Science may have found a cure for most evils; but it has found no remedy for the worst of them all – the apathy of human beings.

Helen Keller

CARING FOR PEOPLE WITH INTELLECTUAL DISABILITY

A household survey in

13 locales

in the vicinity of Star Mountain

Institute of Community and Public Health
Birzeit University

In cooperation with

Star Mountain Rehabilitation Center
Moravian Church

December 2013

Acknowledgments

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Without CBM's dedication to the cause of disability, Star Mountain would not have easily managed to plan for such an important task.

Content

EXECUTIVE SUMMARY

This house-to-house survey of 13 communities in the vicinity of Birzeit was commissioned by Star Mountain Rehabilitation Center with the aim of identifying persons who endure the consequences of disability, with a focus on intellectual disabilities. Start Mountain had conducted focus group discussions in these locales previous to commissioning the Institute of Community and Public Health, Birzeit University (ICPH/BZU) to complete the survey. These meetings revealed that representatives of these communities requested specific information about their communities in general, and about persons with disabilities, including intellectual disabilities in particular.

This report was completed by ICPH/BZU, an institution which has had a long-standing interest in research and advocacy regarding the needs of people with disability and the fulfillment of their basic human rights. The survey, upon which the report is based, was completed with the cooperation of 3 Star Mountain supervisors who oversaw the details of the field work with ICPH assistance. The report is divided into the following sections:

- a general introduction on disability around the world, including a literature review on the complexities of measuring disability;
- a section on disability in the occupied Palestinian territory(oPt), which is important to compare national level data with the data obtained in this survey;
- a section on the history and current activities of Star Mountain Rehabilitation Center, including the reasons why Star Mountain commissioned this study;

- a methods section;
- a results section divided into persons over and under 3 years of age in these communities;
- A conclusions section, which uses the information obtained from the survey to delineate future actions.

Main Results

HOUSEHOLDS

- The survey included the following locales: Abu Qash, Atara, Birzeit, Burham, Dura al-Qare', Ein Sinia, Jalazone Palestinian refugee camp, Jibia, Jifna, Kobar, al-Mizra'a al-Gharbieh and Abu-Shkeidem, (otherwise known as Zaitouna), and Surda.
- We were able to reach over 80% of households in the 13 communities, considered widely as adequate for a house-to-house survey in smaller towns and villages.
- The 4919 households visited contained a total of 26135 persons, with an average family size of 5.3, consistent with the national average. Of the total, there were 2277 children three years or under. The data on these children was analyzed separately.
- 91% of households were nuclear households (mother, father and children, and no other relatives living at home), with more village families composed of extended households compared to the town of Birzeit and the Jalazone Palestinian refugee camp.

- 25% of household heads were married to first cousins, most commonly in villages at 28% of household heads there, compared to 21% for Jalazone refugee camp and 18% for the town of Birzeit.
- The educational level of male heads of household was low, probably due to their relative old age compared with others in the family: 57% had less than high school education, 19% high school and 23% more than high school education.
- 82% of male heads of household were working at the time of the survey, 10% were unemployed and 8% retired.

INDIVIDUALS IN THESE HOUSEHOLDS

- Of the total, 51% were male. Ages ranged from under one month to 98 years with a mean age of 24.4 years, indicating a youthful population.
- 93% of persons of school age (6-18 years) were attending school at the time of the survey, 5.3% dropped out before completing high school, 0.5% graduated, 0.4% never attended school and 0.8% did not start school yet.
- For those 10 years or over, 51% of men and boys were working at the time of the survey compared to 11% of women and girls.

DISABILITY AMONG PERSONS OVER THREE YEARS OLD

- Responses to the Washington Group questions pertaining to ability-related difficulties among those over three years old revealed the following:
  - ✓ 1.8% of all the population reported difficulties seeing
  - ✓ 1.1% hearing

- ✓ 2.3% walking
- ✓ 1% remembering or concentrating
- ✓ 0.9% in self-care
- ✓ 0.5% communication.

- There were 1137 persons with one or more disabilities, including a total of 1787 disabilities (excluding children). In all, 4.7% of the population had at least one disability according to the wide definition, and 2.2% according to the narrow definition.
- Movement-related disabilities had the highest prevalence rate at 31% of all disabilities, followed by 24% for seeing difficulties, 14% for hearing difficulties, 13% for self-care difficulties, and 6% for communication difficulties.
- 51% reported that, in their opinions, the cause of disability in their family was illness, 14% from birth, 13% from God and due to old age each, 4% due to accidents, 1.2% due to war, and 0.7% other reasons.
- Disability increased with age, as expected, with 13% between 3.1-19 years, 14% between 15-29, 32% between 30-59, and 41% 60 years or over. There were significant differences in disability by sex for those 30 years and over, indicating a **need to pay special attention to the disabled elderly, especially women**.
- Cousin marriage was positively associated with disability. These are expected results, which indicate a need for health education. However, cousin marriage is sometimes a family survival need in this country, a rational choice people make where they accept the risk of having disabled children by marrying cousins.

COMPARISONS BETWEEN THE DISABLED AND PERSONS WITHOUT DISABILITIES

- 6% of men with disability are widowed compared to 35% of women with disability, once again pointing to **elderly women as a priority for action.**
- There was a higher proportion of people with disability who were not married, with 24% of those with physical and sensory disabilities unmarried (compared to a high of 56% among probable intellectually disabled (IDs)), and only 10% among those with no disability.
- Disabled persons lived in extended households significantly more than non-disabled persons, at 19% compared to 11% among those with no reported disability. This type of household arrangement was an indication of family poverty, either inducing disability or disability inducing poverty. That is, **families with disabled people seem to be poorer than the rest of the families in these communities**.
- Households with disabled members had less educated female heads of household as well**,** often related to their older age and poverty.
- Comparisons of educational levels between people with disability and others in these communities also demonstrate significant differences in favor of those with no reported disability. That is, **people with disability are less educated than others in all age groups**. These results point to the need to address the issue of education among people with disability as an issue requiring future attention.

- **People with disability seem to also suffer from significantly higher levels of unemployment** compared to others in their communities, raising questions as to how to ameliorate the employment levels among people with disabilities.

PEOPLE WITH PROBABLE INTELLECTUAL DISABILITIES (IDS)

- 30% (333 persons) of people with disability were reported as having intellectual disabilities in addition to other types of disabilities (such as movement and sensory disabilities) which we call here probable persons with intellectual disability (IDs). These estimates are compatible with the national average.
- A high of 43% of probable IDs were 60 years or older, again identifying **the elderly as a priority for action.** IDs were found in all 13 locales with proportions relative to the size of the population in general.
- Families with a member with ID suffered from high levels of unemployment among heads of household, at 30% compared to 28% among other people with disability, and 10% among households with no reported disabilities. This points to a probable higher poverty level among families of all disabled, not only IDs.

DIFFICULTIES ENDURED AND NEEDS FOR ASSISTANCE

- People with probable IDs reported significantly more difficulties in completing activities of daily living - such as standing for 30 minutes, completing

household chores, learning new tasks and joining community activities - compared to other people with disability**. While all people with disability need assistance in both daily activities and social integration, people with IDs seem to be a priority for action**. Females were found to be in more need of help compared to males, again **pointing to women as a priority for assistance**. The highest reports of difficulties completing activities of daily living came from villages, a result which requires further inquiry, as it could not be explained given the limitation of the data set at hand.

- There were more females reporting cognition difficulties compared to males, and significantly more over 60 years old**,** once again reinforcing the idea that the need for help is most acute among elderly women.
- Movement difficulties were higher among people with IDs compared to people with other disabilities, but substantial among all people with disabilities, especially those 60 years or over, once again pointing to elderly care as a priority for action.
- Likewise, people with IDs reported higher levels of problems dealing with self-care and completing household tasks (especially among women), compared to people with other disabilities.
- **Overall, people with IDs reported higher levels of difficulties we asked about compared to people with other disabilities,** pointing to IDs as a priority for action on these specific difficulties, but also pointing to the needs of people with other disabilities for assistance as well.

- **Finally, the social participation questions revealed significantly more problems in this area among people with IDs compared to people with other disabilities.** These results demonstrate the burden of disability on IDs and older women in particular — though not solely — including burdens on their families in dealing with disability on a daily basis as well as its financial and social consequences. There is no doubt that assistance in these areas is a need and a priority for action.

CHILDREN THREE YEARS AND UNDER

- Our analysis of the questionnaire specially developed for children three years and under revealed 65 persons with possible developmental delays, although proper diagnosis requires further investigation. Those with possible developmental delays add up to 2.9% of all children in this age group, a proportion which is compatible with the national average of disability among children in general.
- It is imperative that these children are visited as soon as possible, and, without stigmatizing them, find out more about their developmental progress, in addition to referring them for further investigation elsewhere if need be.

OVERALL CONCLUSIONS

- We would like to express our appreciation to Star Mountain for this important initiative, which has allowed us to understand the needs of people with disabilities and identify priority groups. Indeed, the occupied Palestinian territory is undergoing important demographic and epidemiological transitions, away from high infant mortality rates and communicable diseases (including childhood diseases), and moving rapidly towards non-communicable and chronic diseases. Meanwhile, instances of disability continue to arise at a young age because of a combination of genetic/familial and environmental reasons. Because such disabilities are not spotted on time, if at all, they end up increasing in severity, sometimes leading to childhood death or permanent disability.

- At the same time, the population is also beginning to age, bringing in the issues and problems of not only chronic diseases, but other problems related to old age such as dementia. The country's health and other systems are, however, not equipped to absorb the increasing needs of the elderly. This is precisely why this study is so important. We hope that the data presented in this report, which prioritizes people with IDs and women, will assist in helping people with disabilities to better function and participate in society. Moreover, we hope that it functions as a wakeup call to all those concerned about ensuring that the needs of all are met.

INTRODUCTION

Disability in general

PREVALENCE AND CAUSES

Disability is a worldwide phenomenon, and it appears to be on the rise. This is believed to be due to aging populations (including in the occupied Palestinian territory [oPt]), and the increased risk of disability among older people. Reports indicate that the rising disability rates are primarily due to increases in the prevalence rates of chronic diseases such as cardiovascular disease, hypertension, diabetes mellitus, cancer, and mental health disorders (World Health Organization and World Bank, 2011). Although there are differences between developing and developed nations, projections indicate that median ages will increase in all countries.

Aging and the rise of chronic diseases are not the only reasons for the continual growth of disability among populations. Poverty, wars and armed conflicts, and the AIDS epidemic are all contributing factors. Data on conflict-related disabilities is scarce , and difficult to obtain because disabilities due to war are generally assessed by reviewing cases of patients attending health facilities (Murray, CJL; King, G; Lopez, AD; Tomijima, N; Krug, EG, 2002), which does not account for all instances of people with disability. Selected national level statistics can nevertheless be revealing. For example, a 1982 study in Zimbabwe indicates that 13% of all physical disabilities were due to the armed conflict. Six thousand people were disabled due to

accidentally stepping on a landmine in one year alone (1990) in Cambodia (Krug, EG; Dahlberg, LL; Mercy, A (eds), 2002).

Data from the oPt indicates that around 25000 people were injured in the West Bank by the Israeli army during the first year of the First Palestinian Uprising (1988-1999) alone. An ICPH examination of 2500 hospital records revealed that 472 of these cases suffered from disability, or around 19% of the injured in one year, and only in the West Bank (we could not reach the Gaza strip at the time) (Giacaman,R; D'eibes, I, 1989).

Although global data is unavailable regarding disability due to occupational injury and road traffic accident, these factors are also known to contribute to disability. Reports indicate that about 1.2 million people died from road traffic crashes in 2002, and that 2.1% of all global deaths are due to road traffic injuries. It is also estimated that 20-50 million people are injured in road crashes every year (Peden, 2004).

More than one billion people in the world live with disability, including a minimum of around 15.6% and a maximum of around 19.4% persons 15 years and older globally (World Health Organization and World Bank, 2011). However, not all experience difficulties in functioning, although a substantial number is believed to have **important functioning problems, estimated at 2.2% of the world population.**

Several estimates of the prevalence of disability in the world are found in the literature, ranging from under 1% in Kenya and Bangladesh to 20% in New Zealand (Mont, 2007). This is thought to be mainly due to how disability is defined, the varied methodologies of data collection, in addition to the variability of the quality of available data. This of course makes comparability difficult. The WHO reports that severe disabilities affect 2.9% of the world's population (all ages), 3.2% in high income countries, 3.1% in Africa, 2.6% in the Americas, 2.9% in south-east Asia, 3% in European countries, 2.8% in eastern Mediterranean countries and 2.7% in the western Pacific. If we combine moderate with severe disability, the percentages jump to a high of 16.4% in European countries, and a low of 14% in Eastern Mediterranean countries (World Health Organization and World Bank, 2011).

CONTESTED DEFINITIONS OF DISABILITY

To date, there seems to be no agreed upon or 'correct' definition of disability since the type and severity of disabilities can vary. According to the literature, disability is a complex and evolving concept, which continues to be contested. Disability has often been defined as "a physical, mental, or psychological condition that limits a person's activities" (Mont, 2007). The concept underwent a gradual transition from an individual and medical conceptualization towards a structural, social perspective. The medical model was the most dominant model during the 1980's (McDermott & Turk, 2011). This model defines disability from an impairment viewpoint, and has been linked to measuring 'deficit,' and counting diagnoses and problems, using the International Classification of Disease (ICD-9 or 10).

