 1.2% of people were pending registration. In 0.6% of the cases, the question on registration status was not answered.

28. The WHO Report on Disability (2011) estimates that 15.3% of the world's population has a moderate or severe disability and this rises to 18% to 20% in conflict-affected populations.

29. Médecins Sans Frontières, *Misery beyond the war zone: Life for Syrian refugees and displaced populations in Lebanon*, New York, Médecins Sans Frontières, 2013

30. UNHCR. *Winterization 2013-14 Baseline Report*, <http://reliefweb.int/report/lebanon/lebanon-winterization-2013-14-baseline-report> (accessed 14 March 2014)

31. UNHCR, Syria Regional Response Plan, <http://reliefweb.int/sites/reliefweb.int/files/resources/2014-01-08RRP5fundingtrackingallagencies.pdf> (accessed 14 March 2014)

Recommendations

Humanitarian responders should:

- Collect, analyse and use sex, age and disability disaggregated data (SADDD)
- Sensitise and build the capacities of staff to identify and include people with specific needs (people with impairment, injury, those suffering from chronic disease and older people) in response activities.



Section 2

People with specific needs: in-depth analysis of individual conditions

People with specific needs: in-depth analysis of individual conditions

This section explores the numbers and needs of those affected by the three conditions comprising this study's definition of 'specific needs'.

Impairment

Of surveyed Syrian refugees, 22 per cent³² have an impairment; 6 per cent³³ have a severe impairment.³⁴

In comparison, the WHO *World Report on Disability (2011)* estimates that 15.3 per cent of the world's population has a moderate or severe disability, and that this proportion is likely to increase to 18-20 per cent in conflict-affected populations.

Understanding impairment in humanitarian contexts is always complex. For the purposes of this study, data collection was completed using a set of questions evaluating a range of impairments divided into five categories (moving and reaching/using objects, seeing, hearing, speaking, and learning/understanding) to develop a more detailed picture of both the breadth of impairments affecting the refugee population and their severity.

At the time of data collection in Lebanon, 1.4 per cent of registered refugees were recorded by UNHCR as having a 'disability'. The recorded disabilities can be compared to what the survey defines as 'impairments', and their distribution is shown in Chart 3. Similar data was not available for Jordan.

Chart 4 shows the distribution of types of impairments identified by the survey.

32. n=716; 22.4 ± 1.76%

33. n=193; 6.03 ± 1.01%

34. By serious impairments, we mean those that completely, or almost completely, affect one or more bodily functions.

Chart 3: Breakdown of impairments among registered refugees in Lebanon

UNHCR, 2013

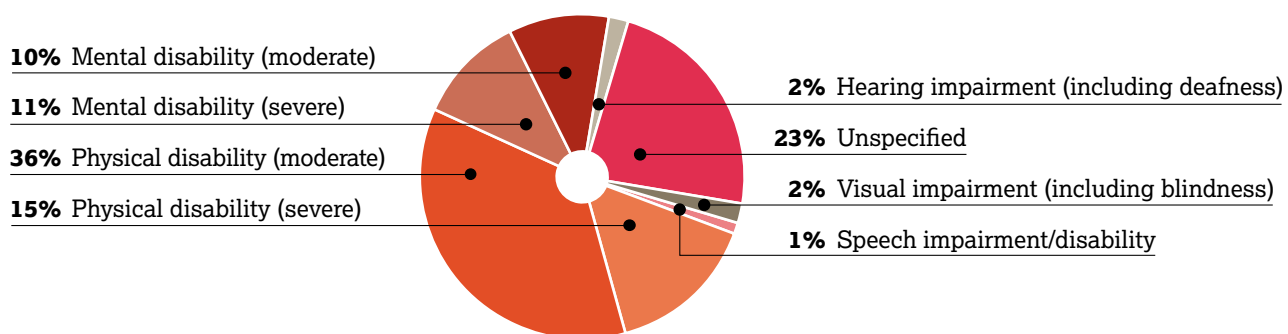
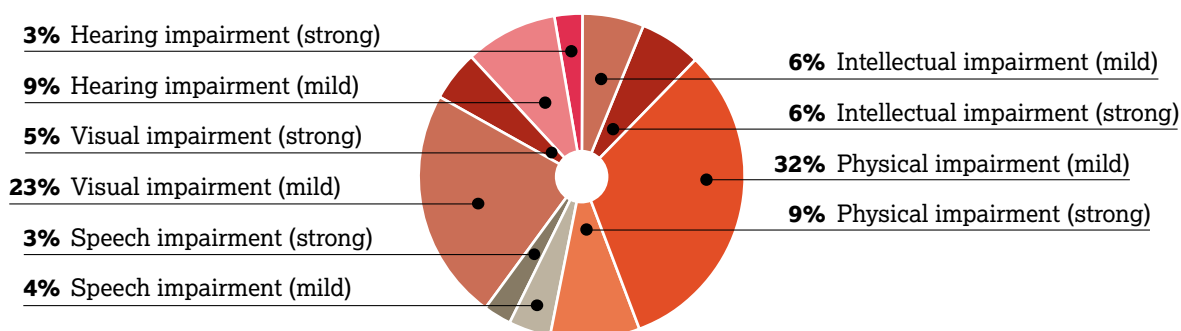


Chart 4: Breakdown of impairments among surveyed refugees in Jordan and Lebanon

Handicap International and HelpAge International, 2013





Gwenn Dubourthoumieu/Handicap International

Differences in definitions and data collection methodologies mean the data collected by UNHCR and the findings of the survey are not directly comparable. Nonetheless they provide an interesting and important insight into the current identification of impairment in the refugee population.

Limitations of the current registration system

In the UNHCR data, a significant percentage (23 per cent) of disabilities are ‘unspecified’. Furthermore, the survey results show that sensory impairments are less likely to be identified than physical impairments. Visual impairments account for just 2 per cent of impairment identified by UNHCR in contrast to 28 per cent of impairments identified in the surveyed population. Similar but less extreme differences can be found with hearing (2 per cent in UNHCR data and 12 per cent in survey data) and speech impairments (1 per cent in UNHCR data and 7 per cent in survey data).

The difference between the survey findings and the available data from Lebanon is stark. However, identifying impairment is a complex process and one that cannot be done easily by untrained staff. While the current UNHCR registration process includes a section on specific needs, the level of detail collected sometimes fails to identify all people with impairments and to differentiate between types of impairments. The survey process shows that in cases where impairments are not always visible but have consequences for people’s ability to undertake daily activities, these often only become apparent when more specific and tailored questions are asked.

The discrepancies in the findings indicate that those with debilitating but less severe conditions, such as visual impairments, are not being identified and are not receiving the support they need to access services. Consequently, there is an urgent need to build the capacity of UNHCR staff responsible for registration to identify those with impairments and to revise the current UNHCR registration format to ensure this information is accurately recorded and used in programme design. If people with impairments are not identified by service providers, they may be inadvertently excluded from assistance and support programmes.

Debriefings with data collection teams involved in the survey did indicate that some families are able to identify and access specific services such as physiotherapy and provision of assistive, prosthetic and orthotic devices at local level from providers such as Arc en Ciel in Lebanon, Jordan Health Aid Society (JHAS) in Jordan, and Handicap International or the International Committee of the Red Cross (ICRC) in both countries. However, the services available do not have sufficient capacity to address the specific needs of all those identified.

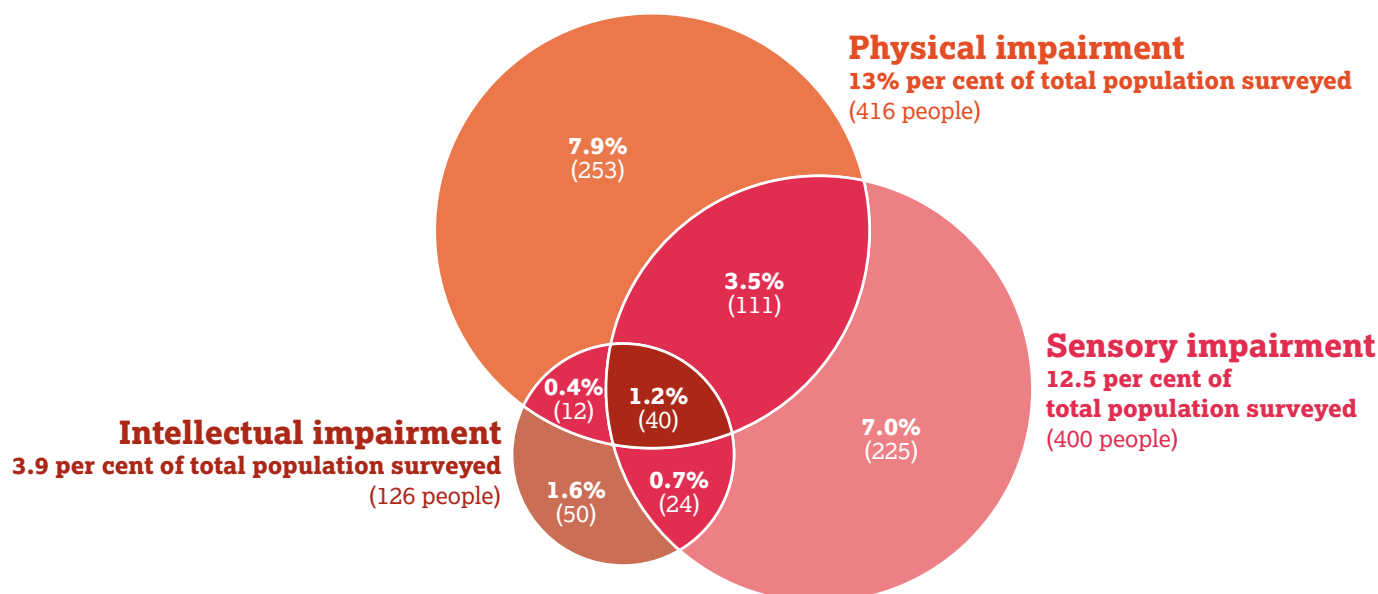
Interconnections between impairments

As with the presentation of specific needs above, the study did not simply classify people as being affected by impairment, but rather aimed to investigate the inter-connection between different conditions. The findings illustrate a much more complex picture than that found in previous analyses of the refugees in Jordan and Lebanon.

Among people with impairments, one in five is affected by more than one impairment. Chart 5 shows the interconnections. (Sensory impairments includes visual, hearing, and speech difficulties.)

Chart 5: Impairments of surveyed refugees broken down by type

Handicap International and HelpAge International, 2013



In Jordan and Lebanon the most commonly identified impairments were physical and/or sensory,³⁵ with one in five surveyed Syrian refugees affected.

Almost 4 per cent of all surveyed refugees have an intellectual impairment – a category of problem often under-reported by agencies and organisations. The prevalence is slightly higher among children (4.8 per cent)³⁶ and twice as high among older people (7.7 per cent). In two-thirds of these cases, intellectual impairment is associated with other types of impairment.

Teams reported that of all types of impairment, people with an intellectual impairment and their families face particularly extreme challenges in coping in their new environment due to the limited availability of specialised services and the lack of advice and support.