More recently, the functional model has become the more dominant approach to the classification of disability. This model focuses on the ability to function as opposed to diagnoses (which are sometimes very difficult to ascertain, especially in developing world settings). The social model of disability focuses on environmental, economic and political obstacles to the inclusion of people with disability, with disability conceptualized as a social construct. This model points to societal attitudes as the deficiency, and not the impairments within. That is, there has been a shift from a medical to a social model in which disability is viewed as being due to a disabling society, as opposed to their bodies (World Health Organization; World Bank, 2011). A balance, however, needs to be reached. It is recommended— by the WHO and others —that an appropriate (and not one-sided) model is needed where disability is viewed as a medical but also a social issue, and where disability can be conceptualized on a continuum from minor difficulties in functioning to major impacts on a person's daily life.

COMPLEXITIES OF MEASURING DISABILITY

The nature and severity of disabilities can vary depending on the purpose of measurement (Centers for Disease Control, 2006) and the cultural context. This means that measuring disability depends on why the exercise is being completed; that is, the kind of question one asks when studying disability (for example, prevalence of types versus a focus on functioning) (Loeb, ME; Eide, AH; Mont, D, 2008)(Mont, 2007).

It is also important to mention that different measurement instruments often used within the same country often report very different rates of disability. There are different approaches used to measure the prevalence of disability, which depend on the reason one is collecting data. They include: a] self-identification, where persons are asked directly if they have a disability; b] diagnosable conditions, here respondents are asked to point to any conditions read from a list, such as polio, paralysis etc; c] activities of daily living (ADL), where respondents are classified as disabled if they have difficulty performing basic activities such as dressing, bathing and feeding oneself; d] instrumental activities of daily living (IADL), which focuses on higher order tasks such as problems with managing money, shopping or maintaining a household and e] participation, focusing on conditions affecting social roles, such as schooling and work (Mont, 2007).

Studies have found important differences in the prevalence of disability between measures obtained from censuses (for example, using a limited choice of impairments), versus those compiled from self-reports of disability, or data using more than one indicator of disability/impairment. Countries reporting higher prevalence of disability are known to use survey methods to collect data (not censuses), and also record activity limitation and participation restrictions, in addition to impairments (World Health Organization and World Bank, 2011).

Cultural differences make measuring and comparing disability even more difficult. Disability is usually interpreted in relation to what is seen as normal functioning. And this varies based on context, age group, and income group (older people may not see themselves as having a disability, even though they have difficulty functioning because their status is seen culturally as expected for their age). In addition, instruments are designed based on the idea that they are culturally neutral, and therefore, applicable in cross-cultural setting. However, questions have been raised regarding the possibility of such neutrality. This is because the perception of the 'normal' versus the 'disabled' is culturally laden, and the consequences of impairment (personal, practical and social) can differ substantially in various settings because different impairments can be understood differently across cultures, and therefore, will have different consequences socially and in terms of functioning as well (Grut & Ingstad, 2005).

On the whole, it seems that measuring functional limitations, rather than disability, have become an increasingly adopted approach. This is in contrast to the formerly more widespread practice of using different severity thresholds, such as including mild functioning problems into the overall disability prevalence versus only the moderate and severe problems, based on the specific purpose of measurement (Mont, 2007).

DISABILITY IN LOWER INCOME COUNTRIES

Data from the 2011 World Report on Disability indicates that there is a higher prevalence of disability in lower income countries compared to higher income countries (World Health Organization and World Bank). However, country-specific estimates of disability prevalence in low income countries vary widely from 3% to a high of 16% (Nitra, S; Posarac, A; Vick, B., 2011). In addition, disability prevalence is higher among women, compared to men, and higher among the poorest sectors of societies, including elderly people. People with disability are reported as having statistically significant lower educational statuses, and lower employment rates compared to people without disabilities. That is, people with low income, the unemployed and those with low educational levels are at an increased risk of disability. Evidence also seems to suggest that households with disabled persons are worse off compared to those who do not have disabled members of the household.

Thus, poverty is believed to be both a cause and a consequence of disability. A person with disability is: less likely to complete primary education; less likely to secure long-term employment; is more likely to have low levels of social capital and relational bonds; and is more likely to lack social protection, as is the case with most other citizens of lower income countries. A poor person can usually not afford basic health care, proper housing, and clean water. Thus disability can cause poverty and poverty can cause disability (Lang, 2010).

THE COSTS OF DISABILITY

Disability carries with it economic, social and psychological costs. People with disability, their families, and friends as well as society at large bear these costs (World Health Organization and the World Bank, 2011). Much of this cost is due to environments which are not accessible to people with disability and to lack of attention paid to including them as contributing members of society. If people with disability are not included, for example through special education for children with disability, or if they are outside the labor force, it is society which may bear the cost through loss of potential tax revenues and general productivity. Social isolation and stress for people with disability and their families (as well as a low quality of life and low wellbeing in our opinion), are also part of the costs incurred by disability, though they are difficult to quantify. This is especially true for stigma, which appears to affect people with disability differently, depending on culture and ethnicity (Saetermoe CL; Scattone, D; Kim, KH, 2001).

OBSTACLES TO DISABILITY CARE

Studies from low income countries indicate that the main obstacles to the care of people with disabilities include lack of services in the area and transportation (cost, distance and lack of transport), in addition to services not being useful any more or the lack of satisfaction with the services (World Health Organization and World Bank, 2011). The 2011 World Health Survey indicates that not being able to afford services was the main reason why people with disabilities did not receive the needed care, in addition to transport costs. Even when services exist for people with disabilities,

there are other obstacles to care, such as physical, communication, and information barriers. For example, inaccesssible buildings, parking spaces, narrow doors, steps, inadequate bathrooms are all impediments.

Intellectual disability

Intellectual disability (ID) refers to learning disabilities in people with 'mental retardation,' a term which is increasingly being abandoned because of its negative connotation (Allison & A, 2009). The World Health Organization defines ID as a: "significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence)." This results in a reduced ability to cope independently (impaired social functioning), beginning before adulthood, with a lasting effect on development (World Health Organization, 2013).

ID is distinct from mental illness not only in the West, but in most other cultures as well. It is estimated that the prevalence of ID is 1% if functional impairment is included in the assessment. ID rates vary among groups and over time, since they are influenced by factors such as antenatal and neonatal care, screening during pregnancy for genetic abnormalities, and socioeconomic factors including poverty and malnutritition. In the case of the oPt, cousin marriage is often blamed as a main cause of ID, although data is unavailable to ascertain this claim. The prevalence of severe mental "retardation" is around 3-4 per 1000 (children and adults) in developed and developing countries (Allison, L; Strydom. A, 2009).

People with ID are more vulnerable to stigmatization and prejudice compared to other people with disability (Allison & A, 2009). Stigma also results in discrimination. There seems to be evidence to show that employers, for example, discriminate against and have negative attitudes towards those with intellectual disabilities (Scheid, 2005). People with ID are also shown to be socially excluded, not only economically. If people with ID are institutionalized, their social relationships are limited to other people with disabilities. When they are in the community, as the common understanding goes: "it is not the same as being *of* the community." In other words, even when they are part of the community, people with ID suffer from what is called social poverty (Metzel, 2005), although this may differ from culture to culture. In the end this stigma gives rise to discrimination and exclusion thus requiring a special kind of disability care (Allison, L; Strydom. A, 2009)

The Occupied Palestinian Territory (oPt)

Attention to disability and the needs of people with disability in the oPt began to take shape following the beginning of the First Palestinian Uprising (*Intifada)* with the escalation of political violence against Palestinians by the Israeli army (Giacaman,R; D'eibes, I, 1989). During a period of 21 months, at least 40,000 were estimated to have been injured, mostly young adults and children. The physical, psychosocial and mental toll of such high levels of exposure to political violence, including the consequences on people and society at large, caught the public eye locally and internationally. This is when the oPt witnessed a transformation in the concept of disability, from a personal and family problem bringing shame to both, to

a honorable condition caused by political heroism. This was the beginning of the Palestinian Community Based Rehabilitation (CBR) programme. Since that time, various pocket studies intended to assess the need for CBR indicated that the prevalence of disability in the studied areas (we were prohibited from conducting censuses by the Israeli military during this period) ranged from 1.9% to about 4.5% (Giacaman et al, 1993; Giacaman et al, 1994; Giacaman et al, 1995).

These results do not seem to have differed much over time, although care should be taken in comparing data given the different methods of measuring disability. In 2011, the Palestinian Central Bureau of Statistics (PCBS) conducted a survey representing all the Palestinian population in the Gaza Strip and West Bank, including East Jerusalem,(15,680 households) and reported an overall disability rate of 7%, or about 292000 persons, based on a population projection of 4168860 for the oPt for 2011 (Palestinian Central Bureau of Statistics, 2013). The 7% is calculated based on the wide definition of disability, which according to the Washington Group criterion includes all 'yes' responses ('some difficulty,' 'a lot of difficulty,' 'can't do at all' (Mont, D, 2006). This can be further broken down into the following categories: 2.4% seeing, 1.3% hearing, 2.9% mobility, 1.5% remembering and concentrating, 1.1% communication, 1.1% learning, and 0.7% mental health (this covers stress, anxiety, uncertainty and so-called "excess neurons" as well as drug abuse and addiction, which make these persons face difficulties in performing daily activities).

When adopting the narrow definition (limited to those responding with a lot of difficulty or an inability to function in a particular area), PCBS reported a 2.7% prevalence of disability among the population (or about 113,000 persons): 0.6% seeing, 0.4% hearing, 1.3% mobility, 0.6% remembering or concentrating, 0.6% communication, 0.7% learning, and 0.4% mental health disabilities.

The prevalence of disability was 2.9% for the West Bank and 2.4% for the Gaza Strip, including 2.9% for males overall and 2.5% for females overall (Palestinian Central Bureau of Statistics and Ministry of Social Affairs, 2011). PCBS data also indicates that the prevalence of disability among children 0-17 years was 1.5%, with 1.8% for male children compared to 1.3% for female children, raising questions regarding the possible neglect of female children with disability at home, although males are also known to be more prone to disability compared to females. The prevalence of disability among adults 18 years and over was 3.8%, including 4% in the West Bank and 3.4% in the Gaza Strip. The Ramallah governorate was found to have a 2.1% prevalence of disability according to the narrow definition.

This survey also indicates that the highest prevalence of disability in the oPt is for mobility at 49% of all persons with disability, followed by 24.7% for learning. Of the total disabilities, 4.6% were due to Israeli measures, with 2% of those with hearing difficulties reporting that this was due to Israeli measures, 3.2% for communications, 5.3% for movement, 4.1% for remembering, 3.2% for learning, and a high of 7.7% for mental health problems (PCBS Disability Survey 2011 micro data calculated for the

purpose of this report). It was also found that 87.3% of persons with disability did not work during the survey implementation period, and one third was never married. Illness was reported as the main cause.

STAR MOUNTAIN REHABILITATION CENTER

A brief history

Star Mountain Rehabilitation Center (SMRC) is a non-profit and non-governmental organization of the worldwide Moravian Church Unity and active in rehabilitation in Palestine for more than 100 years. The first field of work of SMRC focused on leprosy patients, first in Jerusalem until the year 1948. With the establishment of the state Israel, the leprosy hospital was taken over by the Israelis who forbade the Moravian Church from continuing to run it. That was the point when a new location was sought by a Moravian nun named Sister Johanna Larsen who believed in the great need to care for and provide a decent life for Arab leprosy patients at that time.

By the year 1959, the Leprosy Hospital was established on the same premises where Star Mountain is located today, in Abu Qash village in the center of the West Bank. This facility remained functioning as such until the year 1980, when a medication was found for curing leprosy allowing leprosy patients were sent home to live with their families.

After conducting several needs assessments through discussions with local community members and influential figures at the time, the Moravian Church

decided to shift the focus of its work to a different marginalized social problem, namely girls and women with ID. ID in the late seventies and eighties was a taboo issue rarely acknowledged or spoken about because of stigma. Persons with IDs were therefore kept mostly hidden at home in shame.

Since 1981, SMRC has provided training, rehabilitation and educational services, as well as assistance and empowerment for people with IDs living in the Birzeit area, particularly in 13 locales including one official and one non-official Palestinian refugee camp. SMRC has also been offering support and guidance to their families, communities and professionals working in the field. It is worth noting that since the year 2000, Star Mountain serves both males and females with ID.

SMRC TODAY

Currently, SMRC employs 35 persons and serves 75 children and adults with IDs who are daily transported to and from the center. In addition, 92 persons with ID are served in the villages through the community work program.

There are **five programs** operated by the center:

- The Integrative Kindergarten (3 months - 6 years old)
- The School Program (school-aged children: 6 - 14 years old)
- The Autism Program (6 - 14 years old)
- The Vocational Training Program (14 - 40 years old)
- The Community Work Program (birth till old age)

In addition to these programs, SMRC offers specialized support services such as individual and group psycho-social support, physiotherapy, speech therapy, art education, basic music education and sports. All programs are complementary and provide unique rehabilitation, training and integration opportunities for persons with IDs.

SMRC'S NETWORKS

Over the years, SMRC has built a strong network with governmental institutions, national and community-based organizations (CBOs), and non-governmental organizations (NGOs), mainly those working in the field of disability, but also those working in the fields of anti-violence, protection from abuse, legal issues, health and social affairs. The aims behind such cooperation have been: raising awareness in issues related to persons with IDs; mainstreaming issues of ID into the agendas of governmental and non-governmental bodies; calling for the rights of persons with intellectual disability; and helping persons with IDs access services or referrals to other parties for support.

SMRC is known by the community to be one of the few specialist groups working with persons with intellectual disability. The long experience of more than 30 years working in this field is often shared with school and university students, institutions and guests in the form of workshops, lectures, guided tours and in-class trainings.

AIM OF THE STUDY

As mentioned above, one of SMRC's programs is the Community Work Program (CWP), which operates based on the principals of community-based rehabilitation (CBR), but focuses on persons with intellectual disability as their main target (noting that the CBR program of the Patients Friends Society works with other types of disability in the same locales where SMRC works).

SMRC's CWP was launched in the year 1995, first focusing on all types of disability and then gradually moving into a specialization addressing the needs of persons with IDs. In 2010, one of the main partners of SMRC and the donor of the CWP program, the Christoffel Blind Mission, conducted a thorough assessment of all SMRC's programs and came out with several recommendations, one of which was to conduct a needs assessment at the level of CBOs along with people with disability and their families to redefine the CWP's aims and goals based on actual needs.

In 2013, focus group discussions were conducted by SMRC staff in all target locations, out of which rich results were presented. Among many needs, all communities stated the need for a comprehensive survey that would identify information about their communities in general, and about persons with disability, especially intellectual disabilities, in particular.

As a result, and in cooperation with ICPH, a house-to-house survey was conducted to identify as many persons as possible who suffer from IDs that not already known to

SMRC, which could only be achieved by surveying all people with disabilities in these communities who agree to participate in the survey. The aim was to know who and where these people are along with their needs for assistance in functioning, so as to be able to develop SMRC's programs for the highest benefit of persons with ID and to alleviate their families as well. We also aim to share the results of the survey with other institutions and policymakers with the goal of including issues of persons with ID into their strategic thinking and policies.

METHODOLOGY

RESEARCH INSTRUMENTS

It was decided that a house-to-house survey would be conducted in 13 locales in the immediate vicinity of Star Mountain in the central West Bank, and its catchment area (see Table 1). After some discussions about which measurement instrument to use, we decided to use a combination of instruments, in the hope of obtaining **prevalence data**, and also **data on functioning**. We therefore used first, the **Washington Group Short set of questions for person over three years old**. The questions identify persons who are at a greater risk than the general population of experiencing restrictions in performing activities such as activities of daily living or participating in particular roles (such as working) if no accommodations are made. These questions were designed to provide comparable data cross-nationally for populations regardless of culture or economic resources (Centers for Disease Control, 2006).

The Washington group questions cannot identify every person with a disability in every community. The focus is on simplicity, brevity, and comparability. The information resulting from using these questions represents the majority, but not all disabled persons with limitations in basic activities. It represents the most commonly occurring disability domains in the locales where the survey is implemented. And it captures persons with similar problems across countries or regions (in our case comparing with PCBS national level data using the same instrument with the locales we are working with).

After obtaining approval from WHO to use the tool, we also used the **World Health Organization's WHODAS2 13/24 interviewer-administered version** (approval from Dr. Somnath Chatterji from WHO Geneva). Dr. Chatterji advised us to use the interviewer-administered version as a proxy (asking mothers of children under 13 and over 3 years of age) because one was never created. This is a generic tool for the assessment of health and disability. It is applicable in clinical and general population settings, and produces disability levels which are standardized, and applicable across various cultures. The WHODAS2 questions are linked to the International Classification of Functioning, Disease and Health. [1]

We first translated and back-translated the Washington Group and WHODas2 questions with bilingual Arabic and English speakers. We also translated the sections related to training in the WHO manual to produce a local manual, with selected modifications in line with our questionnaire and the context. We conducted 3 days of training (two days before and 1 day after the questionnaire piloting phase) for 20 field workers and two trainers. The field work supervisors (3) were also there during the training. A pilot to test the clarity and appropriateness of the instrument was completed in a village in the vicinity of Birzeit University, which was not included in the study, with 40 participants. Minor modifications were made in line with the results to ensure clarity and meaning equivalence.

[1] For further details see:(WHO, http://www.who.int/classifications/icf/whodasii/en/index.html).

We also used the validated in the local setting screening for developmental delay instrument, which a member of ICPH (Dr. Samia Halileh) developed for children up to three years of age, given that the other instruments did not include specific questions about children's developmental delays (see questionnaire in the annex).

Child development under the age of three years for Palestinian children was standardized locally by Dr. Halileh in the year 2000. The standardization included nine age groups using the age at which 90% of children within an age group achieve the developmental item in a developmental domain. The developmental domains include four domains: gross motor skills, vision and fine motor skills, social skills, and hearing and speech. The developmental attainments, when standardized, were selected based on the 90th percentile attainment for all domains. Since then, the Palestinian child health records have incorporated child development as one of the indicators of child well-being.

For this research, the children were organized into 7 age-groups:

1. (3 months and under)
2. (3.1-6 months)
3. (6.1-9 months)
4. (9.1-13 months)
5. (13.1-18 months)
6. (18.1-24 months)
7. (24.1-36 months)

The analysis was based on the child's attainment of the developmental items expected for the particular age group. If a child is reported as not having attained these developmental items, further developmental assessment was required.

Children 3 months or under should be able to: lie down on their stomach and move their head from time to time; look carefully at their mother while she is breastfeeding; feel afraid or calm down when hearing a high voice, and quiet down when mother holds the baby.

Children just over 3 months and just under 6 months should be able to: calm down and or turn head when they hear a voice; follow a colored toy 15-30 centimeters away; lie down on stomach and raise their head; and react happily with playing and singing.

Children just over 6 months and just under 9 months should be able to: raise their head and chest while resting on hands and lying on stomach; and hold a toy for several minutes in hand.

Children just over 9 months and just under 13 months should be able to: hold a toy in both hands and clap hands together; be attracted by music from the television or radio; and imitate hand clapping.

Children just over 13 months and just under 18 months of age should be able to: understand the meaning of ‘no’; enjoy discovering what is around him/her; and raise himself/herself while lying and tries to sit down.

Children just over 18 months and just under 24 months of age should be able to: walk on their own; move while pulling large toys; hold a glass by hand and drink from it; and help or hinder dressing, i.e. by raising hands up.

Children just over 24 months and just less than 36 months of age should be able to name a picture or familiar shape like a cat; and climb stairs standing without help.

Finally, children 36 months old should be able to use the toilet alone and tell stories about what happened during the day.

FIELD WORK

Field work began at the end of April and was completed at the beginning of July 2013. Data entry and coding followed, with various interruptions related to general strikes in the West Bank, and university student strikes throughout August-October. Data was cleaned and entered into computer in November 2013 using the statistical software SPSS version 19. All significant differences reported between and among groups were set at the p=<0.05 level.

The total number of families in these communities — according to the Palestinian Central Bureau of Statistics PCBS projections for 2013based on the 2007 census — should be 7108 families (Table 1) with about 37,800 persons as estimated based on an average family size of 5.3. However, these are only estimates based on fertility rates and natural population growth (3% yearly) obtained in 2007. These estimates

do not take into account declines in fertility, or outmigration. In addition, it has often been observed that Palestinians return to their homes and locales for census purposes, to ensure that their Israeli government issued Palestinian identity cards are maintained, and then travel out of locales for work, study, or even living. This is why the PCBS population and family size estimates are probably overestimates of how many people in fact live in these villages.

Our survey revealed 5234 households, that is about 74% of what is expected based on PCBS projections. Given the above, we believe that we may have reached well above 80% of households, which is a reasonable proportion considering the movement and flow of people in and out of locales in addition to changes in the structure of communities over time.

Of the total households, there were 315, or 6% who refused to respond and participate in our survey. Those were almost equal in number of males and females, with a wide age range, indicating little bias in non-response. The highest levels of non-response were for Birzeit town at 1.4% of refusals (or 11% of Birzeit households), and Jalazone refugee camp at 22% of total refusals (6% of Jalazone households).

Table 1: PCBS population projections 2013 compared to survey findings

http://pcbs.gov.ps/Portals/_Rainbow/Documents/ramallah.htm

Villages	Total – PCBS	Total households	Average family size	Projections (2013): Persons	Estimated households (2013): from PCBS projection	Number of households visited: ICPCH survey	Number refused interview: ICPH survey	Total household: ICPH survey
	Persons	PCBS	PCBS	PCBS				
Abu Qash	1404	273	5.1	1603	314	247	44	291
Atara	2270	413	5.5	2592	471	324	9	333
Birzeit	4529	1005	4.5	5172	1149	615	72	687
Burham	616	130	5.1	703	138	90	6	96
Dura al-Qare'	2897	541	5.4	3308	613	237	16	253
Ein Sinia	711	136	5.2	927	178	94	2	96
Jalazone refugee camp	7813	1401	5.6	8922	1593	1185	69	1354
Jibia	148	26	5.7	169	30	21	2	23
Jifna	1716	378	4.5	1959	435	217	18	235
Kobar	3677	668	5.5	4199	763	671	27	698
Al- Mizra'a al-Gharbieh and Abu Shkeidem (Zaitouna)	6190	1027	6	7068	1178	1043	41	1084
Surda	1031	214	4.8	1177	245	175	9	184
Total	**33002**	**6202**	**5.3**	**37799**	**7108**	**4919**	**315**	**5234**

RESULTS

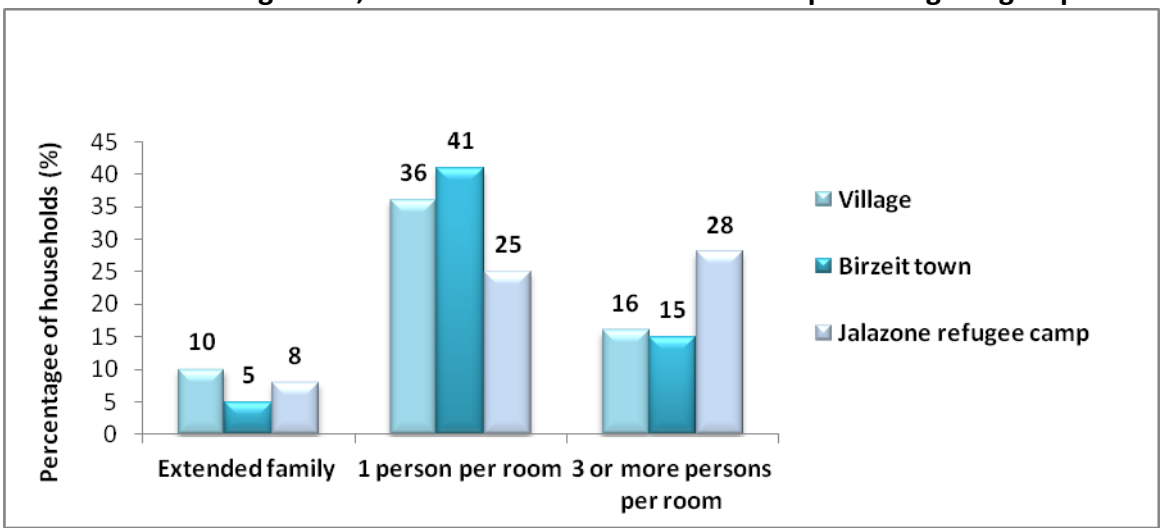
THE HOUSEHOLDS

We visited 4919 households in the selected communities. Jalazone refugee camp had the largest number of households (1185) and Jibia (21) the smallest in. Of the total households, 43% reported that they were Palestinian refugees of the 1948 Arab-Israeli war (primarily): the majority (55%) of these were living in the Jalazone refugee camp, followed by 15% for the Birzeit town (informal) refugee camp and the town itself, Jifna at 8% of refugee households, and the rest scattered across the other locales. This is an indication of what we know, which is that not all Palestinian refugees live in camps, and that many were able to get out of camp locales and integrate into local communities.

Of the total households, 91% were nuclear families (mother, father and children). The remainder included extended families. There were significant differences in the proportion of extended families between locales, including 10% of village households, compared to 8% in Jalazone camp and 5% in Birzeit town. The number of rooms in these households (excluding kitchen, bathroom and open verandas) was 3.75 rooms per household, with a minimum of 1 room and a maximum of 15. The mean number of persons living in each of these households was 5.3, and ranged from 1 person per household (4%) to a high of 22 persons in one household. This brings the mean crowding rate to 1.4 persons per room (an important indicator of poverty). The highest levels of crowding were found in Jalazone refugee camp, at 28% of households with three or more persons/room at home compared to 16% for

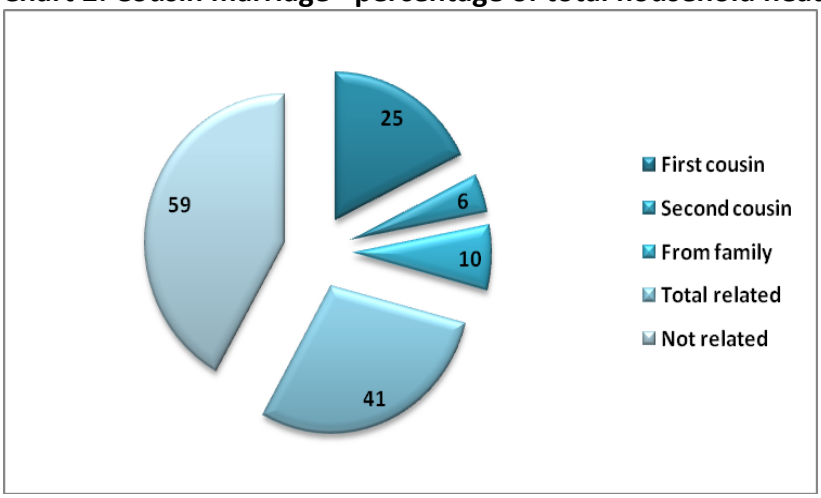
the villages and 15% for Birzeit town. The least crowding was found in Birzeit town at 41% of households with one person per room, followed by 36% of households in villages, and 25% of households in Jalazone refugee camp (Chart 1).