It is difficult to compare the survey data with global statistics on impairment because of the different systems of classification that are in use. The most similar reliable global data set comes from the Centers for Disease Control and Prevention (CDC).³⁷ If these data, drawn from the US population, are compared with our survey findings, common themes emerge around levels of impairment. As such, the survey findings can be said to present a clearer picture of the overall level of impairment than currently available to partners working in Jordan and Lebanon.

35. Sensory impairments includes visual, hearing and speech difficulties.

36. Where mothers were happy to discuss the status of their children, children were included in the survey sample and data was collected using the same survey format. The response rate was therefore slightly lower for children.

37. Centers for Disease Control and Prevention, www.cdc.gov/nchs/fastats/disable.htm (accessed 14 March 2014)

Gender and age analysis

Older people are disproportionately affected by impairments. Nearly 70 per cent of older people present with at least one type of impairment and they are nearly twice as likely as children to present with an intellectual impairment.

In contrast there is no significant difference in the sample between the proportion of men and women with impairment and the general refugee population (ie those refugees without specific needs).

Geographical distribution of refugees with impairment

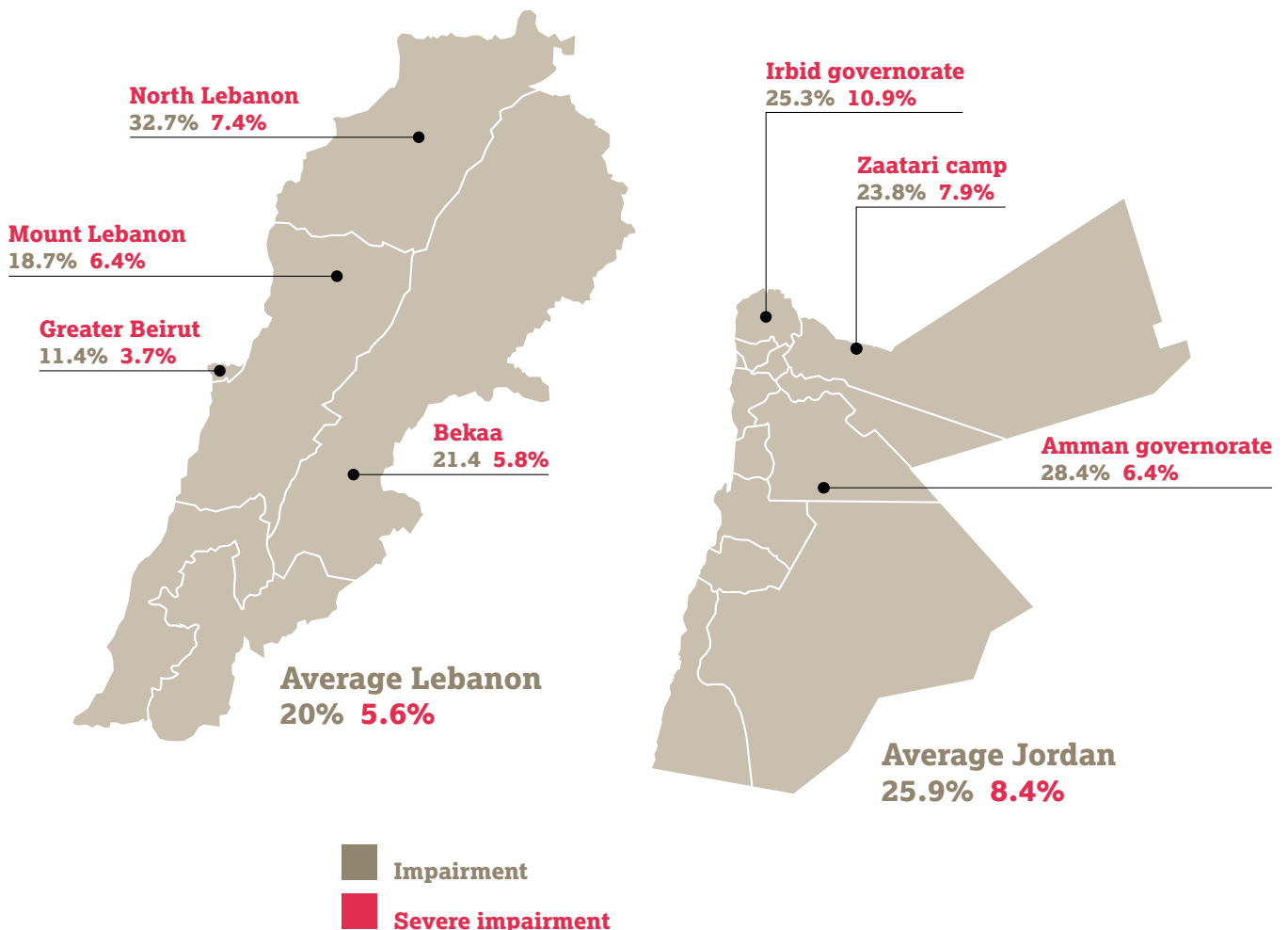
The survey highlighted a higher prevalence of impairment in Jordan (25.9 per cent)³⁸ than in Lebanon (20 per cent).³⁹ This situation is in part explained by the fact that the Jordanian border is easier to access, meaning a higher number of people with impairment are able to cross it. As illustrated by Map 2, the survey also identified differences in the distribution of refugees with impairment between the governorates of the two countries.

38. n=334; 25.93 ± 2.92%

39. n=382; 19.96 ± 2.18%

Map 2: Proportion of surveyed refugees with impairment in Lebanon and Jordan

Handicap International and HelpAge International, 2013



In Lebanon, there is an unequal distribution of people with impairments between governorates, with higher proportions in Bekaa (21.4 per cent) and North Lebanon (32.7 per cent), and in lower proportions in Mount Lebanon (18.7 per cent) and Beirut (11.4 per cent), as illustrated by Map 2. Generally speaking, people with impairments are less likely to live in urban areas than in peri-urban and rural areas. This can be explained mainly by two factors:

- Refugees tend to settle in areas similar to those they have left behind, meaning Syrian refugees from rural areas will settle in rural and peri-urban areas in Lebanon.
- Refugees who have grown up in rural areas with poor access to pre-natal services include higher numbers of people with impairments caused at birth.

Recommendations

Humanitarian responders should:

- Collect, analyse and use sex, age and disability disaggregated data (SADDD)
- Sensitise and build the capacities of staff to identify and include people with specific needs (people with impairment, injury, those suffering from chronic disease and older people) in response activities
- Improve access to primary healthcare services for those with specific needs
- Enhance the range of specific services provided to people with specific needs and their families
- Support mainstream response to ensure people with specific needs can access services.

Injuries

In Jordan and Lebanon, 5.7 per cent⁴⁰ of Syrian refugees surveyed have a significant injury.⁴¹ There is a higher proportion of injured refugees in Jordan (8 per cent)⁴² than in Lebanon (4.5 per cent).⁴³

The overwhelming majority of wounded refugees (80.3 per cent) sustained their injury as a direct consequence of war in Syria, as shown in Chart 6. The prevalence of conflict injuries is higher in Jordan where 90 per cent of injuries are conflict related compared to 70 per cent in Lebanon.

40. n=183; 5.7 ± 0.98%

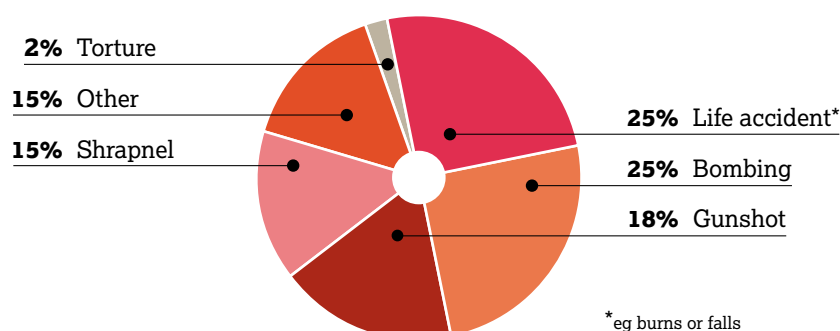
41. An injury that has the potential to impact the function of the body, therefore a potential disabling impact

42. n=96; 8.05 ± 1.81%

43. n=87; 4.55 ± 1.14%

Chart 6: Causes of injuries among surveyed refugees in Jordan and Lebanon

Handicap International and HelpAge International, 2013



This means that:

- In Jordan, 1 in 15 Syrian refugees has been injured as a result of the war.
- In Lebanon, 1 in 30 Syrian refugees has been injured as a result of the war.

As illustrated in Chart 6, bombing, gunshot and shrapnel wounds account for 58 per cent of the causes of injuries. Accidents such as burns and falls also account for a significant proportion (25 per cent) of injuries reported by the surveyed refugees. However, many of these accidents (60 per cent) were caused by living in homes damaged by the conflict or by fleeing from attacks. As such, these injuries can be seen as indirectly caused by the conflict.

Feedback from the survey teams suggested a large percentage of those affected by injury lacked adequate care, including access to physical rehabilitation support to avoid the worsening of an injury-related health condition, and to mitigate the possible development of permanent disabilities. This finding echoes the fact that 52 per cent of families reported access to healthcare as a serious problem.

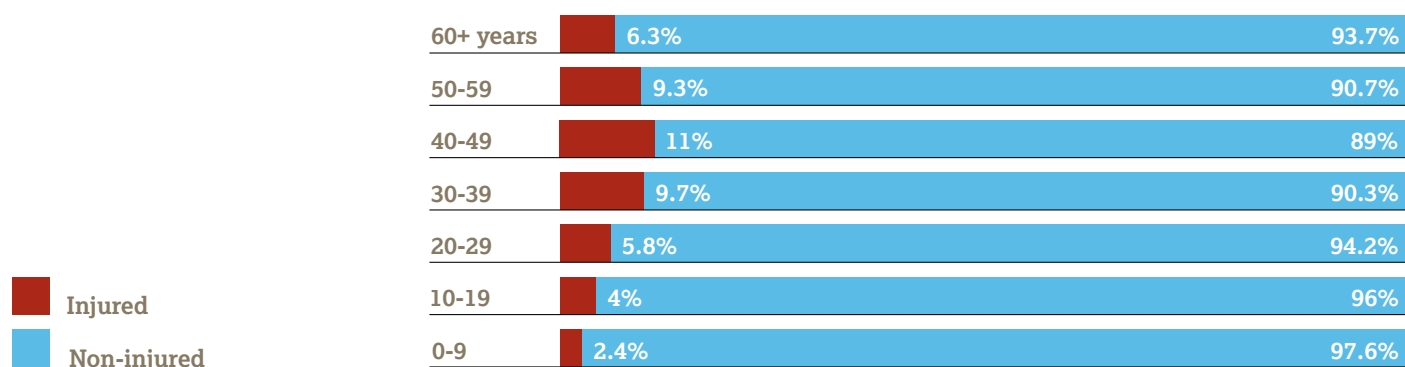
Gender and age analysis

Gender analysis reveals a distinct imbalance among those with injury in Jordan and Lebanon. Men account for 72 per cent of injured people and women for 28 per cent.

Combining the age and gender analyses shows the greatest level of injury is found among men aged 30 to 50. In this age and gender group, approximately 1 in 10 of the surveyed population is injured.

Chart 7: Proportion of people with injuries by age

Handicap International and HelpAge International, 2013



For the older population the proportion of injuries is similar to that found among the younger adult population. For children the proportion of injury is the lowest of all age groups.

The particular pattern of injury among age and gender groups clearly illustrates that working-age males are bearing the brunt of exposure to conflict-related injury risk. This is because of their roles as combatants and as the family member most responsible for providing support to families such as fetching food and water (with the attendant risks associated with these activities). In addition, interviews with refugees in Jordan and Lebanon highlighted the fact that men regularly travel back to Syria to visit relatives and check on property and assets. They repeatedly cross conflict lines and are exposed to risk of injury and death. Conversely, the findings show a relative under-representation of injuries among men aged 20-29, despite this group representing a significant proportion of combatant forces. This is an issue that requires further investigation.



Geographical distribution of people with injuries

Data released by the ICRC in December 2013 shows that more than half a million people had been wounded during the Syrian conflict – more than 2 per cent of Syria's population.⁴⁴

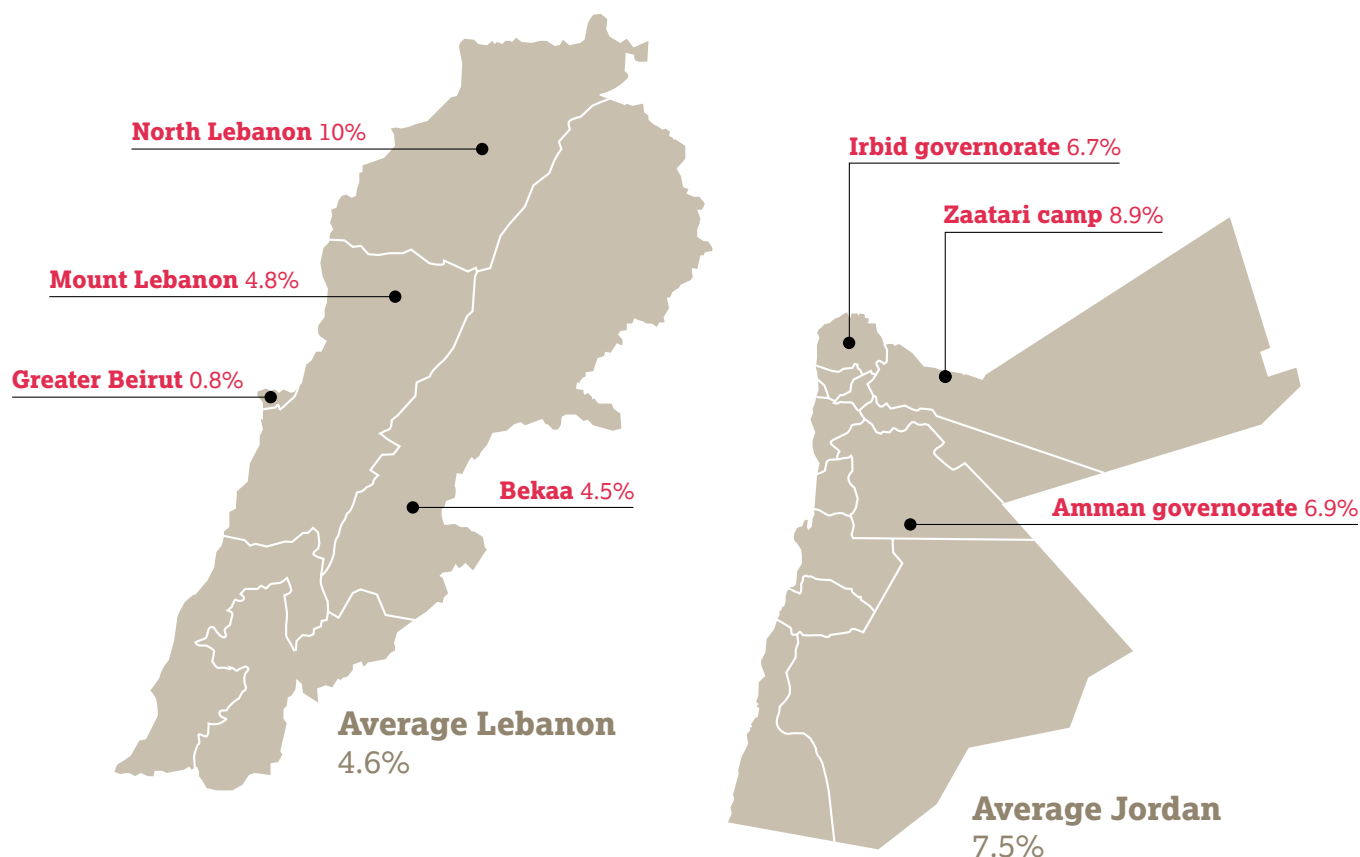
The survey shows, however, that levels of injury in Jordan and Lebanon are significantly higher than estimates for Syria. This indicates that people with injuries are more likely than the general population to leave Syria in search of medical assistance.

As illustrated by Map 3, the study also found that people with injuries are not equally distributed in the different locations where data collection was carried out in Jordan and Lebanon. In Jordan, the highest percentage of people with injuries is found in Zaatari camp (8.9 per cent), compared with almost equal distributions in Amman (6.9 per cent) and Irbid governorates (6.7 per cent). In Lebanon, people with injuries are found in the largest numbers in the North governorate (10 per cent) and are less present in Mount Lebanon (4.8 per cent) and Bekaa (4.5 per cent). In Beirut they are almost absent from the surveyed refugee population (0.8 per cent).

44. www.abc.net.au/news/2013-12-22/half-a-million-people-wounded-in-syria-conflict-red-cross-says/5171780 (accessed 28 March 2014)

Map 3: Proportion of surveyed refugees with injury in Lebanon and Jordan

Handicap International and HelpAge International, 2013



The survey findings have already provided some insights into the factors that influence refugee families' decisions on where to settle. However, for those affected by injury, the study identified a range of other factors that explain regional differences.

- In Jordan, many of those with injuries have been evacuated from medical facilities inside Syria and taken straight to Zaatari camp.
- In Lebanon, the management of refugees arriving with injuries (under the supervision of the Lebanese Red Cross and the International Committee of the Red Cross, in partnership with UNHCR) directs refugees to the largely Sunni areas of Bekaa and the Northern governorate for initial treatment. The objective of this policy is to admit the injured to appropriate health facilities, of which there are more in the North and to avoid tensions with local communities on Lebanon's border with Syria (a substantial proportion of the injured people crossing the border are Sunni and have been involved in the conflict).
- Differences between Lebanon and Jordan can be further explained by the challenges in reaching the Lebanese border because of the intensity of conflict in the border regions.
- The limited number of injuries found in Beirut may be explained by the household-level focus of the data collection. Many of those with injuries will be cared for outside the home in informal medical units.

Care needs of refugees with injuries

Several organisations including Handicap International, Médecins Sans Frontières (MSF), International Medical Corps (IMC), and the ICRC have raised concerns about the situation of people with injuries in Syria and the wider region. Handicap International has identified the challenges faced by people with injury and disabilities in accessing the support, services and assistance they need.⁴⁵ Furthermore, evidence from Handicap International's programmes in Jordan and Lebanon reveals the high number of injuries leading to amputation and the high levels of spinal cord injuries that are generally related to gunshot or shelling, and result in serious and permanent impairment.

Beyond immediate healthcare needs, treating such complex injuries involves long-term physical rehabilitation, psychological and psychosocial support. The study shows 74.9 per cent of the surveyed refugees with injuries presented with an impairment; 13.1 per cent had a severe impairment. This indicates that 55.2 per cent of injured Syrian refugees have difficulties in daily living activities and 32.8 per cent have severe difficulties. For those with severe injuries such as amputation, peripheral nerve injuries or spinal cord injury, many will suffer from a permanent impairment and need lifelong physical rehabilitation support and care. A coordinated effort by local, national and international health providers is required to ensure the necessary care is provided and that there is a suitably trained cadre of medical staff in place to address the long-term consequences.

45. Handicap International, *Causes and types of injuries encountered by Handicap International while working with internally displaced people in Syria: A focus on the impact of explosive weapons*, Handicap International, 2014, https://d3n8a8pro7vhmxc.cloudfront.net/handicapinternational/pages/428/attachments/original/1390264602/Syria-Causes_and_types_of_injuries_report.pdf?1390264602 (accessed 14 March 2014)

Recommendations

Humanitarian responders should:

- Ensure medical assistance addresses the need for post-operative care (to avoid creating disabilities)
- Enhance the range of specific services provided to people with specific needs and their families
- Sensitise and build the capacities of staff to identify and include people with specific needs (people with impairment, injury, those suffering from chronic disease and older people) in response activities
- Improve access to primary healthcare services for those with specific needs.

Chronic disease

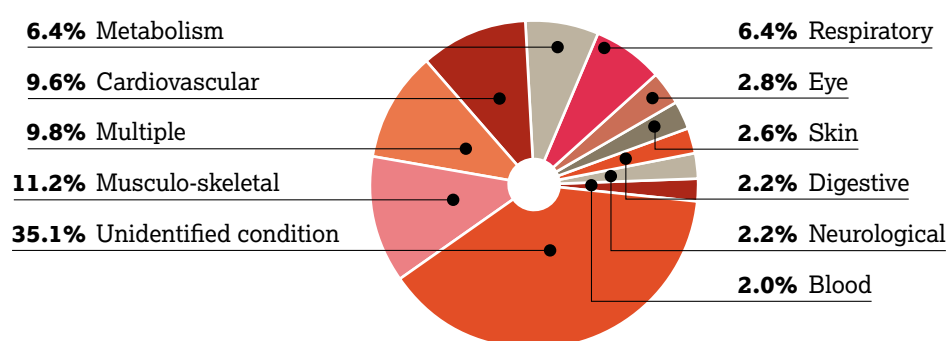
15.6 per cent⁴⁶ of surveyed Syrian refugees and 54 per cent of older surveyed refugees are affected by chronic disease.

Chart 8 presents the ten most frequently reported conditions. Together with unidentified conditions, these represent 90 per cent of reported cases.⁴⁷

Survey teams also identified other chronic conditions in lower proportions, including cancers, genital conditions, problems related to pregnancy and the perinatal period, and hearing problems.

Chart 8: Top 10 conditions for chronic disease and medical conditions in Jordan and Lebanon

Handicap International and HelpAge International, 2013



The disease profile and the consequences for the health systems are clearly illustrated by secondary data. This shows that in Jordan, Lebanon and Iraq, the most common reasons for refugees seeking healthcare result from three chronic conditions: diabetes, cardiovascular conditions (including hypertension and coronary heart disease) and lung disease (asthma and chronic obstructive pulmonary disease).⁴⁸

‘Silent casualties’ – barriers to treatment for chronic disease

Untreated chronic diseases often lead to severe complications such as stroke and diabetic complications such as gangrene and increased levels of mortality and morbidity. This issue has been highlighted by agencies including HelpAge International and Médecins Sans Frontières (MSF). MSF has identified those suffering from non-communicable diseases as the ‘silent casualties’ of the war.⁴⁹ They are dying as a result of previously manageable chronic illnesses and a lack of access to regular healthcare and medication.