Chart 1: Crowding levels; Nuclear and extended families – percentage of group



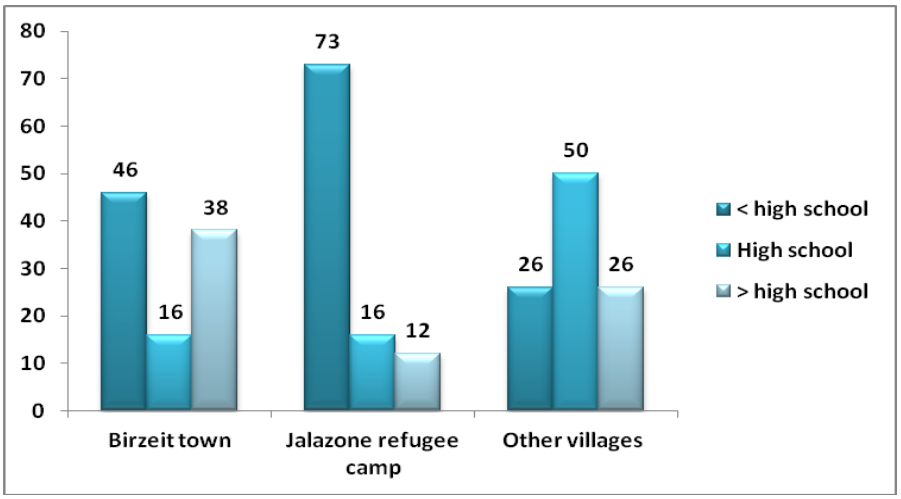
Twenty-five percent of householeads were married to first cousins, 6% to second cousins, 10% from the extended family and 59% were not related (Chart 2). As one would expect, first cousin marriage is more common in villages, with 28% reporting first cousin marriage for heads of households, compared to 21% for Jalazone camp and 18% for Birzeit town. This information will be important in analyzing disability in the family later. It is interesting to note that there were 28 second wives reported for these households: 10 from the camp and the rest from the villages.

Chart 2: Cousin marriage - percentage of total household heads



Fifty-seven percent of male heads of household were reported to have less than high school education, 19% high school and 23% more than high school education. Once again, the highest level of education was found for Birzeit town at 38% of head of household, compared to 26% for villages and 13% for the camp (Chart 3).

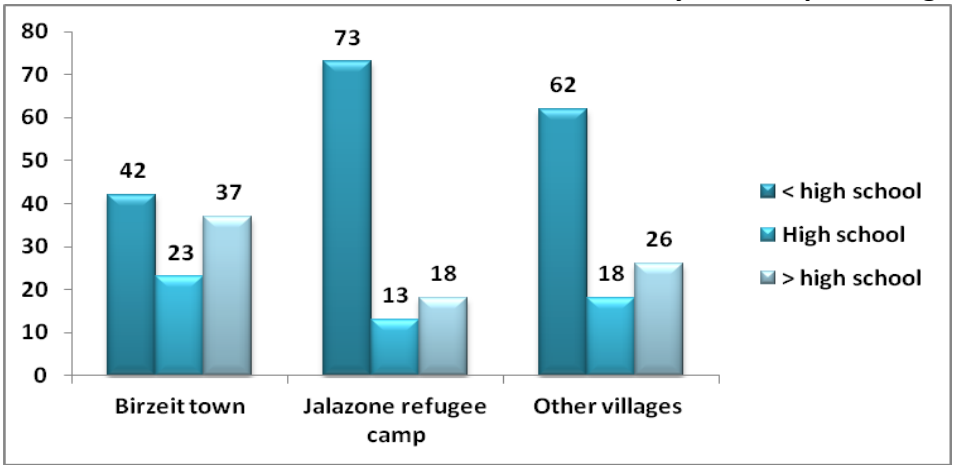
Chart 3: Education of male head of household by locale – percentage of locale



The level of education of female heads of household was similar to that of males with 57% reporting less than high school education, 17% high school and 25% more

than high school education (Chart 4). Once again Birzeit fared best with 37% of female heads of household reporting more than high school education, compared to 26% for villages and a low of 18% for the refugee camp.

Chart 4: Education of female heads of household by locale – percentage of locale



Turning to employment, we found that 82% of householeads were reported as working, 10% as unemployed and 8% retired. Eight percent of male heads of households were reported as dead, probably because their wives are still alive and either heading the family or their sons were heading the family. The majority of female heads of household were housewives at 85%, 14% worked for pay, and the rest were retired or unemployed (1%).

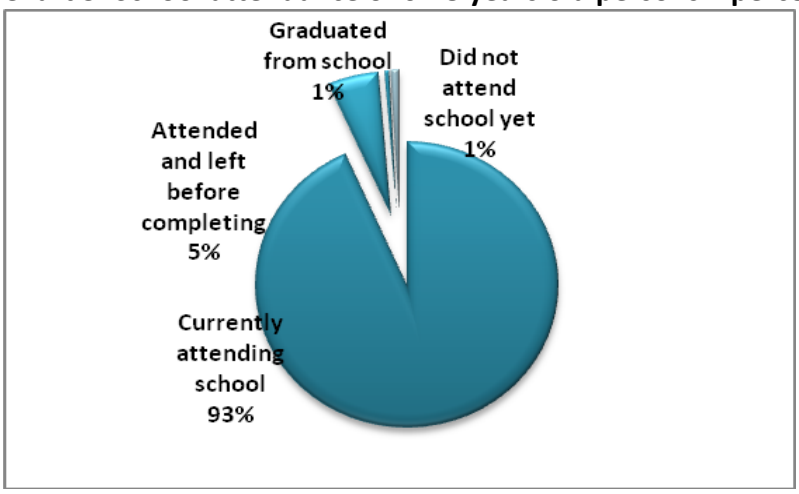
INDIVIDUALS IN THE FAMILY

Our data indicates that there were 26135 persons living in the 4919 households we visited, bringing the average family size to 5.3 persons per household, including an almost equal number of males and females (49% females). Ages ranged from under

one month to 98 years with a mean of 24.4 years. Of the total, 8.7% were three years or younger (with data on developmental delay analyzed separately from the rest of the population). Overall 36% were under 15 years old, 31% 15-29 years old, 27% 30-59 years old and 5.5% 50 years old or above.

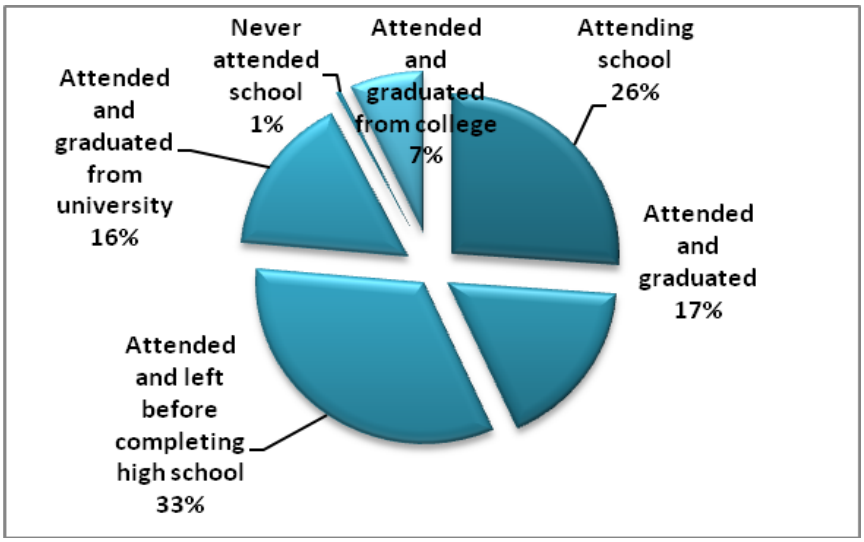
For schooling, we find that 93% of those 6-18 years old are currently attending school, 5% attended and left before completing high school, 1% graduated from school, and 1% never attended school or did not attend school yet (Chart 5).

Chart 5: School attendance of 6-18 years old persons – percentage of total



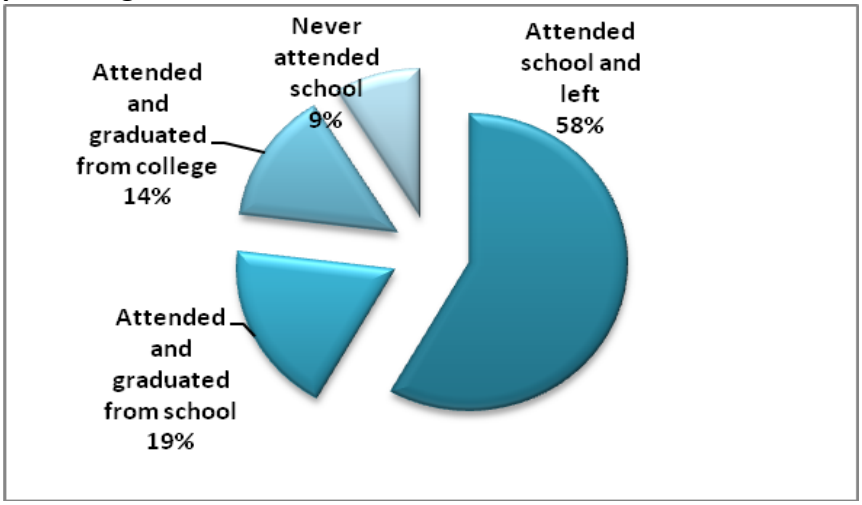
Twenty six percent of those 19-29 years old were still attending school, 33% attended and left before completing high school, 17% attended and graduated, 16% attended and graduated from university, 7% attended and graduated from college and 1% never attended school(Chart 6).

Chart 6: School and university attendance of 19-20 years old persons – percentage of total



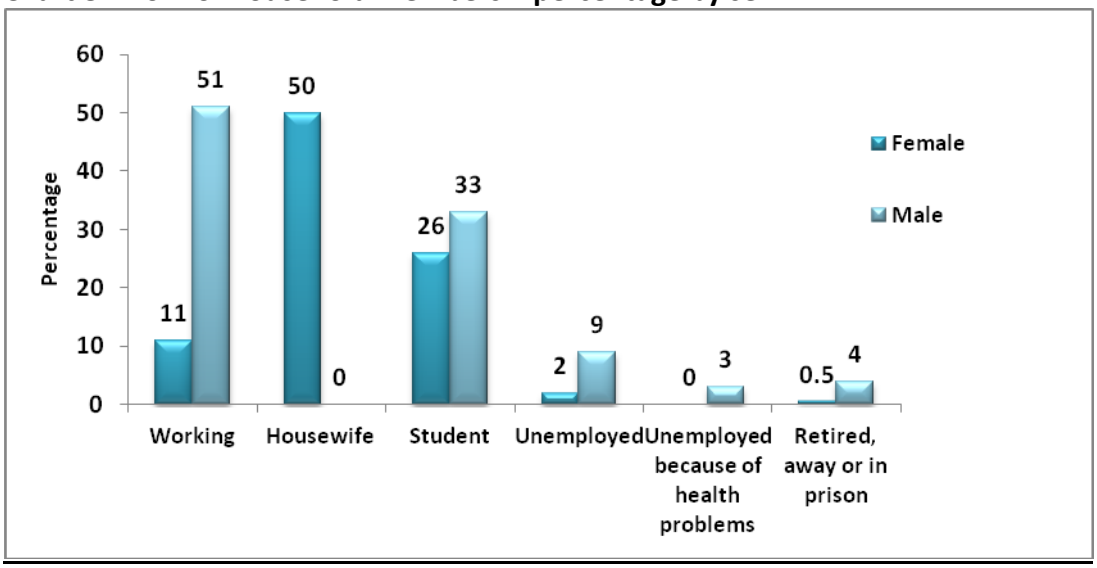
Finally, for those 30 years or over, 58% attended school and left, 19% attended and graduated from school, 14% attended and graduated from college or university and 9% never attended school. Thus a significantly higher proportion of those 30 years or older had attended school and left before completing high school compared to those 19-29 years old (Chart 7).

Chart 7: Schooling and university attendance of persons 30 years old or above – percentage of total



Regarding work(among those 10 years or above): 51% of men were reported as working compared to 11% of women; 33% of males and 26% of females were reported as being students; 50% of women were housewives; 4% of men were reported as retired, away or in prison, as opposed to 0.5% of women; 9% of men were reported as unemployed as opposed to 2% among women; 3% of males were reported as unemployed because of health problems, compared to 0.1% for women (Chart 8).

Chart 8: Work of household members – percentage by sex



Disability among persons over three years old

The questions regarding disability analyzed below **pertain to all persons over 3 years of age in these communities**. Children 3 years and under will be analyzed separately, given that a different instrument was used to assess developmental delay. The Washington Group wide and narrow definitions of disability were used in this analysis to identify type of disability, followed by the WHODAS2 questions which focus on the ability to function.

DISABILITIES

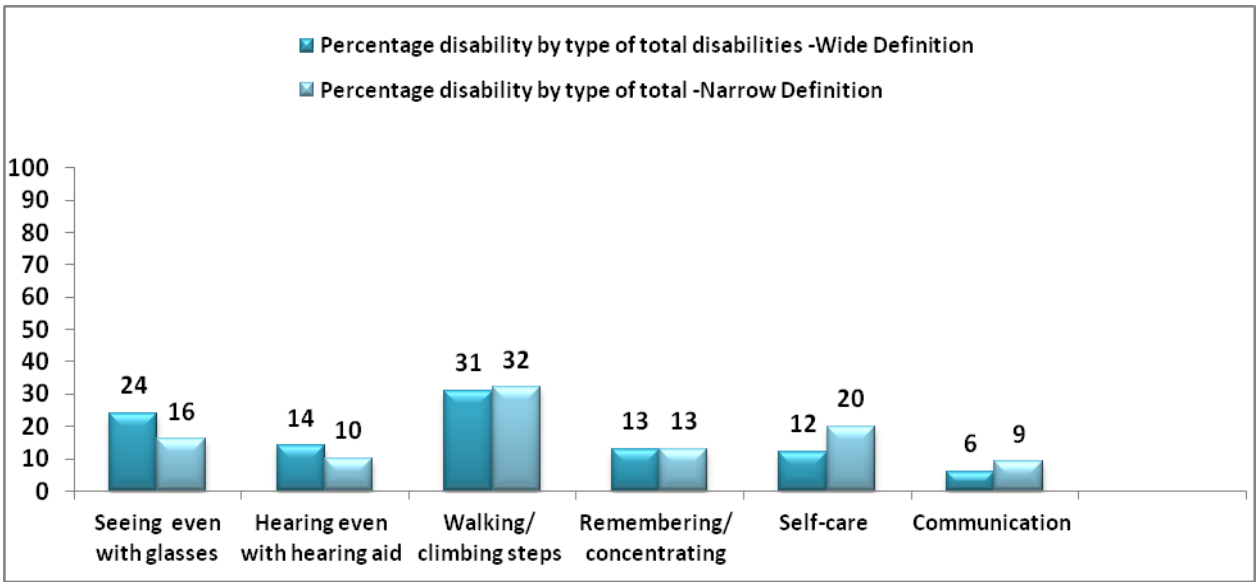
Using the Washington Group questions for the wide definition or any reports of difficulty(difficulty seeing even with glasses, difficulty hearing even with hearing aid, difficulty in walking a few steps or climbing stairs, difficulty remembering or concentrating, difficulty in caring for oneself such as bathing, dressing, and difficulty in communicating), we found the following: 1.8% reported seeing difficulties, 1.1% hearing difficulties, 2.3% walking difficulties, 1% remembering or concentrating, 0.9% difficulties in self-care, and 0.5% communication difficulties. A total of 1137 persons reported one or more disability, amounting to 1787 specific disabilities in these communities, and 4.7% of the population with at least one disability. If we use the narrow definition by selecting cases with a lot of difficulty or those not able to hear see, hear, walk, remember, care for oneself, or communicate at all, we find that there were 789 disabilities reported, and 2.2% of the population reporting at least one disability as the table below shows (Table 2).

Table 2: Number of people with disability over 3 years of age and disability prevalence according to the Washington Group's wide and narrow definitions.

Number of difficulties	Total persons with disability		Percent with disability of total population		Total disabilities	
	(Wide)	*(Narrow)*	*(Wide)*	*(Narrow)*	*(Wide)*	*(Narrow)*
1	723	324	3.0	1.4	723	324
2	239	108	1.0	0.5	478	216
3	100	43	0.4	0.2	300	139
4	43	18	0.2	0.1	172	72
5	18	6	0.1	0.0	90	30
6	4	3	0.0	0.0	24	18
Total	**1137**	**502**	**4.7**	**2.2**	**1787**	**789**

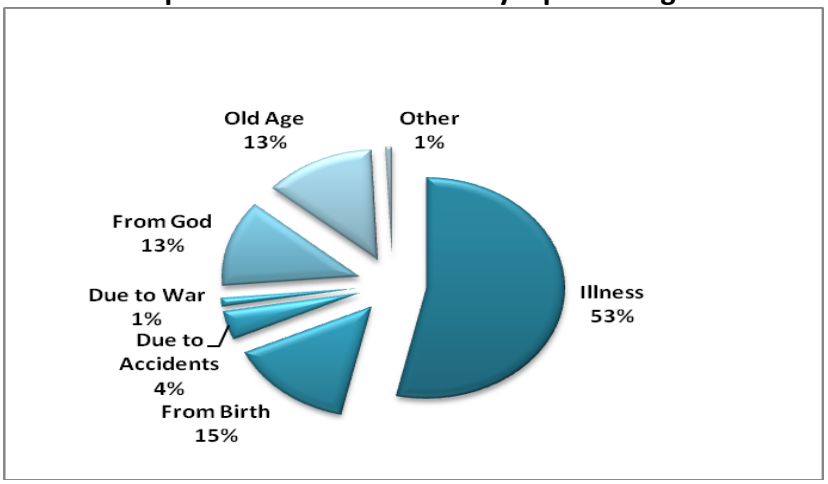
Of the total disabilities, we found that the **highest proportion of disabilities were movement-related disabilities** at 31% for the wide and 32% for the narrow definitions. This was followed with 24% and 16% for seeing difficulties, 14% and 10% for hearing difficulties, 13% and 20% for self-care and 6% and 9% for communication difficulties for the wide and narrow definitions respectively. Later on in the report, we will be combining responses to these questions, and others, to select for persons who are probable IDs (Chart 9).

Chart 9: Type of disability according to narrow and wide definitions – percentages of total disabilities



We asked respondents about the causes of disabilities and found that: 909 of 1787 or 51% of the reported causes were illness; 252 or 14% of all disabilities were reported as existing since birth; 70 or 4% due to accidents; 22 or 1.2% due to war; 209 or 13% from God; 221 or 13.4% due to old age; and 13 or 0.7% other reasons (Chart 10).

Chart 10: Reported causes of disability – percentage of total disabled

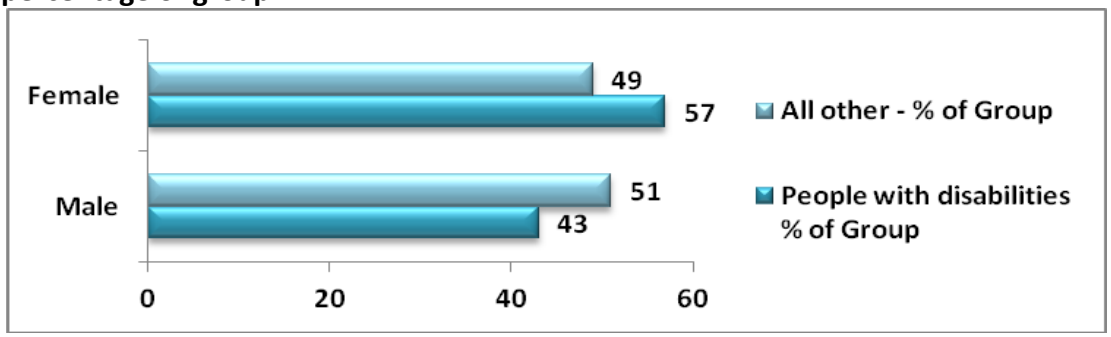


BASIC CHARACTERISTICS OF THE DISABLED > 3 YEARS OLD

Given that Start Mountain is interested in locating all people with probable IDs, we will proceed with the analysis in this section utilizing the wide definition of disability in order to make sure that we have included all who need help. Once people with probable IDs are identified, it will be possible for Star Mountain personnel to visit their homes and assess particular needs for assistance.

Forty-three percent of the disabled included in this study were males, and 57% females (Chart 11). **These results differ from the proportions found for the Palestinian population and are likely on account of the presence of significantly more disabled women compared to men, as Palestinian women live longer than men. In addition, women's health needs are often neglected by health services, which could also be a reason for the presence of higher levels of disability among women compared to men** (Lamarca, R, ; Ferrer, M; Andersen PK; Liestol K; Keiding N; Alonso J, 2003).

Chart 11: Comparison of people with disability and without according to sex – percentage of group



As expected, disability increases with age, with 13% of people with disability between the ages of 3.1 and 19 years, 14% between 15 and 29 years, 32% between 30 and 59 years, and a high of 42% for those 60 up to 98 years. And indeed, the data demonstrates that, while there were no significant differences in the proportion of people with disability by sex for those over 3-29 years old, there were statistically significance differences in disability reports by sex for ages 30 years and over, with 39% of people with disability found to be men compared to 61% women for the age group 30-59, and 37% of the disability found to be men compared to 63% among women in the age group 60-98 years old ($P<0.05$). **These results indicate the need to pay special attention to the elderly with disabilities, especially women, and identify disabled elderly women as a priority for action.**

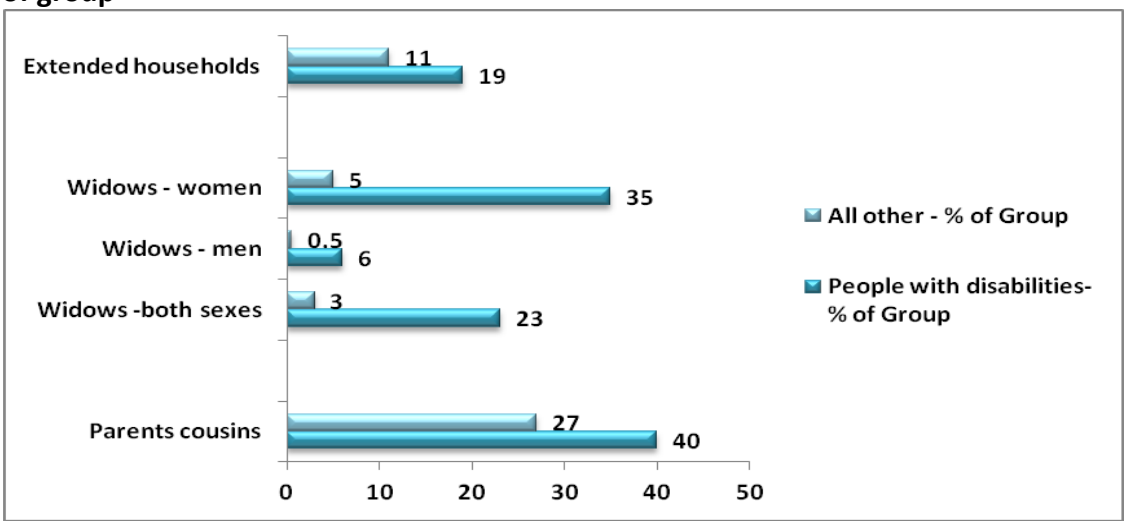
We found an expected association between cousin marriage and disability. Among 13593 children of heads of households, we find that 40% of those with disability had parents who were first cousins, compared to 27% among the non-disabled with no effect for second cousin marriage. **While these are expected results, and families could clearly benefit from health education, it remains true that cousin marriage is seen as a survival need in this country for several reasons**: it maintains land ownership within the family; it is assumed to protect women from abuse by a husband outside the family; and with the increasing fragmentation of communities from each other because of checkpoints, barriers, as well as periodic invasions of villages, towns and camps by the Israeli army, marriage to a cousin nearby is a rational choice people make, despite the risk of having disabled children.

COMPARISONS BETWEEN PEOPLE WITH DISABILITY AND PEOPLE WITHOUT DISABILITY

Selecting those within the age range of 19-29 years (when people normally get married according to local standards), **we find that 62% of those with no disability were reported as single, compared to a close 63% among those with physical and sensory disability, and a high of 91% of those with probable IDs**. If we then select those who are 30-39 years (by which point most are married),we find that 10% of people with no disabilities in these communities were single, compared to 24% among those with physical and sensory disabilities and a high of 56% among those with probable IDs. **That is, there were a significantly lower proportion of those with probably IDs who were married, followed by those with physical disabilities and those with no disabilities in these communities.**

A significantly higher proportion of people with disability lived in extended households at 19% compared to 11% among those with no disability in the family. These results remained significant even when controlling for age, and with more people with disability 30 years or over living with their extended family. Twenty-six percent of probably IDs lived in extended families compared to 21% among those with physical and sensory disabilities and a low of 13% among those with no disability **(Chart 13). This is one of the indications of family poverty, either inducing disability or disability inducing poverty**.