For many refugees the cost of accessing services is a major barrier to treatment. In Lebanon, health service delivery is privatised, profit-orientated and fee-paying. Although refugees can usually access health facilities, they are expected to cover the costs of treatment but this maybe significantly above their means.⁵⁰ Some refugees in Lebanon stated that they were unable to afford the cost of transport to health centres, let alone the required 25 per cent contribution to their hospital bills.⁵¹ The management of chronic conditions also often have additional day-to-day costs such as the needles, syringes and blood glucose test strips needed by diabetics. These add further to the financial burden.

In Lebanon and Jordan there is also a gap in the quality of the management of chronic diseases. A health assessment carried out by HelpAge International found there was almost no health education for patients, limited capacity among health staff to properly assess patients with chronic diseases, limited services available to support early screening for chronic diseases such as diabetes and hypertension and no proper monitoring with laboratory tests or follow up.⁵²

46. x n=501; 15.6 ± 1.55%

47. About one third of respondents were not able to precisely explain their conditions and only reported a need for long-term medication or regular medical follow-up. When possible, various medical conditions were reported (including acute or chronic ones) according to International Classification of Disease (ICD). People presenting with chronic disease or medical condition in more than one area have been classified as ‘multiple’. These were usually a combination of cardiovascular, musculoskeletal and sometimes diabetes problems.

48. Inter-Agency Regional Response for Syrian Refugees, Health and Nutrition Bulletin: Egypt, Iraq, Lebanon, Jordan, October, 2013, <https://data.unhcr.org/syrianrefugees/download.php?id=3685> (14 March 2014)

49. Ravi S. Katari, ‘Medical Neutrality and Solidarity in the Syrian Armed Conflict – Statement by Stephen Cornish, Executive Director of Médecins Sans Frontières, Canada’, *Journal of Global Health*, 2013

50. Inter-Agency Regional Response for Syrian Refugees, Health and Nutrition Bulletin: Egypt, Iraq, Lebanon, Jordan, October, 2013, <https://data.unhcr.org/syrianrefugees/download.php?id=3685> (14 March 2014)

51. ACAPS/SNAP, Relief actors in Syria. Syria needs-analysis project, 2013, www.acaps.org/en/pages/syria-snap-project (14 March 2014)

52. HelpAge International (2014). Lebanon Health Assessment. Internal report.

In both Jordan and Lebanon, there are shortages of drugs and laboratory tests for chronic diseases. When drugs are available, patients are often simply prescribed drugs with no advice or monitoring of their condition.

Gender and age analysis

More than half (54 per cent) of older surveyed refugees are affected by chronic diseases.

In Jordan, the survey found two-thirds of the older people surveyed report having chronic conditions. Broader age analysis allows us to identify three main groups: people aged up to 30 years, of whom 10 per cent are affected by chronic diseases; those aged 30-50, of whom 30 per cent are affected; and those aged 50 or over, of whom half are affected. This analysis provides a more nuanced picture of the needs of different age groups and has major implications for the design and delivery of health services.

The evidence from surveyed populations does not indicate any difference in the prevalence of chronic disease between men and women.

Geographical distribution of refugees with chronic diseases

19.6 per cent of surveyed refugees in Jordan⁵³ and 13 per cent in Lebanon⁵⁴ report they suffer from chronic diseases.

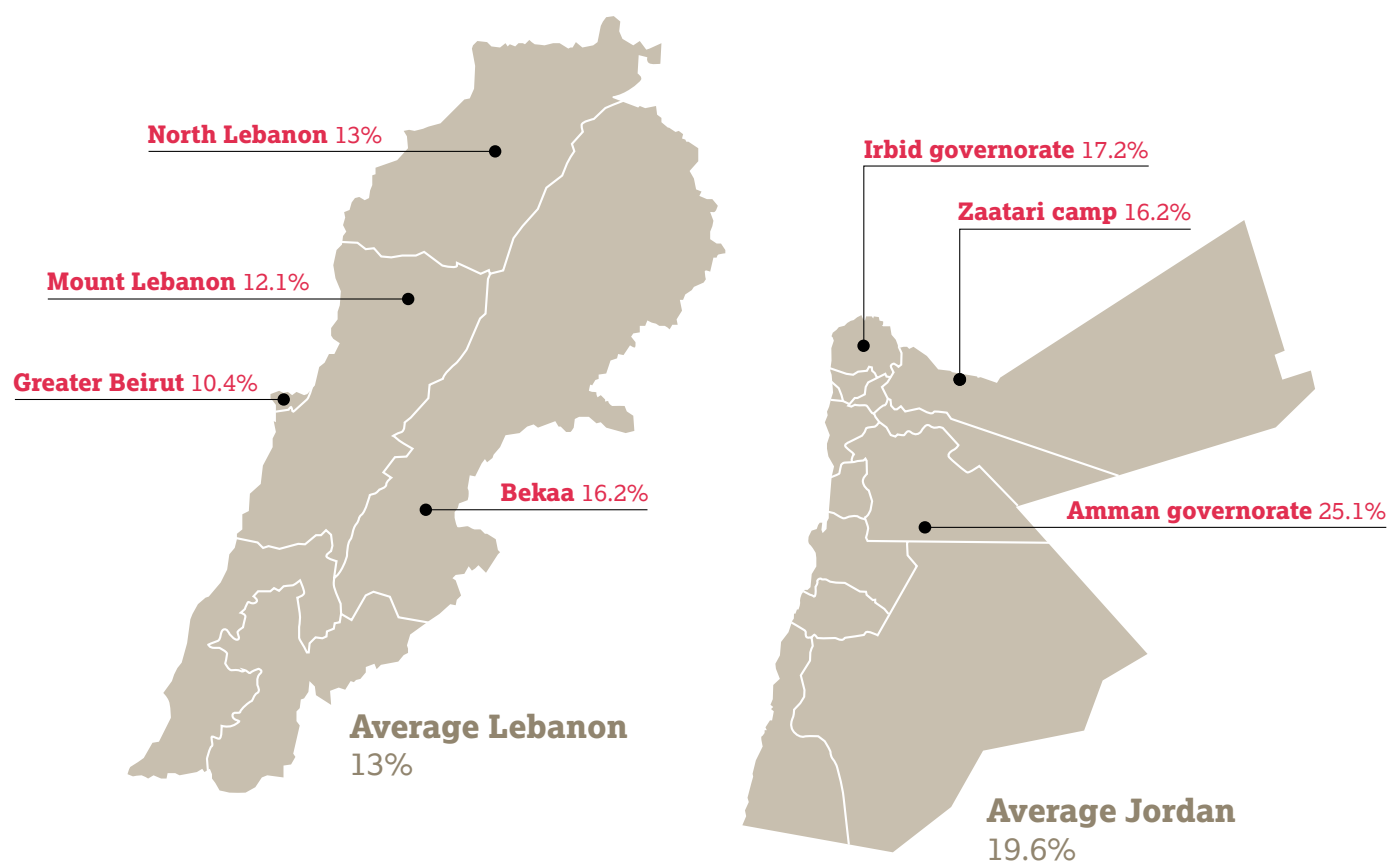
In Jordan, it is possible to identify clear differences in the location of refugees with chronic diseases. Of those surveyed in Amman, 25.1 per cent report chronic diseases compared with 17.2 per cent in Irbid and 16.2 per cent in Zaatari camp, as illustrated by Map 4.

53. n=253; 19.64 ± 2.64%

54. n=248; 12.96 ± 1.83%

Map 4: Proportion of surveyed refugees with chronic disease in Lebanon and Jordan

Handicap International and HelpAge International, 2013



The survey does not allow for in-depth analysis of the reasons for the difference. However, it is likely to be due in part to the availability of health services in these areas and to refugees sharing their knowledge and experience of healthcare access.

In Lebanon, the lower reporting of chronic disease can probably be explained by the higher proportion of refugees who originated in rural areas of Syria (having had less exposure to healthcare services, they are less likely to consult medical specialists) and the fact that the rural population is significantly older in Bekaa (where 16 per cent of the surveyed population are affected by chronic disease) compared to other governorates.

Chronic disease and impairment

It is important to recognise the link between untreated chronic disease and disability. The findings of the survey presented in Chart 1 on page 12 show that 7 per cent of those interviewed are affected by both. Experience shows that a large number of people living with chronic diseases are likely to develop impairments as the disease progresses. According to studies, between 13 per cent and 65 per cent of people living with diabetes will develop neuropathy, leading to chronic ulcerations and amputations in up to 17 per cent of cases. Between 10 per cent and 47 per cent of people living with diabetes will develop retinopathy, leading to visual impairment.⁵⁵

Amal and Fatima's story, Lebanon

Amal is 65 and lives with his sister Fatima. He has cancer.

Amal recently suffered a stroke which affected the movement of his left leg and arm. He sought hospital treatment but was unable to pay the required 25 per cent of his medical costs and was discharged against his will after only five days. After returning home he developed an infection in his leg which worsened his condition. With no money to pay for his treatment in Lebanon, Amal was forced to travel back to Syria to seek medical care, risking his life and that of the friend who accompanied him, before returning to the relative safety of Lebanon once again.

Amal's sister Fatima has a younger son, Mohammed, who has an undiagnosed psychiatric condition that causes serious mood swings and violent outbursts. Amal and Mohammed require full-time care by Fatima. The entire family depends on the income of Fatima's other son, Bilal.

55. http://ncdalliance.org/sites/default/files/resource_files/Brief%20%20%20Disability%20and%20NCD.pdf

Recommendations

Humanitarian responders should:

- Address gaps in the quality of primary healthcare services for those with chronic diseases
- Ensure adequate provision of NCD drugs at primary healthcare level
- Improve access to laboratory tests at primary healthcare level
- Improve access to primary healthcare services for those with specific needs.



Gwenn Dubourthoumieu/Handicap International

Section 3
Needs and challenges
of people with
specific needs and
their families

Needs and challenges of people with specific needs and their families

This section looks at the consequences of displacement for those with specific needs and the challenges they face in adapting to their new environment. To obtain a clear picture, the study investigated three distinct issues: first, refugees' description of their problems and needs using a set of questions based on the HESPER scale;⁵⁶ second, the level of psychological suffering experienced by the refugee population; and third, the difficulties faced by refugees in 'activities of daily living'.

Activities of daily living (ADL) is a term commonly used by healthcare professionals to refer to daily self-care activities. These are defined as those activities we normally do every day such as feeding ourselves, bathing, dressing, grooming, work, homemaking and leisure. Assessment of an individual's capacity to perform these activities forms a central part of the measurement of functional status, particularly for people with disabilities and older people. It is also a key element of the World Health Organization definition and measurement of disability.⁵⁷

Humanitarian actors rarely assess ADL and the use of this approach in the study design therefore contributes to a more detailed picture of impairment and related vulnerabilities of refugees.

Challenges faced by refugees in addressing basic needs

The study shows that the concern of meeting basic needs is similar for all refugee families, regardless of whether they include a person with specific needs.

The primary concern of families interviewed in both contexts was to secure an income, followed closely by related concerns about shelter, access to basic healthcare, food and essential household items. In addition to these needs, families in Jordan expressed particular concern about the quality of drinking water, while families in Lebanon stressed problems related to access to children's education (see Table 1).