Chart 13: Comparison between people with and without disabilities – percentage of group

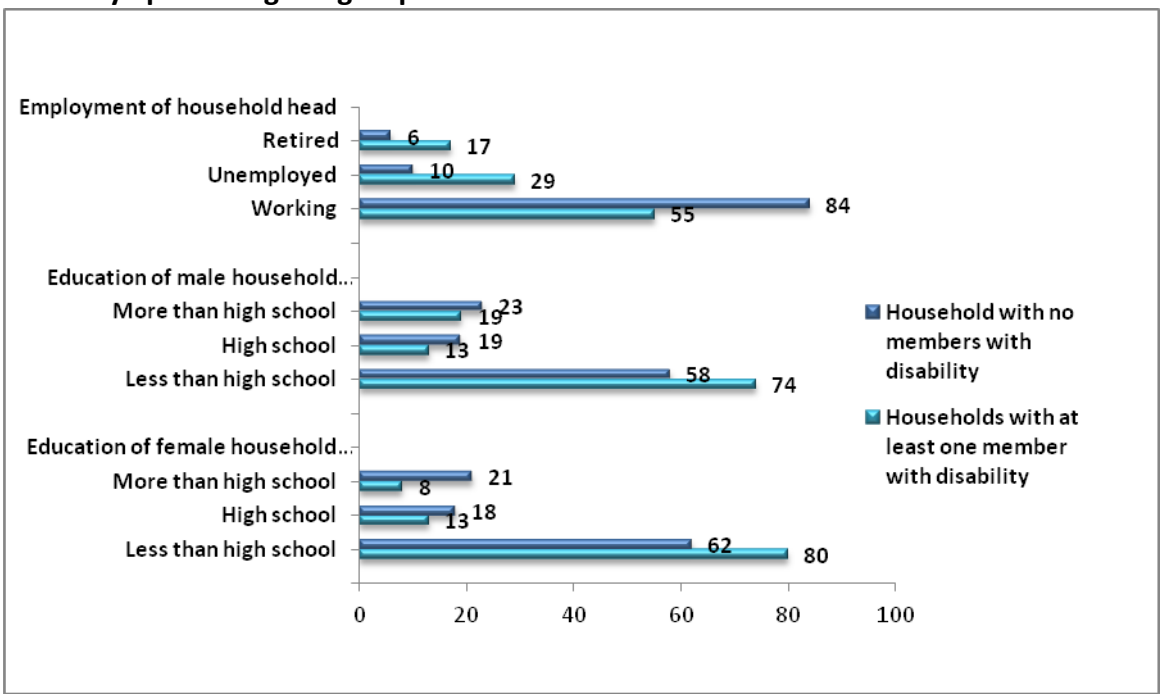


In addition, households including members with disability had less educated female heads, with 80% reporting less than high school degrees compared to 62% among households with no disabilities,13% compared to 18% with high school degrees , and 8% compared to 21% with more than high school education. The same pattern was observed for male heads of household including members with disability, with 74% reporting less that high school education compared to 58% among those without disability, 13% reporting high school education compared to 19%, and 13% reporting more than high school education compared to 23%.

Likewise, there were important differences in employment patterns between households with and without members with disability. Fifty five percent of heads of household which include members with disability were reported as working, compared to 84% among those which don't include members with disability, 29% reported being unemployed compared to 10%, and 17% were reported as retired

compared to 6% (Chart 13). This is likely due to the head of household being an elderly person, who, even if not working, is considered the household head in Palestinian society. Checking for the above in another way, we find that 27% of male heads of household, a high of 36% of female heads of household, and 6% of parents of heads of households were reported as having disability. There were even grandparents of heads of household listed as having disability, at 1.3% of those with disability. This indicates that households which include members with disability tend to have a higher proportion of elderly persons compared to households which don't include disabled members.

Chart 13: Comparison between households with and without members with disability– percentage of groups.

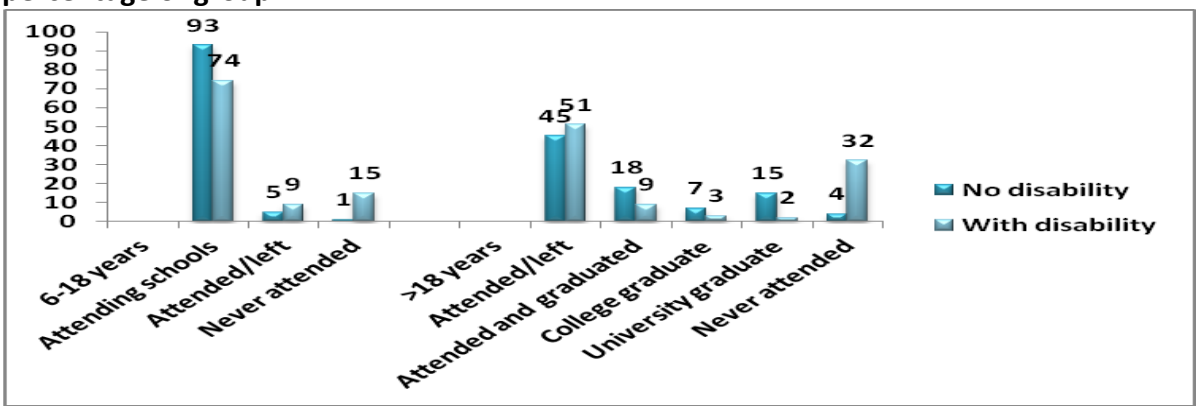


Comparisons by educational levels between people with and without disabilities in these communities also demonstrate significant differences in favor of those without disability. Selecting children 6-18 years old(of schooling age), we find that

93% of people without disability were currently attending school, compared to 74% only among those with disability, 5% attended school and left before completing compared to 9% with disability, and 0.1% never attended school (9 persons) compared to a high of 15% among those with disability.

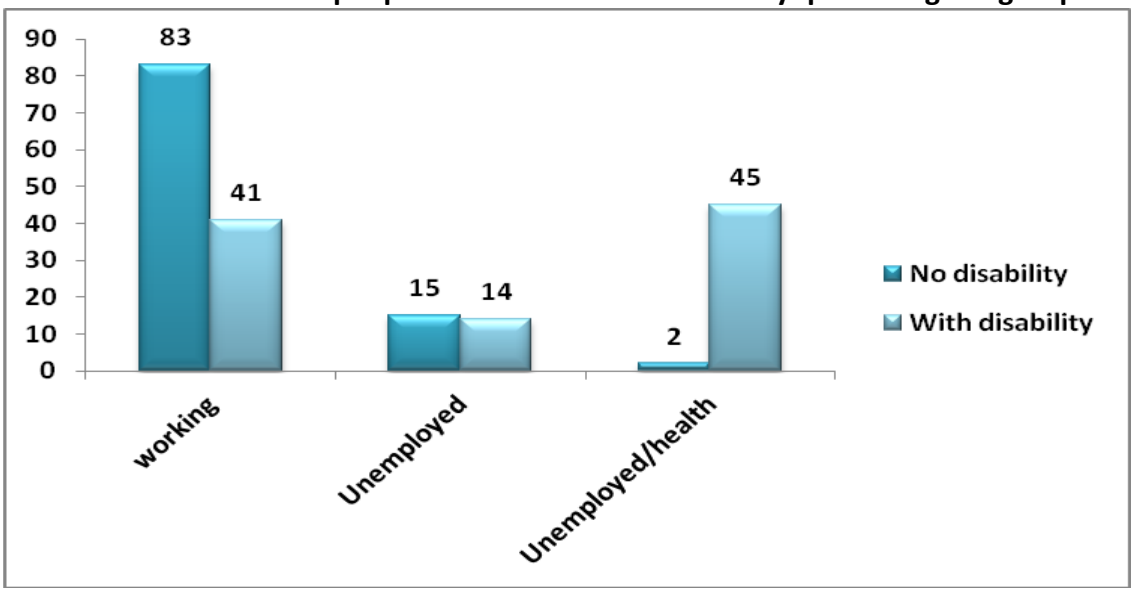
A similar pattern was observed among those older than 18 years: 13% of those reported that they were currently attending school compared to 1.5% among people with disability; 45% of those with no disability reported having attended school and left before completion compared to 51%; 18% of those with no disabilities reported that they attended school and graduated compared to 9% with disability; 15% of those without disability reported that they attended and graduated from university compared to 2% with disability; 4% of those with no disability reported that they never attended school compared to a high of 32% with disability; and 7.4% of those with no disability having attended and graduated from college compared to 3% with disability (Chart 14). **While these are expected results, they nevertheless point to the need to address the issue of education among people with disability in general, an issue requiring further action**

Chart 14: Educational levels of people with disability and those without disability - percentage of group



Looking at disability and employment (selecting for those 19-69 years old and excluding students and housewives), **we also find important differences in work status between people with and without disability,** with 83% of those with no disability reported as working compared to 41% among people with disability,15% of those with no disability reporting unemployment compared to 14% among people with disability, and 2% of those with no disability reporting being unemployed because of health problems compared to 45% among people with disability (Chart 15). While these differences in the working status between people with and without disability is significant, the number of people with disabilities that are working is surprising considering that in this country, there are very few jobs available for them. This may be due to the presence of mild disabilities among those who are working.

Chart 15: Work status of people with and without disability- percentage of group.



PROBABLE IDS AND THEIR NEEDS (AGES >3 YEARS)

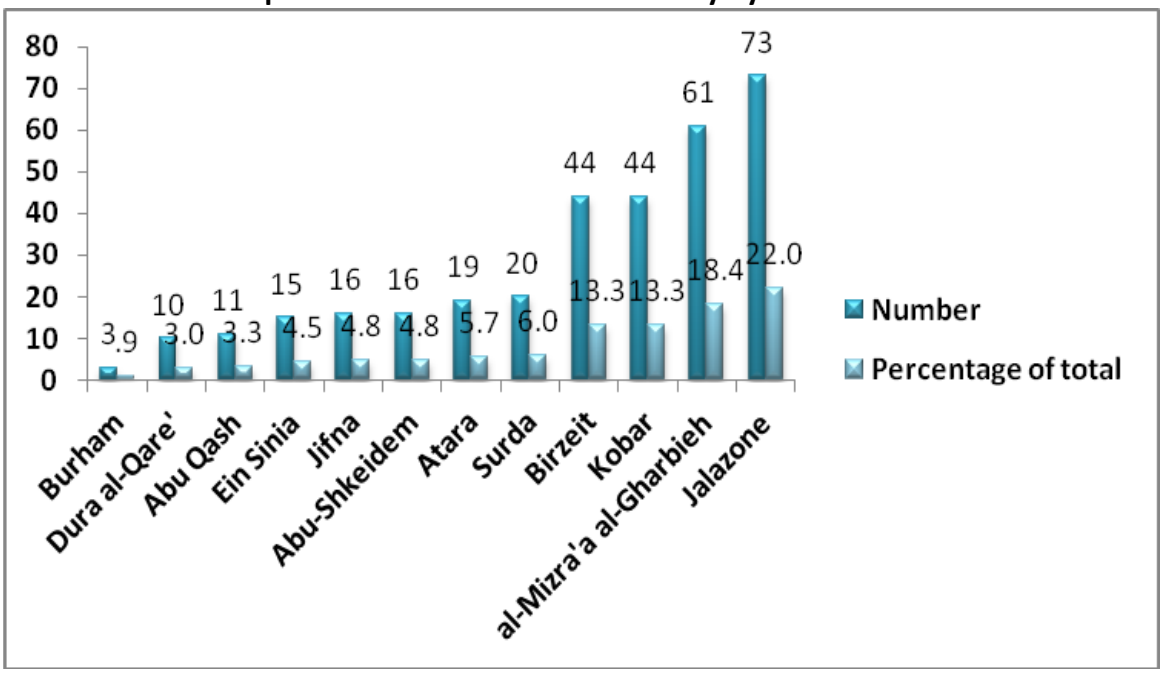
Recoding the data to identify persons who have both probable intellectual and other disabilities (like remembering or concentrating) or those who suffer from multiple disabilities (like remembering, concentrating and communicating, self care etc), we find that 30% reported intellectual-mixed disabilities (333 persons) and 70% other types (such as physical or sensory disabilities). These estimates are compatible with national averages in the oPt, and also elsewhere.

In our study, 68 persons with ID were reported as being students at Star Mountain, with the majority young, and under 18 years old. Of these, 19 persons were not reported as having difficulties in any way, which implies that the rehabilitation they have been having is effective, as well as the likelihood that their disabilities are not severe.

Seventeen percent of the probable IDs found in this survey were over 3 and up to 14 years old, and 15-29 years old each, 23% were 30-59 years old and a high proportion, 43%, were 60 years and up to 98 years old, **once again identifying the elderly as a priority for action.** There were significantly more females with probable IDs at 54% of all people with probable IDs compared to men at 46%, **identifying women again as another priority for action.** People with probable IDs were found in all the locales without exception, with proportions compatible with the size of population in these locales, and ranging from a high of 22% of the total people with probable IDs from the Jalazone refugee camp (73 persons), followed by 18% for al-Mizra'a al-Gharbieh

(61 persons), Kobar and Birzeit at 13% each (44 persons each), and with the lowest proportion in Burham village at 0.9% (3 persons), the least of all the locales included in this survey (Chart 16)

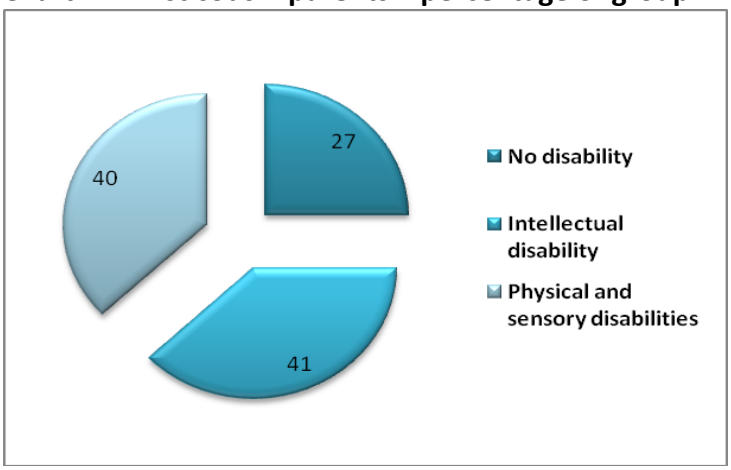
Chart 16: Probable persons with intellectual disability by residence



A comparison between people with probable IDs, people with other disabilities and the rest of the population is revealing of the needs of people with probable IDs and their families. Interestingly, there were significant differences in the rate of cousin marriage between those with disability and those with no disability in these communities, but not between people with physical disabilities and people with probable IDs. We selected all who were reported as children of household heads with information on cousin marriage and found that 40% of those with physical and sensory disability, 41% of those people with probable IDs had parents who were first cousins compared to 27% among those with no disabilities (Chart 17). Clearly, cousin marriage is an issue which can be addressed through health education. However, as

explained above, there are economic, social, cultural and political reasons for the continuation of this practice. Indeed, the presence of checkpoints and blockades against the movement of people from one locale to another may also be a contributing factor to cousin marriage, as accessibility is higher to cousins who live in the same locale, and may therefore encourage this practice.

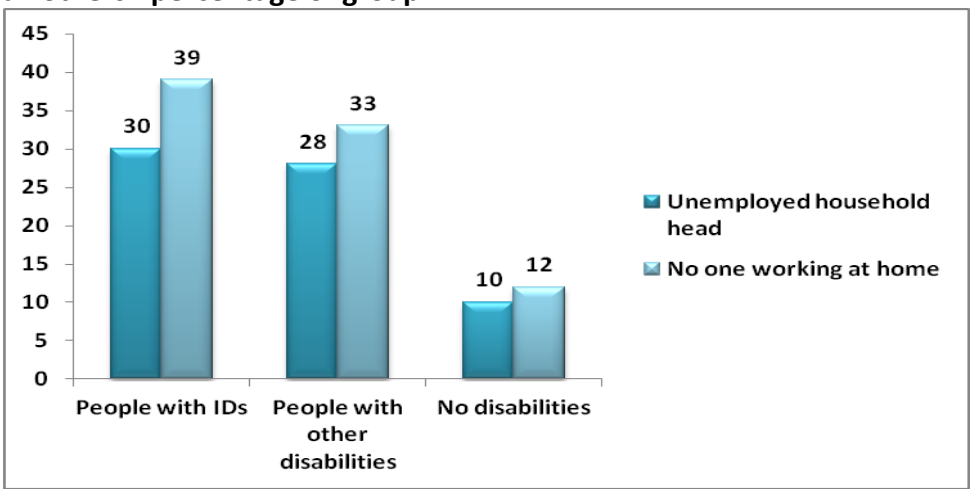
Chart 17: First cousin parents – percentage of group



A high of 30% of heads of households with IDs were unemployed at the time of the survey compared to an almost equal (28%) number of those with physical and sensory disabilities, compared to a lower 10% among those with no disabilities (Chart 18). Thinking that this may be due to the age of the head of household, we controlled for age, but the results remained significant. It is not clear from the data at hand why heads of households that have family members with disability would be significantly more unemployed than other heads of household. **However, this result points to the likelihood of a higher poverty level among the families of all people with disability in these communities, and to another possible need people with disability and their families, including those with IDs**. Likewise, a high of 39% of

people with IDs were living in households where no one was working, compared to 33% among the other disabilities and a low of 13% among those with no disabilities ($p<0.05$). If we combine these results with the finding that 19% and 21% of persons with physical or sensory disabilities and IDs respectively live in extended families (another indication of poverty) compared to a lower 13% among the rest, **we find that the data points to the poverty of families which include members with disabilities and the need to investigate how this poverty can be alleviated.**

Chart 18: Unemployment among household members of people with disability and all others - percentage of group



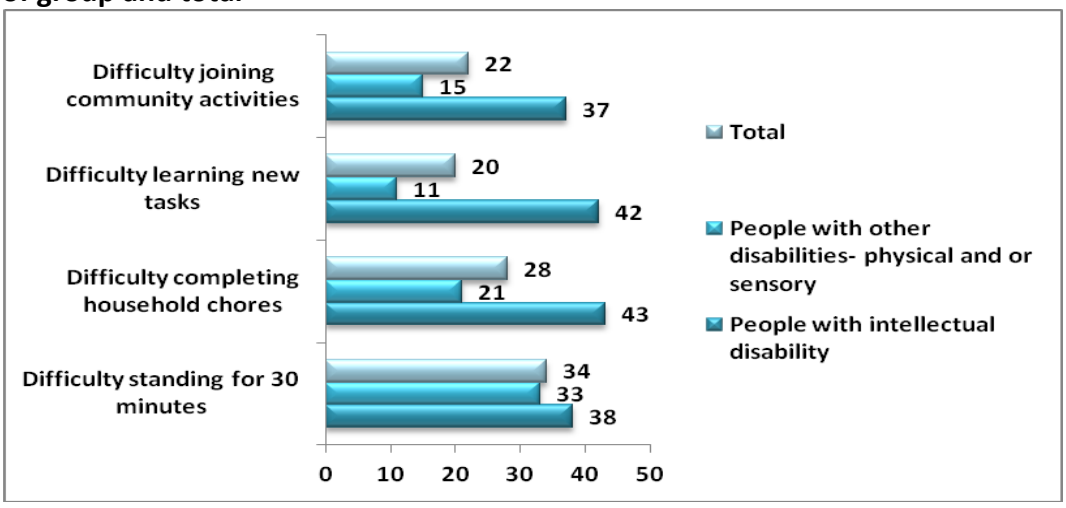
Functioning difficulties endured by people with disability: A comparison between people with ID's and those with physical or sensory disabilities.

ACTIVITIES OF DAILY LIVING

We asked those who reported any disability to respond to several questions related to their ability to function in relation to the activities of daily living (ADL) and social integration. Of the total, 34% reported difficulties (ranging from some to not at all) when standing for around 30 minutes, with 38% of IDs reporting this difficulty compared to 33% among those with other disabilities. This difference was not

statistically significant. Twenty eight percent reported difficulties in completing household chores, with 43% for IDs compared to 21% for the other disabled. Twenty percent reported difficulties in learning new tasks, with a high of 42% for people with IDs compared to 11% for people with other disabilities. Finally, 22% reported having difficulties in joining community activities, with a high of 37% for people with IDs compared to 15% for people with other disabilities (Chart 19). **These results demonstrate that IDs face more difficulties in activities of daily living, and have more difficulties in integrating into their community, which is reported by the literature elsewhere and point to people with IDs as a particular priority for action**. However, people with other disabilities are also in need of assistance in dealing with these difficulties, perhaps through programs which can at least alleviate the suffering if not improve the functioning of all people with disabilities.

Chart 19: Difficulties in activities of daily living and social integration –Percentage of group and total

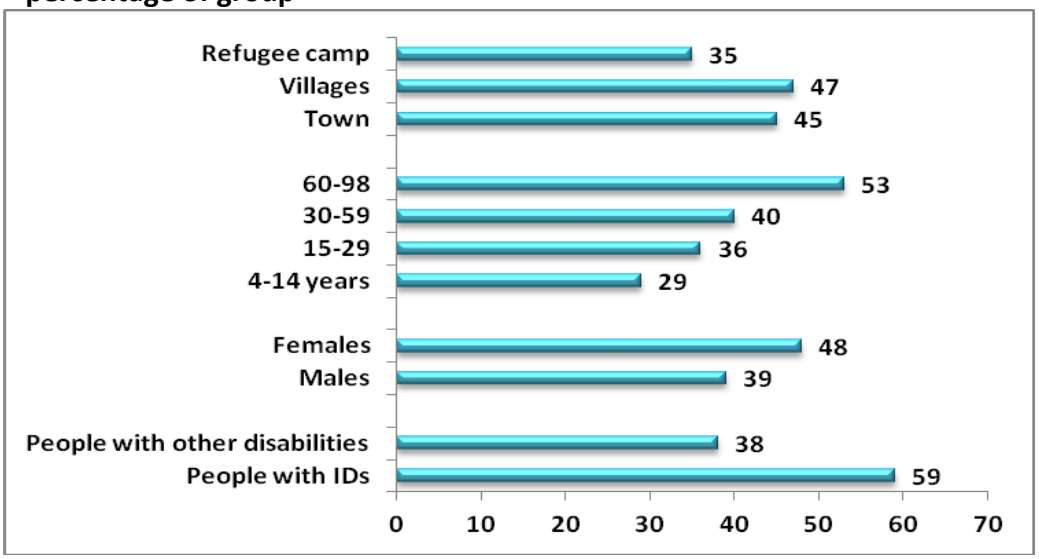


Computing a scale composed of the four difficulties described above with a very good internal consistency (Alpha=0.87), meaning that the four questions measure a particular phenomenon related to ability to function, we find that of all people with

disability 56%, did not report difficulties (perhaps because their disabilities are mild) 14% reported one, 10% two, 10% three and 9% all four difficulties**, with a total of 44% reporting ADL and social integration problems. And as expected, people with IDs had significantly more reports of difficulties at 59% compared to 38% among the** people with other disabilities. **These results point to people with IDs that have difficulties in functioning as a first priority for action, but also indicate that the other disabled are also in need of assistance.**

Once again, females were found to be in more need of help. 48% of females reported 1-4 difficulties compared to 39% of men. Ability to function also declined with age, as expected, with 29% of those 4-14 years old reporting 1-4 difficulties compared to 36% among those 15-29 years old, 40% among those 30-59 years old, and 53% among those 60 years old or over. **The highest reports of functioning difficulties came from the villages**, with 47% of people with disabilities reporting 1-4 difficulties, compared to 45% for Birzeit town and a low of 35% for the Jalazone refugee camp (Chart 20). It is difficult to explain these findings based on the data at hand. **However, these results point to villages as a priority for further investigation and action.**

Chart 20: Reports of 1-4 of activities of daily living and social integration difficulties – percentage of group



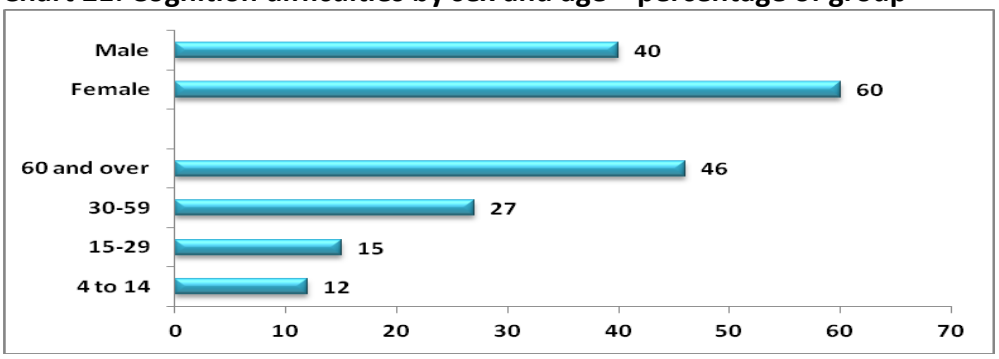
COGNITION

We constructed a special scale for the assessment of cognition (questions on difficulties remembering to do important things, difficulties analyzing and solving daily problems, difficulties understanding what people say, and difficulties starting and maintaining a conversation) with very good internal consistency (Alpha= 0.88). Using this scale, we found 272 persons requiring special attention because of difficulties in cognition. This excludes children 3 years or younger, other probable IDs who have milder symptoms and/or who are currently attending Star Mountain as students, with 47 of these ID students reported by parents as having no disability or doing well (an indication of the positive effects of Star Mountain work).

It is important to note that 45% of people with probable IDs reported 1-4 cognition problems compared to 13% among those with other disabilities. **Of the total with cognition difficulties 60% were female and 40% were male**. 13% were children 4-14 years old, 15% 15-29 years, 27% 30-59 years and a **high of 46% 60 years or over**

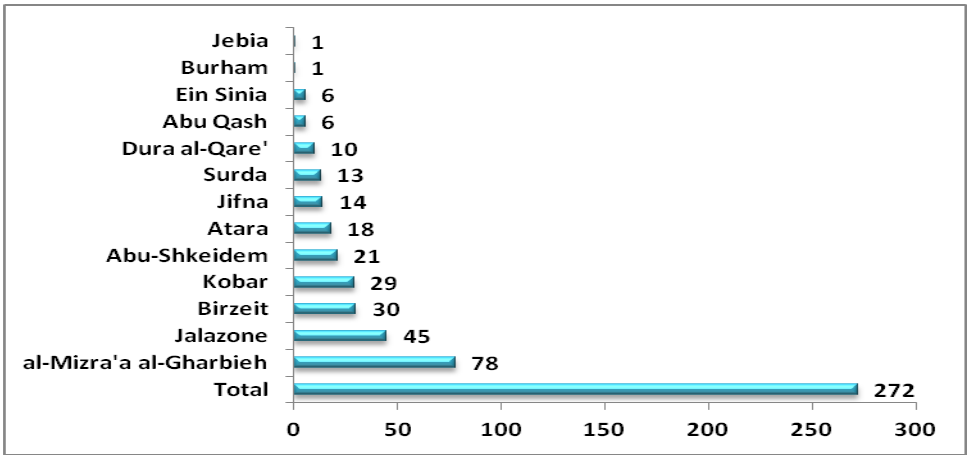
(Chart 21), indicating a rise in cognition problems with age (it may also be that children born with IDs do not receive the needed attention or treatment and eventually die before adulthood).

Chart 21: Cognition difficulties by sex and age – percentage of group



29% of those with cognition problems come from al-Mizra'a al-Gharbieh, followed by 17% for Jalazone camp, 11% each from Birzeit and Kobar, 8% from Abu Shkeidem, 7% from Atara, 5% each for Jifna and Surda, 4% from Dura al- Qare', and 2% each from Ein Sinia and Abu Qash and 0.1% each from Burham and Jibia (tiny villages) (Chart 22).