Table 1: Concerns identified by Syrian refugees in Lebanon and Jordan

Handicap International and HelpAge International, 2013

Concerns	Identified priority	Concerns	Identified priority
Lebanon		Jordan	
Income, livelihood	27%	Income, livelihood	25.6%
Shelter	13.9%	Shelter	11.4%
Healthcare	11.9%	Essential, non-food items	10.1%
Food	9.6%	Water	9.3%
Essential, non-food items	6.9%	Healthcare	8.6%
Education	5.5%	Food	7.9%

56. www.who.int/mental_health/publications/hesper_manual/en (accessed 28 March 2014)

57. See Annex 2

Consequences of unmet needs for people with specific needs

The needs identified by families with and without members with specific needs were similar. However, the study shows that for the latter group, the failure to meet both basic needs (income, shelter and healthcare) and specific needs has a major impact on their living conditions.⁵⁸

Protracted displacement depletes the financial reserves of refugee families and, as noted above, financial constraints are a major barrier to access to healthcare. For those with specific needs and decreased financial capacity, access to adequate healthcare is a serious concern. An assessment of livelihoods in Lebanon by Handicap International in August 2013, found that expenditure on healthcare was an average of US\$65 per month per household. For 15 per cent of Syrian refugee households in Lebanon, costs related to health were the main reason for falling into debt.⁵⁹

Table 2 shows the results of the identified needs analysis for the general population and for families with specific needs by sector, as well as the concerns of those with specific needs.

58. There is growing understanding that disability is a key issue for development. Disability, poverty and exclusion are closely linked (WHO/World Bank 2011, Mitra et al, 2012) and there is evidence that the exclusion of disabled people from labour markets has a negative impact on economies in poorer countries (Buckup, ILO Report 2009).

59. Handicap International (August 2013). *Livelihoods Assessment Report*

60. The concerns related to those with specific needs are drawn from the survey findings as well as from the operational experience of HelpAge International and Handicap International more generally. Therefore these concerns do not result solely from the survey findings in Lebanon and Jordan.

Table 2: Analysis of expressed needs by sector and by group of family surveyed

Handicap International and HelpAge International, 2013

Families without members who have specific needs	Families with members who have specific needs	Concerns related to those with specific needs ⁶⁰
Income		
<ul style="list-style-type: none"> • There are significant concerns around ability to secure an income to meet daily expenditure and reduce dependency on others. • Lack of income is identified as the greatest barrier to meeting the basic needs of the family – rent, health, food, education, household items etc. 	<ul style="list-style-type: none"> • Heads of families report major challenges with the additional financial burden of a dependant with specific needs who may require medical treatment or specialised care. • Families report having to make distressing choices between meeting the basic needs of the entire family and the specific needs of people with impairment, injury or chronic diseases. 	<ul style="list-style-type: none"> • Where people with specific needs are less able to work, they may face great financial difficulty. • Families with a member who has specific needs are often considerably smaller, resulting in a reduced support network. • Financial difficulties can reduce access to basic services and coverage of basic needs such as nutrition and healthcare. • Older people and people with disability often face difficulties in accessing income-generating activities. The situation is particularly acute for those with a new disability who cannot continue their existing profession and need to learn a new one.
Shelter		
<ul style="list-style-type: none"> • Families report serious concerns with the quality of shelter: it may be unsafe, poorly insulated, damp, cramped, lacking privacy, and without running water. 	<ul style="list-style-type: none"> • Shelter is the second most important concern of families in Lebanon and Jordan. 	<ul style="list-style-type: none"> • Cold and damp have a negative impact on older people's conditions such as osteoarthritis and joint pain and can cause manageable conditions to become acute and debilitating. • Inappropriate shelter can confine older people and people with disabilities to their homes, restricting their independence, and their ability to access services and engage in livelihood and social activities.
Essential non-food items		
<ul style="list-style-type: none"> • Refugees' accommodation often lacks basics such as mattresses, blankets, pillows, basic furniture, kitchen and cooking utensils and heating fuel. 	<ul style="list-style-type: none"> • Refugees surveyed in Jordan expressed a greater need for non-food/household items than refugees in Lebanon. 	<ul style="list-style-type: none"> • Lack of mattresses and blankets aggravate the impact of cold and damp on older people and on people living with chronic diseases/medical conditions. • Lack of specific items for people with a disability (eg a toilet chair, an anti-pressure sore mattress) can lead to a deterioration in condition.

Families without members who have specific needs	Families with members who have specific needs	Concerns related to those with specific needs
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Healthcare

<ul style="list-style-type: none"> • There is concern about limited access to basic essential healthcare for maternal and child health issues and chronic diseases as well as to specialised services. • Financial constraints are a major barrier to basic healthcare access. • Other factors affecting access to healthcare include shortages of drugs and medical supplies due to increased demand, and the fact that health staff at primary and secondary level are overwhelmed. 	<ul style="list-style-type: none"> • Access to health and specialised services is identified as more important for families that include people with specific needs. • Treatment of chronic conditions (asthma, diabetes, hypertension and cardiovascular disease) are often very expensive. • Additional barriers to care include a lack of information about available basic and specialised care such as physical rehabilitation. 	<ul style="list-style-type: none"> • Untreated chronic diseases often lead to severe complications (stroke, coma, gangrene, kidney problems and blindness) and higher mortality. • In emergencies, minor health conditions (a cold, a minor wound) can quickly become debilitating and have serious consequences for older people. • Untreated injuries, even minor ones, can have major consequences on health conditions, including creating a permanent or aggravated impairment. • The absence of, or deterioration of, an assistive device (such as a wheelchair or mobility aid) can make a disability more severe and create a barrier to accessing services. • The absence and/or lack of appropriate medication can increase the risks of onset or progression of disability.
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Food

<ul style="list-style-type: none"> • Lack of access to regular and appropriate food is closely related to financial constraints. • Vouchers have been of great help, but this type of assistance is decreasing. Half of the surveyed families were solely reliant on their own resources to buy food. 	<ul style="list-style-type: none"> • Food is prioritised similarly by families with a member with specific needs as in the general population (fourth priority in Lebanon, sixth in Jordan). 	<ul style="list-style-type: none"> • Older people may have specific nutritional needs because of dental problems and different micronutrient requirements in older age. • Irregular and insufficient food intake can have severe health repercussions for older people and people with a chronic disease. • People with disabilities may require additional calorie intake (for example, people with stroke or spinal cord injuries may be less able to regulate their body temperature to facilitate the healing process). • Some people with disabilities need a special diet to facilitate the healing process and avoid complications (for example, food in liquid form). • Health and nutritional messages may not be available to people with visual or hearing impairment or low mobility.
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Water and sanitation

<ul style="list-style-type: none"> • Findings related to water access are specific to Jordan, where the presence of Syrian refugees has placed increased stress on already limited water supplies. The majority of Syrian refugees in Jordan reported having to buy drinking water on a daily basis due to a lack of access to quality drinking water. 	<ul style="list-style-type: none"> • Water and sanitation facilities are not accessible for people with disability. This increases their dependency on others and can affect their health. • Some people with disabilities have specific hygiene requirements (diapers, urinals etc). If unavailable, their disability may worsen.
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Families without members who have specific needs	Families with members who have specific needs	Concerns related to those with specific needs
Education		
<ul style="list-style-type: none"> • Parents living outside camps report they cannot afford the cost of school fees, uniforms, books and teaching materials or school transport. • Refugee children attending school face difficulties because of different curricula, language barriers and difference in their level of education. • In some cases, families report taking children out of school so they can provide additional support for their families. 	<ul style="list-style-type: none"> • Access to education is reported to be more difficult for children with disabilities. • Parents report that teachers are usually untrained in inclusive education practices and are often afraid to take children with disabilities into their class. • Few schools in Lebanon and Jordan are accessible for children with disabilities. • Parents do not see education of children with a disability as a priority. 	<ul style="list-style-type: none"> • Access to education is usually more difficult for children with disabilities because school infrastructure does not cater to their needs (there may be no accessible toilets, access ramps, handrails or doors wide enough for wheelchairs). • Teaching methods are often not inclusive (communication means are not adapted, teachers are not sensitised to specific needs etc). • Lack of access to education for children with disabilities will have a negative effect on their future capacity to be autonomous, take part in income-generating activities and participate actively in society.

Finding suitable shelter is increasingly challenging for many Syrian refugees, as illustrated by the story of Sahar (see below). Growing demand for accommodation has pushed up rents and forced families into smaller, more basic and more remote accommodation. For families with members with specific needs, the cost of transport to access assistance and basic services have severe consequences for their ability to meet their family's needs.

Sahar's story, Jordan

Sahar is a Syrian refugee living with her husband and two daughters close to Amman. They live in a small, unfurnished apartment without the most basic amenities such as a bathroom, windows or door. The family cannot afford to buy proper windows and use a wooden board to cover the doorway.

Sahar's two children, Fadi (12) and Chadi (10), both suffer from severe cerebral palsy and have extreme difficulties in moving, speaking and communicating. Sahar is their full-time carer and is extremely worried about their situation and the risk of disease resulting from their living conditions.

Sahar's husband has been unable to find regular work so works occasionally for low wages. He and Sahar are struggling to meet even their children's basic food and healthcare needs.

Recommendations

Humanitarian donors should:

- Ensure projects that address the needs of refugees with specific needs receive necessary support, and encourage projects that ensure accessible services
- Support organisations to develop and implement new approaches that are inclusive of refugees with specific needs.

Psychological distress

Half of refugees surveyed (49 per cent)⁶¹ reported at least one frequent or permanent sign of psychological distress.⁶²

In Jordan and Lebanon, more than 65 per cent of older people presented signs of psychological distress – three times more than the general refugee population.

People with specific needs are twice as likely to report signs of psychological distress and three times as likely to report cognitive difficulties compared with the general refugee population.

Psychological distress among older and disabled people

Loss of status as a result of displacement (loss of homes and belongings, inability to provide for families) and the hardship of living as a refugee can have major psychological consequences. Whereas younger generations may be occupied with work or the search for work, refugees with specific needs including older people are often excluded from work and have more time to dwell on their plight.

A study of post-traumatic stress disorder (PTSD) among displaced people in Darfur, Sudan, revealed a high rate among older people in particular. This was attributed to difficulties faced by older displaced people in coping with their new social environment created by displacement – particularly the loss of the status they enjoyed in the community before the war – and to the poor quality of life in refugee camps. High levels of PTSD were also closely linked to lack of employment, lack of security and the unsuitability of food items⁶³ – all a feature of refugee life in Jordan and Lebanon.

It is also important to recognise that people with specific needs are often at greater risk of violence and the psychological distress that can follow. People with disabilities are particularly vulnerable to threats and physical, sexual and emotional abuse. A report in 2012 of the Working Group on Violence Against Women with Disabilities, *Forgotten Sisters*, concluded that women with disabilities suffer up to three times greater risk of rape by a stranger or acquaintance and face greater obstacles in reporting abuse and accessing support, justice and rehabilitation services.

A report in 2011 by Handicap International and Save the Children, *Out from the Shadows*, highlighted how boys and girls with disabilities suffer sexual violence at the hands of perpetrators who operate with almost total impunity, enhancing the probability of them presenting with signs of psychological distress. Finally, deterioration of the physical environment and social and family structure following a crisis often further increases the vulnerability of people with disabilities by reducing their ability to care for themselves, which in itself can cause psychological distress.

61. n=1567; 48.94 ± 2.10%

62. Survey questions were designed to provide an insight into the current status of refugees and how they felt. As such, the majority of the reported signs are likely caused by the conflict or displacement. Details on the approach taken to identify signs of distress can be found in Annex 3.

63. HelpAge International, *The neglected generation: the impact of displacement on older people*, London, HelpAge International, 2012



E Ssaade/Handicap International

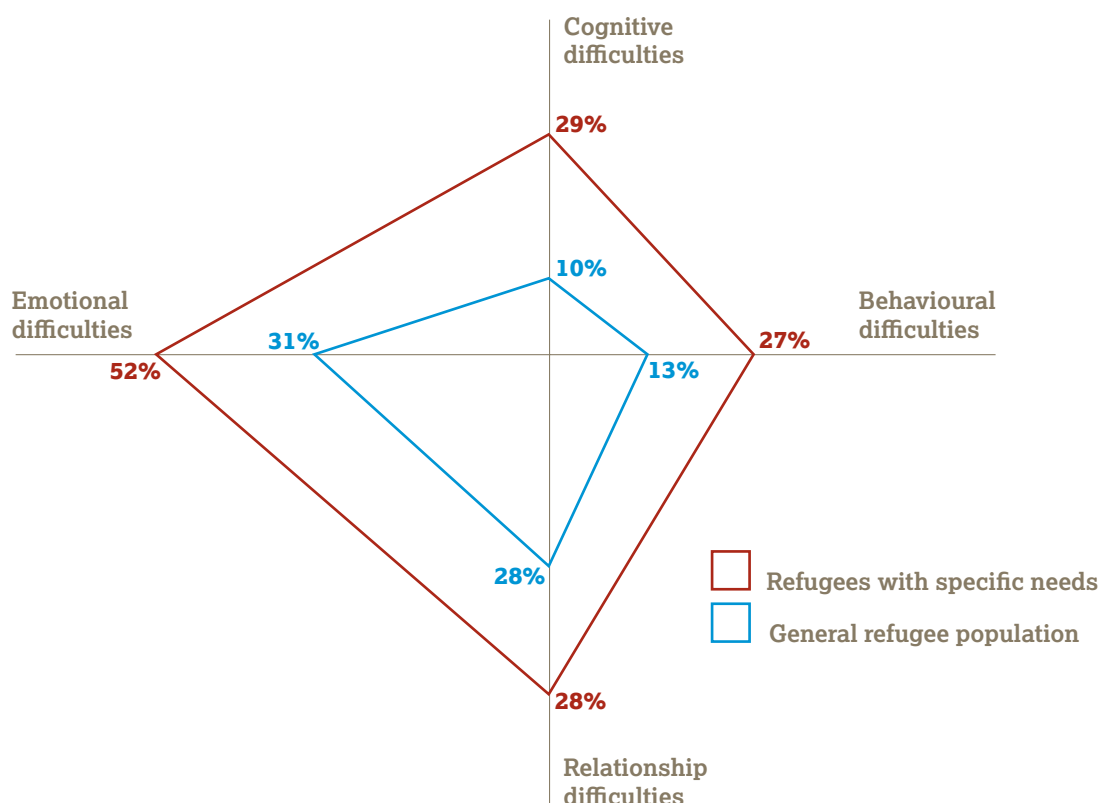
The following signs of psychological distress (in order of prevalence) were either observed by the assessment teams or reported directly by all surveyed families:

- stress and anxiety, fear and anger about their situation in general and the situation in Syria
- fatigue, lethargy and lack of motivation to undertake basic tasks
- feelings of hopelessness regarding their current situation
- depression.

Chart 9 illustrates emotional and relationship issues are the most frequent problems, reported by 50 per cent of interviewed people with specific needs.

Chart 9: Percentage of surveyed Syrian refugees showing signs of psychological distress

Handicap International and HelpAge International, 2013



In a displacement context, certain groups require specific attention because of conditions that are likely to increase the severity of psychological distress experienced. They include:

- people with specific needs who no longer receive the same level of family support (those who have lost caregivers or whose caregivers are no longer able to care for them)
- injured and/or newly impaired people who often need extra help to adjust to and overcome their injuries, trauma and the possibility of long-term disability
- those who are housebound including older people.



Gwenn Dubourthoumieu/Handicap International

Causes of psychological distress

In discussions with refugees, four main reasons for psychological distress were reported in both Jordan and Lebanon. The causes were common for those with specific needs and the general population:

- Past experience in Syria: many refugees experienced horrific trauma during the conflict, including the death, torture and kidnap of friends and relatives.
- Lack of a sense of a 'daily life': lack of social connections to friends and family, the loss of daily routines and normal activities.
- Growing insecurity: refugees reported increasing signs of community tensions and disrespect and insults from host communities, particularly in cities. In Lebanon, sectarian differences and violence contribute further to insecurity.
- Loss of dignity: in line with previous HelpAge International research (see page 34), heads of households in both countries reported feeling a loss of dignity because their current situation did not allow them to fulfil their roles as providers for their families and put them in a position of dependency.

People with specific needs highlighted additional sources of distress:

- Fear of separation from families, of being alone and of further displacement and separation from support structures.
- Loss of coping mechanisms and support networks. When they fled Syria, people with specific needs and older people often left supportive social and physical environments that had been built up over the years. For example, accessible homes and workplaces for people with low mobility, known and trusted sources of treatment and care, connections with family members, relatives, friends and associations able to understand and support their specific needs.
- Feelings of powerless and being seen as a burden. As a result of challenges in meeting even basic family needs, levels of care and attention for those with specific needs often decreased, resulting in a loss of voice for those members in family decision-making and discussions.
- Additional stress brought on by a new disability following an injury caused by the conflict.
- Limited opportunities to socialise: women, children and older people face significant challenges because of a lack of opportunity to socialise outside the home, a situation caused and compounded by the breakdown of usual community social and support networks.

Gender and age analysis

In Jordan and Lebanon, more than 65 per cent of older refugees presented signs of psychological distress – three times more than the general refugee population.

Despite evidence of the need, the psychological status of those with specific needs receives scant attention during humanitarian responses. The lack of psychosocial or mental healthcare services (including for those with cognitive impairment) was reported as a major challenge by families in both Lebanon and Jordan. This has a significant impact on the well-being of older people.

Generally, humanitarian assistance is rarely inclusive for people with disabilities and older people. For example, 'child-friendly spaces' are often not physically accessible for children with disabilities and activities are not adapted for them. This compounds the position of children with disabilities who are already vulnerable to exploitation, violence and abuse, and face further risks of isolation and loss of self-confidence. For older people, the primary focus on providing safe spaces for mothers and children often results in the exclusion of older women who would often have traditionally cared for children, and an absence of support for older men.

The study found no significant difference between men and women in relation to the overall prevalence of signs of psychological distress, whether within the general population or among those with specific needs.

Recommendations

Humanitarian responders should:

- Ensure services to address psychological distress are accessible to, and appropriate for, people with specific needs.

Challenges faced by refugees in activities of daily living (ADL)

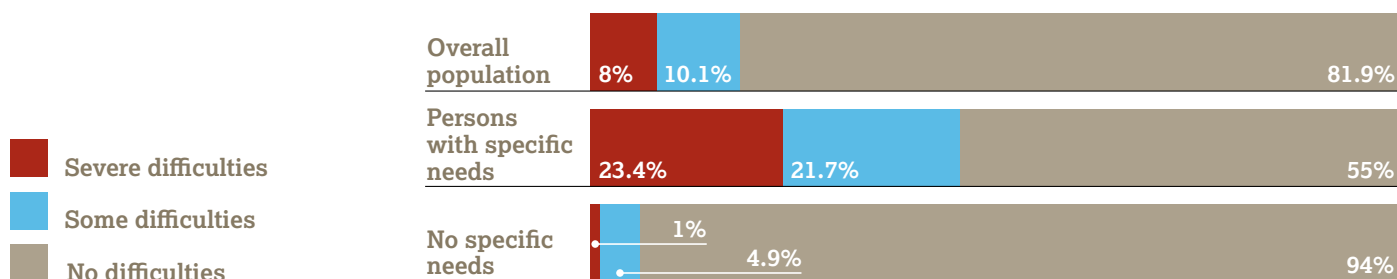
In Jordan and Lebanon, 18 per cent of surveyed refugees experience difficulties in activities of daily living.⁶⁴ For people with specific needs, the proportion was 45 per cent. For older people it was 60 per cent.

In contrast, only 6 per cent of the general refugee population (those without specific needs), face such difficulties, as illustrated in Chart 10.

The third element of analysis focuses on difficulties in activities of daily living (ADL).⁶⁵ As outlined on page 30, this approach provides a critical element in understanding the scale of disability within the refugee population by combining analysis of both personal factors (related to impairment, injury, chronic disease) and the barriers present in the environment in which people live (both physical and social) to understand how these undermine their ability to meet their daily needs.

Chart 10: Presence of difficulties in daily living activities

Handicap International and HelpAge International, 2013



Further analysis of data collected shows that in both countries, age and type of specific need contribute to challenges in daily life.

The age factor is crucial. Difficulties in daily living activities increase as someone ages because of declining mobility, vision, hearing etc. It is unsurprising to see therefore that 60 per cent of older people report difficulties in activities of daily living.

As illustrated by Chart 11 on the next page, the survey findings further show that more than half of those with injuries will face challenges in activities of daily living, and that one in three injured people will be unable to perform essential daily tasks without support. Four out of 10 people living with a chronic disease will face difficulties in activities of daily living.

Refugees facing difficulties in daily living activities are likely to be less autonomous in terms of their ability to take care of themselves and others, and are less likely to access assistance unless it is designed to include them. Research by HelpAge International shows this is rarely the case in international humanitarian response.⁶⁶

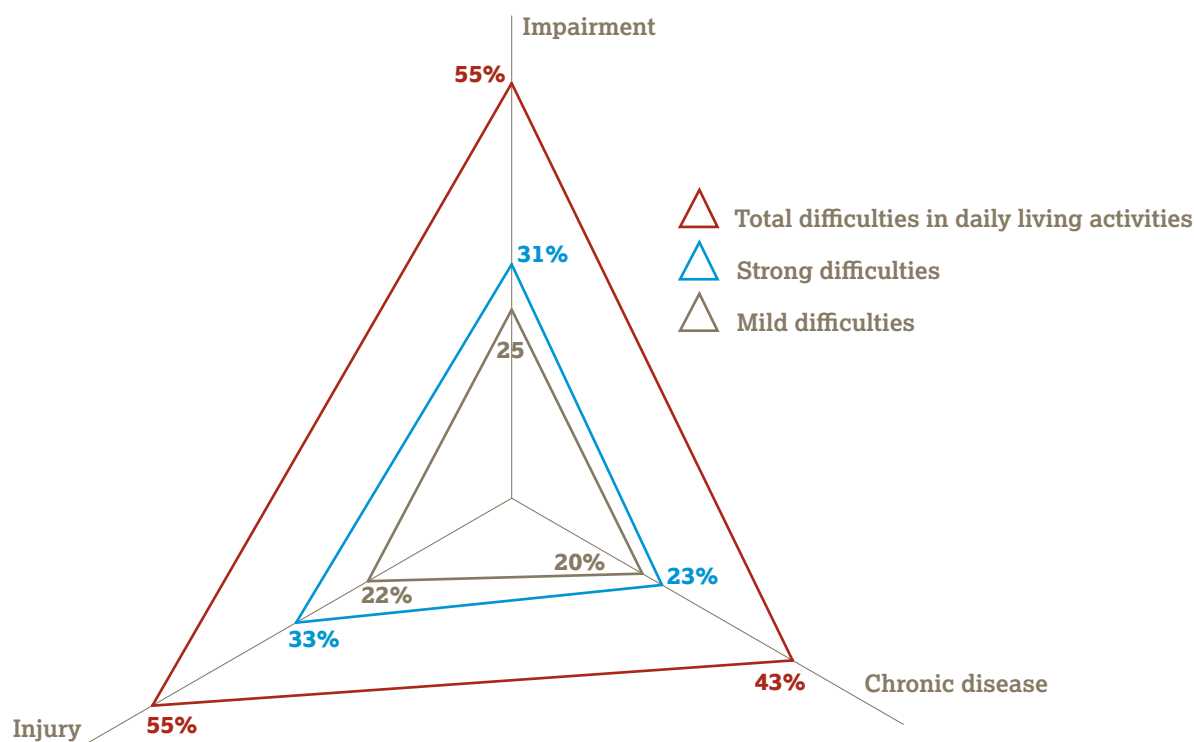
64. n=581; 18.14 ± 1.59%

65. Severe difficulties in activities of daily living is defined by the fact that the person finds it nearly impossible or completely impossible to carry out basic daily activities without the help or support of someone.

66. Analysis of Consolidated Appeals Process appeals in 2010 and 2011 found that less than 1% of funding was allocated to projects that included activities targeting people with disabilities. A 2011 study of submissions to the Consolidated Appeals Process found that only 1.6% of projects included targeted activities for people with disability, and only 0.7% were funded (HelpAge International and Handicap International, *A Study of Humanitarian Financing for Older People and People with Disabilities 2010-2011*, London, HelpAge International and Handicap International, 2012).

Chart 11: Relationship between specific needs and challenges in activities of daily living

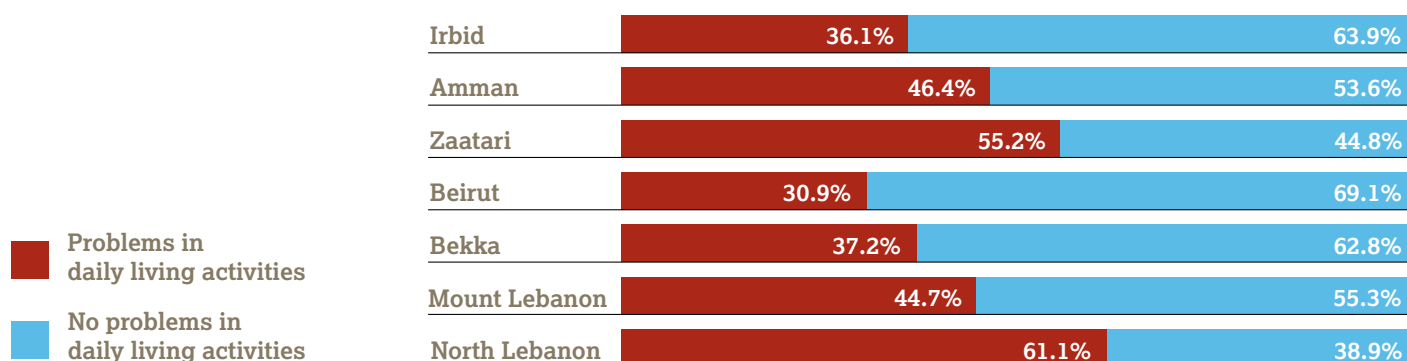
Handicap International and HelpAge International, 2013



It is important also to consider the environment in which refugees live and the degree to which it supports independence. As highlighted in Chart 12, in Jordan, Irbid seems to be a less challenging environment than Amman and Zaatari where higher numbers of refugees report challenges in activities of daily living. In Lebanon, refugees with specific needs living in Beirut and Bekaa face fewer challenges compared to those living in Mount Lebanon and North Lebanon.

Chart 12: Problems in activities of daily living for people with specific needs, according to location

Handicap International and HelpAge International, 2013



Critically, the findings of our analysis of activities of daily living reinforce the importance of undertaking a detailed and rigorous assessment of the levels of disability and impairment in the population. The current approach to identifying these when refugees are registered focuses heavily on visible and easily identifiable needs and fails to recognise the wider impact of the environment in which refugees find themselves on their level of impairment. Analysis of the challenges related to the environment of people with specific needs is developed further in the next section.

Coping strategies of individuals with specific needs and their families

As outlined in the box on page 9, the vulnerability of individuals and communities to the risks that displacement creates depends on the strength of their coping mechanisms. HelpAge International and Handicap International's experience shows that the most important coping mechanism for people with specific needs is often family and community support networks. However, in humanitarian crises and displacement situations these networks often become fractured and break down, with particularly severe consequences for those with specific needs. For those adjusting to new environments and surroundings, knowing where and how to access support and services is a major challenge. If needs are not met, it can lead to increased social isolation and reduced access to services.

Family support networks

The role of the family and caregivers is critical to the quality of life of people with specific needs. In the survey, almost no individuals with specific needs were found to be completely isolated from family support (a total of five people in Jordan and Lebanon). One third of people with specific needs stated that they did not have a regular caregiver. The size of families that include people with specific needs is, as highlighted earlier, much smaller than the average family size in Jordan and Lebanon, thereby placing more pressure on members of those families to provide support. While such families and caregivers can be highly innovative in their strategies for care provision, the challenges they face in meeting basic and daily needs often push them to breaking point. Families are often forced to choose between addressing the basic needs of the family in general, and the needs of family members with specific needs. As the duration of displacement continues and resources are depleted, this trend is likely to increase.

Community support networks

In addition to family support, people with specific needs and their families often seek to build a larger support network through friends, peer groups and associations. However, as displacement continues and the financial reserves of refugees are depleted, solidarity within communities can no longer be relied on to provide financial and material support, care and advice. Those providing assistance and support to people with specific needs do not necessarily have the knowledge or expertise to address health issues or complex needs related to ageing, impairment and injury. In such situations, physical and mental health conditions can deteriorate.

Support networks in urban and rural environments

The experience of refugees in rural and urban environments illustrates how different contexts may create or mitigate the vulnerability of people with specific needs and their families.

Urban contexts offer increased opportunities for employment and access to services including limited specialised healthcare. These are the two most reported reasons why refugee families chose to live in urban areas. However, the decision has financial implications as basic goods and services such as accommodation are more expensive.

In urban environments, heterogeneity of culture, ethnical backgrounds, religion and customs is more likely to exist. Refugees face the challenge of adapting to and fitting into a complex patchwork of communities with new social values and cultural norms – a situation that is most challenging for people moving from rural to urban areas. As a result, refugee families in urban areas are often less well accepted by the local population, resulting in higher levels of stress and psychosocial distress. They are also more socially isolated, with a smaller social circle of support.

Urban settings present more of a challenge for humanitarian actors to identify vulnerable people and provide relief and assistance because families regularly move within those areas. This can further contribute to the vulnerability of refugees in urban areas.

In contrast, refugees in rural areas consistently reported that host communities showed greater solidarity and support for them. In rural areas, refugee families (especially those from rural parts of Syria) can adapt more easily to social values and cultural norms because they are similar to their own. It is easier for families from the same communities to find places to live near each other, increasing the family and community support network. However, choosing to settle in rural settings also comes at a cost as there are fewer employment opportunities and less access to basic services and specialised care.

Rami's story

Rami lives with his four daughters in an unplanned, spontaneous settlement in the Bekaa valley, Al Marj, Lebanon. He lives in a tent among 15 other families also living in tents.

The tent gets very hot in the summer and cold in winter, and when it rains the tent sometimes floods, forcing Rami and his daughters to seek shelter with a Lebanese family in a nearby village. For Rami the experience is humiliating.

Rami was injured in a bombing in Syria and his left leg was amputated. He does not have any crutches or a prosthesis and has serious difficulty moving around. He is therefore unable to work and is reliant on the support of the families around him who are mostly from his village.

Recommendations

Humanitarian responders should:

- Develop strategies that strengthen existing support mechanisms for people with specific needs.



Gwenn Dubourthoumieu/Handicap International

Section 4

Conclusion and recommendations

Conclusion and recommendations

This report provides an insight into the situation and needs of older refugees, and refugees with impairments, injury and chronic disease – people whose needs are under-addressed by the current humanitarian response. It clearly illustrates the under-reporting of conditions known to contribute to the vulnerability of displaced populations including the challenge of adapting to new environments, limited access to services that help them meet their basic needs, and limited access to specialist services that can help address impairments, injuries and chronic diseases and conditions.

To ensure the delivery of a humanitarian response that is appropriate and accessible to people with specific needs, and that fulfils a commitment to impartiality and accountability to affected populations, it is essential that the evidence presented here is used to inform future assistance and services. Agencies and institutions delivering responses in Jordan and Lebanon must ensure that people with specific needs are identified and their needs addressed.

All refugees have the right to dignified and secure lives, based on their ability to meet both their basic and specific needs. Responsibility for ensuring this objective is achieved sits with all involved in the humanitarian response – not only specialist age or disability agencies. The following recommendations are intended to strengthen the capacity of local, national and international partners to fulfil their responsibilities.

The recommendations address five groups of actors, and expand on the recommendations made throughout the report:

- NGOs, UN agencies and other humanitarian organisations
- national and international healthcare providers
- donors
- government and local authorities
- providers of specialised assistance.

NGOs, UN agencies and other humanitarian organisations

Collect, analyse and use sex, age and disability disaggregated data (SADDD)

- Collect data disaggregated by age and gender in line with the Sphere standards.⁶⁷ Age data should be disaggregated by age groups 60-69, 70-79, and 80+.
- Collect data disaggregated by impairment, injury, and chronic diseases.
- Integrate measurements of disability into statistical surveys, using the Washington Group questions⁶⁸ to produce information that can be compared between different contexts.
- Conduct needs assessments and data collection in an inclusive and participatory way, giving all affected groups an opportunity to engage in focus group discussions and key informant interviews and input into programme design.
- Use the data collected to design and deliver programmes that are based on a rigorous analysis of the different needs of different population groups.

Sensitise and build the capacities of staff to identify and include people with specific needs (people with impairment, injury, those suffering from chronic disease and older people) in response activities

- Integrate a focus on refugees with specific needs into staff inductions and training. This can be facilitated by specialist age and disability agencies.

67. Sphere (2011). Core standard 3: Assessment, Guidance note, 4. www.spherehandbook.org/en/core-standard-3-assessment

68. <http://unstats.un.org/unsd/methods/citygroup/washington.htm> (28 March 2014)

- Integrate a focus on refugees with specific needs into operational procedures and protocols, including needs assessment/identification, outreach activities and monitoring and evaluation of project outcomes and impacts.
- Ensure mainstream response activities consider those with specific needs by providing age-sensitive and physically accessible services.

Develop strategies that strengthen existing support mechanisms for people with specific needs

- Assess pre-existing community coping mechanisms and support networks to understand the degree to which they address those with specific needs. Use the evidence collected to inform the design of interventions that support existing mechanisms and networks and effectively address gaps in coping strategies.
- Establish partnerships with local civil society and organisations including disabled and older people's organisations to improve their capacity to strengthen local coping strategies of those with specific needs.

National and international healthcare providers

Address gaps in the quality of primary healthcare services for those with chronic diseases

- Provide health education for patients on early detection and management of chronic diseases, including guidance on diet, healthy living and monitoring and management of conditions.
- Train health staff on chronic disease identification and ensure adequate time for consultations to provide patients with complete information on how to manage their condition.
- Provide early screening for diabetes and hypertension, and ongoing monitoring of conditions including laboratory tests.
- Provide training to health staff on the needs and challenges faced by older people, and basic skills such as communication techniques to support a more age-friendly environment.

Ensure adequate provision of NCD drugs at primary healthcare level

- National health providers should increase the quantities of drugs for chronic diseases available for common conditions, including insulin.
- Health NGOs should include proper management of chronic diseases in their health responses, including early detection of chronic diseases. Health interventions should support government and other national health providers to address chronic diseases.
- In Lebanon, more primary healthcare centres should be enrolled in local schemes for the provision of drugs for chronic diseases such as that provided by the YMCA. In both Jordan and Lebanon, availability of an adequate range and quantity of drugs for chronic diseases should be improved.

Improve access to laboratory tests at primary healthcare level

- Patients suffering from chronic diseases should be provided with subsidised access to laboratory testing for ongoing monitoring of their conditions.
- Laboratory services for chronic diseases should be established and/or existing laboratories equipped with the necessary equipment to perform tests.
- Subsidies should be provided to enable refugees to use individual testing kits such as blood pressure monitors and blood glucose test strips to monitor their conditions.



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Improve access to primary healthcare services for those with specific needs

- Ensure refugees have up-to-date information on the availability and cost of services.
- Support refugees to access UNHCR registration and registration with primary healthcare centres, including support with physical access for those with disabilities or low mobility (for example by subsidising transport costs).
- Put in place systems to ensure patients have continued access to their health files when they move or register with new primary healthcare centres.
- Ensure all health clinics are physically accessible for those with impairment including access ramps and grab rails.
- Ensure community health workers have the skills and time to provide community services for older people, people with impairment and injury, and can support referral. Services should include home visits to those who are bedridden or housebound, health education, and early detection of hypertension and diabetes.
- Ensure availability and accessibility of treatment for eye conditions.

Ensure medical assistance addresses the need for post-operative care (to avoid creating disabilities)

- Where necessary, open emergency post-operative care services in partnership with specialist agencies to complement and relieve pressure on national services.
- In the medium/longer term, support the capacity of national health service providers and health systems to address the post-operative and long-term needs of those with injuries and impairments.
- Before patients are discharged, ensure family/community level support for post-operative patients by identifying carers and addressing their needs for training and support materials.
- Improve referral pathways for people with specific needs to specialised care or other appropriate services.

Ensure services to address psychological distress are accessible to, and appropriate for, people with specific needs

- Provide outreach counselling and support services for those who are unable to attend health centres.
- Ensure psychosocial services consider the needs of those with specific needs, including those coming to terms with long term impairment or loss of freedom of movement.
- Ensure all age groups and people with specific needs have information on, and are made aware of, the availability of psychological support.
- Ensure activities and facilities such as child- and family-friendly spaces are accessible to children and adults with disabilities.
- Consider the needs of older men and women in the development of safe spaces and social activities.

Donors

Ensure projects that address the needs of refugees with specific needs receive necessary support, and encourage projects that ensure accessible services

- Use age, gender and disability marking/scoring of project proposals (following the example of the Age and Gender Marker introduced by the European Commission Humanitarian Aid and Civil Protection Department (ECHO)), to ensure that the activities funded are inclusive of people with specific needs.
- Provide medium- and long-term funding to support key areas of national-level response, in particular weaknesses in health system management of chronic diseases, mental healthcare and post-operative, rehabilitation and care services.

Support organisations to develop and implement new approaches that are inclusive of refugees with specific needs

- Work with partners to identify the factors that constrain the current capacity to ensure refugees with specific needs are included in existing programming.
- Facilitate knowledge sharing and learning between partners through documentation and dissemination of good practice, lessons learned and recommendations on the delivery of inclusive response activities.
- Facilitate engagement and partnership between organisations with expertise in addressing the needs of those with specific needs and non-specialised organisations in order to promote the mainstreaming of inclusion and provision of technical support to build capacity.

Governments and local authorities

Central governments

- Ensure national ageing and disability actors are consulted in the development of national health strategies.
- Ensure national resilience plans consider people with specific needs – especially the accessibility, availability and appropriateness of services supporting older people and people with an impairment or injury.

Local authorities (local antennae of Ministries of Social Affairs and municipalities)

- Ensure regular consultation with civil society organisations and disabled and older people's organisations when collecting information on the needs and numbers of affected populations.
- Sensitise and build the capacity of staff to better identify and include people with specific needs and their families in service provision (in partnership with international specialist organisations where relevant).
- Facilitate links and engagement between international organisations, civil society organisations and disabled and older people's organisations.

Providers of specialised assistance

Enhance the range of specific services provided to people with specific needs and their families

- Provide direct financial support (cash transfers) to people with specific needs and families hosting people with specific needs to support their ability to meet their needs.
- Provide access to tailored livelihood opportunities for these groups.
- Provide comprehensive medical and rehabilitation care, including community-level follow-up and support for people with injuries.

Improve data collection related to specific needs

- Data on specific needs related to age and disability should be collected in a systematic and standardised way as far as possible to prevent discrepancies between data collection mechanisms and to facilitate vulnerability analysis.
- Use activities of daily living (ADL) analysis during needs assessments to improve the identification of disability and the design of support services.

Support mainstream response to ensure people with specific needs can access services

- Enhance the capacity of mainstream operational agencies by providing tools and training on how to ensure physical accessibility and address the needs of older, disabled and injured refugees.
- Disseminate technical advice and tools on accessibility.

Annexes

Annex 1: Further reading

Agency for Technical Cooperation and Development (ACTED) Food security and livelihoods assessment, northern Jordan (August 2013)

CARE Syrian refugees in urban Jordan: vulnerability assessment (April 2013)

Caritas and Caritas Lebanon Migrant Centre Forgotten voices: an insight into to older persons among Syrian refugees in Lebanon (September 2013)

FAFO Ambivalent hospitality: coping strategies and local responses to Syrian refugees in Lebanon (2013)

Handicap International DVFP Bekaa project: facts and figures (internal, December 2012)

Handicap International Disability checklist for emergency response (2009)

HelpAge International The situation of Syrian refugee older people and people with disabilities in northern Jordan: vulnerability assessment (20 March 2013)

Inter-agency Standing Committee and HelpAge International Strong and fragile: learning from older people in emergencies (2007)

International Catholic Migration Commission Outreach analysis (January 2013)

International Medical Corps Mental health and psychosocial support and child protection assessment, Zaatari (July 2013)

International Rescue Committee Assessment report: cash transfer program to Syrian refugees in Jordan (October 2012)

International Rescue Committee Syria: a regional crisis (January 2013)

Oxfam Integrated host community assessment: Jordan (March 2013)

Oxfam Shifting sands: gender roles among refugees (September 2013)

REACH Syrian refugee host community assessment (April 2013)

UN Habitat Lebanon urban profile: a desk review report (October 2011)

UN Women Gender-based violence and child protection among Syrian refugees in Jordan (June 2013)

UNESCO Marginalization of people with disabilities in Lebanon, Jordan and Syria, Susan J Peters (September 2009)

UNHCR Trend analysis: registration of Syrian refugees in Jordan (October 2013)

UNICEF and IMC Mental health and psychosocial support and child protection assessment, Zaatari (July 2013)

UNICEF and Solidarités International Informal tented settlements: vulnerability assessment (August 2013)

WRC Disabilities among refugees and conflict-affected populations (June 2008)

WRC Disability inclusion in the Syrian refugee response in Lebanon (July 2013)

Annex 2: Definitions

Older people For the purposes of this study, older people are defined as those aged 60 or above in accordance with the definition of older people used by the World Health Organization and the United Nations High Commissioner for Refugees.

Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual when involved in daily life situations.

Disability is an evolving concept, resulting from the interaction between people with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others. (Convention on the Rights of People with Disabilities).

Injury is the damage to the physical body of a person, resulting from an event (not from a disease or long-term process). It can result from various causes such as violence (for example, the immediate consequence of war, such as gunshot, shrapnel, torture etc), accidents, consequence of birth, attempted suicide etc.

Mental disabilities are associated with chronic instances of serious mental disorders (schizophrenia, manic-depressive psychosis, depression). Post-traumatic stress syndrome is also considered as a serious mental disorder and can follow a situation in which the physical and/or psychological integrity of the person (and/or those around them at the time of the incident) has been threatened or affected by a serious accident, violent death, sexual aggression, physical aggression, serious illness, war, terrorist attack, serious flooding etc.

Intellectual impairments are usually associated with a developmental disorder or a pervasive developmental disorder, whatever the cause (genetic, chromosomal, bio-organic, and environmental, including nutritional). By intellectual impairment we understand the significant, persistent and long-term limitation of a person's intellectual functions (assessed by measuring Intellectual Quotient) compared with other people of the same age who do not present this limitation. The resulting disabilities affect to a greater or less extent the person's ability to learn, their knowledge acquisition and ability to memorise, their attention, communication, social and professional autonomy, emotional stability and behaviour.

Chronic disease WHO defines chronic or non-communicable disease as one not passed from person to person. They are of long duration and generally slow progression. The four main types of non-communicable diseases are cardiovascular diseases (such as heart attacks and stroke), cancers, chronic respiratory diseases (such as chronic obstructed pulmonary disease and asthma) and diabetes.

Activities of Daily Living (ADL) are routine activities that people tend to do every day without needing assistance. There are six basic ADLs: eating, bathing, dressing, toileting, transferring (walking) and continence. An individual's ability to perform ADLs is important for determining what type of long-term care is needed (eg care home or home care).⁶⁹

Refugee The 1951 Refugee Convention defines a refugee as someone who, 'owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality, and is unable to, or owing to such fear is unwilling to avail himself of, the protection of that country.'

Family For the purposes of this study, a family is considered to be a group of relatives living together – grandparents, parents, children, and sometimes other relatives such as sisters-/brothers-in-law. Several families may live in the same household.

Host family A host family is considered to be one that has allowed refugees to live in the same living space. Renting or giving space to a refugee family without living on the same premises was not considered as a host family.

Annex 3: Psychological assessment

The psychological status of the survey participants was assessed by focusing on the prevalence of simple and clearly expressible signs of psychological signs of distress using a set of 10 questions focusing on categories of needs.

Change in emotion Irritability, anxiety, anger, excitability, mood swing

Change in behaviour Aggressiveness, passivity, tendency to isolation, silence and withdrawal; rigid attitudes, abusive use of drugs or medication

Change in relationships Difficulties in communicating, establishing and maintaining new relationships, difficulties in expressing feelings etc.

Change in cognition Difficulties in maintaining attention, and to focus, think clearly or to take decisions.

The study does not distinguish between severe disorders (psychosis, severe depression, severely disabling forms of anxiety disorder), mild or moderate mental disorders (for example, mild and moderate forms of depression and anxiety disorders, including mild and moderate post-traumatic stress disorder), or standard distress, which would not be considered by the WHO as a disorder.

69. www.investopedia.com/terms/a/adl.asp

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