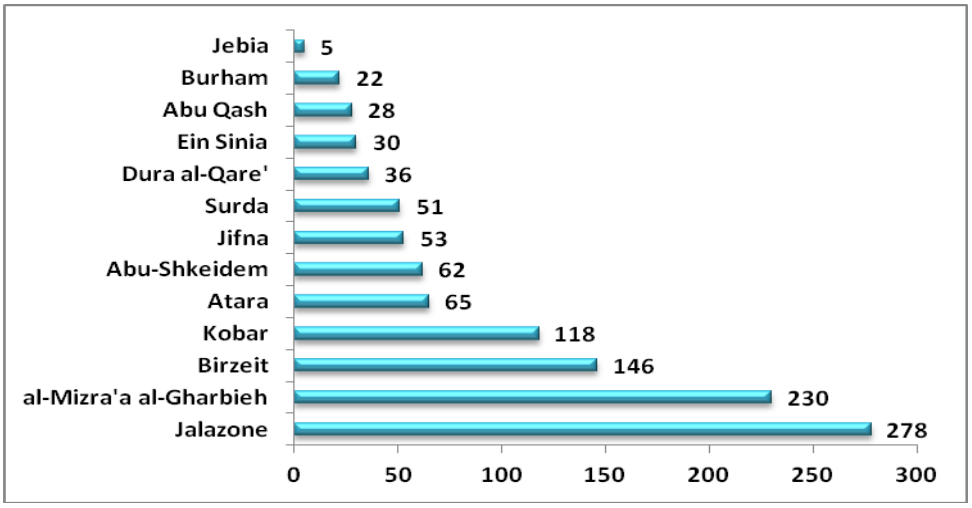
Chart 22: Number of persons with cognition problems by residence



MOVEMENT

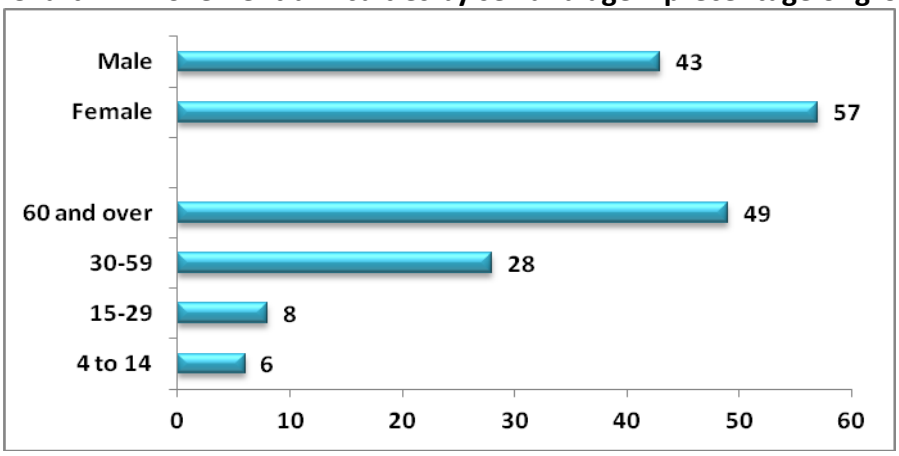
Turning to movement difficulties, we also find three questions which together have very good internal consistency (Alpha =0.89) and can be used to assess overall movement problems in this population. Combining these questions (difficulties standing up from sitting down, difficulties moving around inside the home, difficulties getting out of the home), we found that 402 persons suffer from movement difficulties (Chart 23).

(Chart 23):Number of persons with movement difficulties by residence



What is important to note is also that 40% of those with probable IDs also report difficulties in movement, compared to 34% among those with other disabilities, requiring addressing both types of problems among the IDs. Of those with movement difficulties, **57% are females compared to 43% males**. 6% are children 4-14 years old, 8% 15-29 years,28% 30-59 years, **and 49% 60 years or over (Chart 24), once again, pointing to elderly** people with disability**, especially women, as a priority for action.**

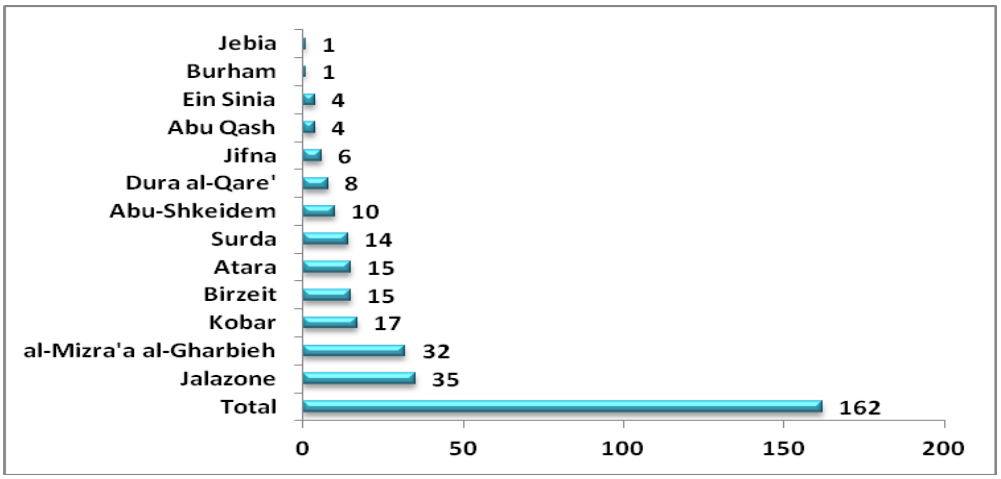
Chart 24: Movement difficulties by sex and age – precentage of group



SELF-CARE

The self care questions (difficulties eating and difficulties staying by oneself for a few days) had reasonable internatal consistency when combined into a scale (Alpha =0.69). We found a total of 162 persons who have self-care difficulties (Chart 25).

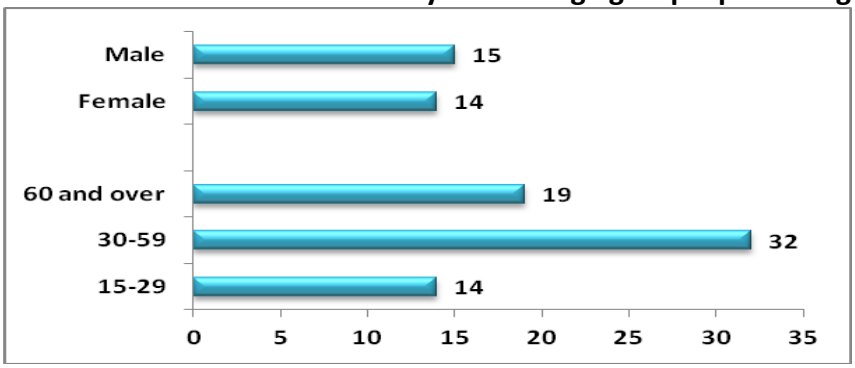
Chart 25: Number of persons with self-care difficulties by residence



Combining these questions we found that 15% of males and 14% of females reported 1-2 self-care difficulties. The age distribution is problematic because children cannot be left alone sometimes, so leaving aside the 0-14 year olds, we find

that 14% of the 15-29 years old, 6% of the 30-59 years old and a high of 19% of the 60-98 year olds with disablilities had difficulties in the self-care domain (Chart 26).

Chart 26: Self-care difficulties by sex and age group – percentage of group



Here as well, **a high of 32% of IDs reported problems with self-care compared to 7% among** people with other disabilities.

COMMUNICATION

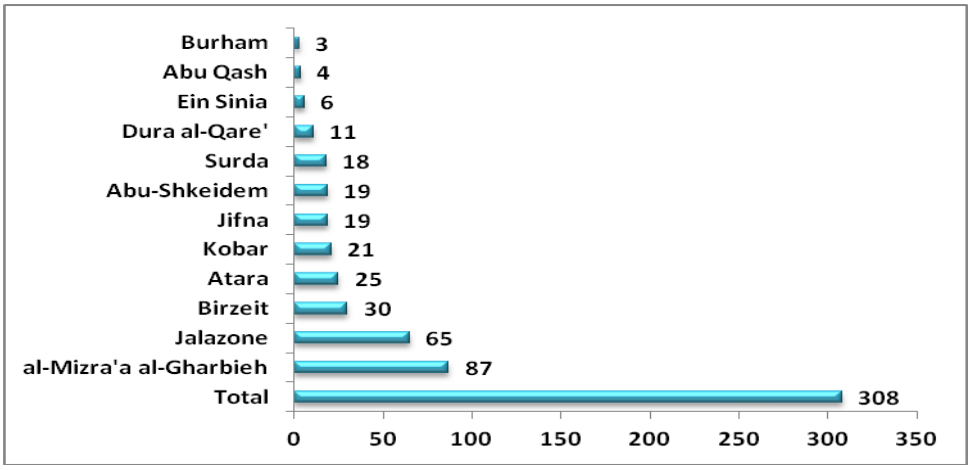
The communication domain had three questions: difficulties getting along with people who are close to you, difficulties making new friends, and difficulty with sexual activities. This last question was not answered in too many cases, given its sensitivity in the local context and it not being applicable for all who are not married, making the use of this question for scaling purposes not very useful (the Alpha was around 0.6). Removing this question and building a scale from the two other questions the Alpha improved to 0.7, which is of moderately reasonable internal consistency. Still, only 8% reported difficulties in the communication domain, making it difficult to analyze this domain further. In fact, we had experienced this problem with the social domain of the Quality of Life Bref instrument developed by WHO, where the sex question was dropped, leaving the social domain with two questions

and making an analysis of the social domain not possible. It seems there is a need to work on questions better related to the social context of the oPt, and perhaps elsewhere.

HOUSEHOLD TASKS

For the domain on household tasks, composed of three questions (facing difficulties doing the most important household tasks well; getting all household work done that you need to do; and getting household work done as quickly as needed) the Alpha was excellent at 0.96, making this a good scale to use to assess functioning. We found 308 persons reporting 1-3 such difficulties (Chart 27)**.**

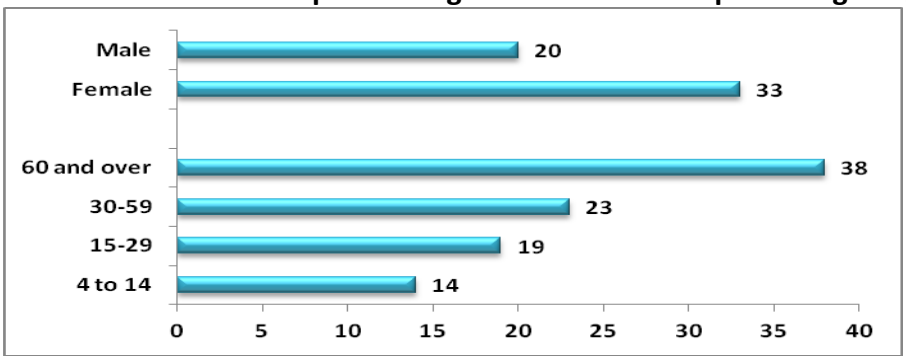
Chart 27: Number of persons with difficulties in completing house tasks by residence



33% of females with disabilities reported having such difficulties compared to 20% among males, perhaps because females are the ones who are responsible for household tasks in the local context. Such difficulties were reported at higher levels for the probable IDs at 41% compared to 22% among those with other disabilities. Likewise, reports of difficulties increased with age with 14% of those 6-18 years old

with disabilities reporting 1-3 difficulties, compared to 19% for those 19-29 years old, 23% for those 30-59 years old and 38% for those 60-98 years old (Chart 28).

Chart 28: Difficulties in performing household tasks – percentage of group

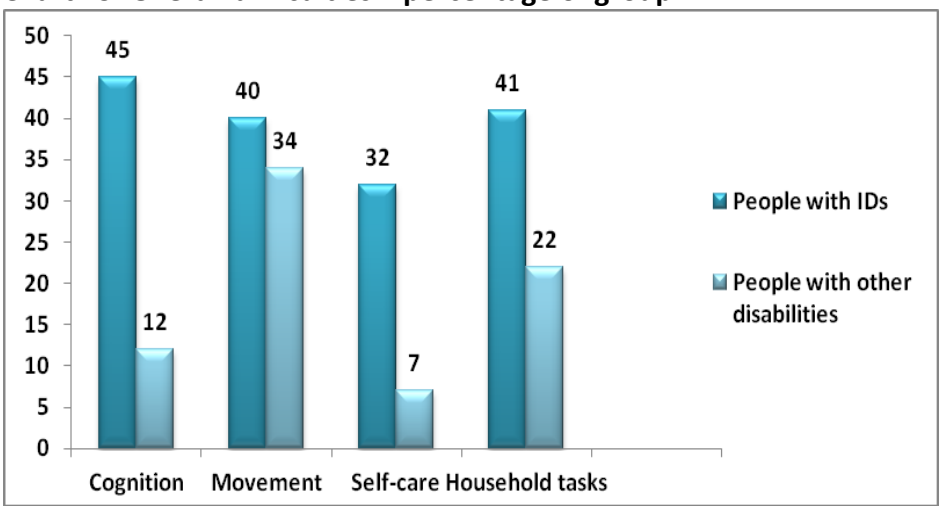


WORK

There were five questions related to the work domain: difficulty doing most important work or school tasks; difficulty getting all the work done that you need to do; difficulty getting work done as quickly as needed; needing to work at a lower level because of health condition; and having earned less money as a result of health conditions. Selecting men (since women generally do not work outside the house), and persons 18 years or over who were disabled (389 persons), only 17 of these adult men with disabilities reported 1-5 difficulties. This is likely due to some of these questions not being answered properly, so we are not able to analyze the data from these questions any further.

Overall, there were important differences in the level of difficulties the disabled endure, with people with ID's reporting higher levels compared to those with other disabilities (Chart 29).

Chart 29: Overall difficulties – percentage of group

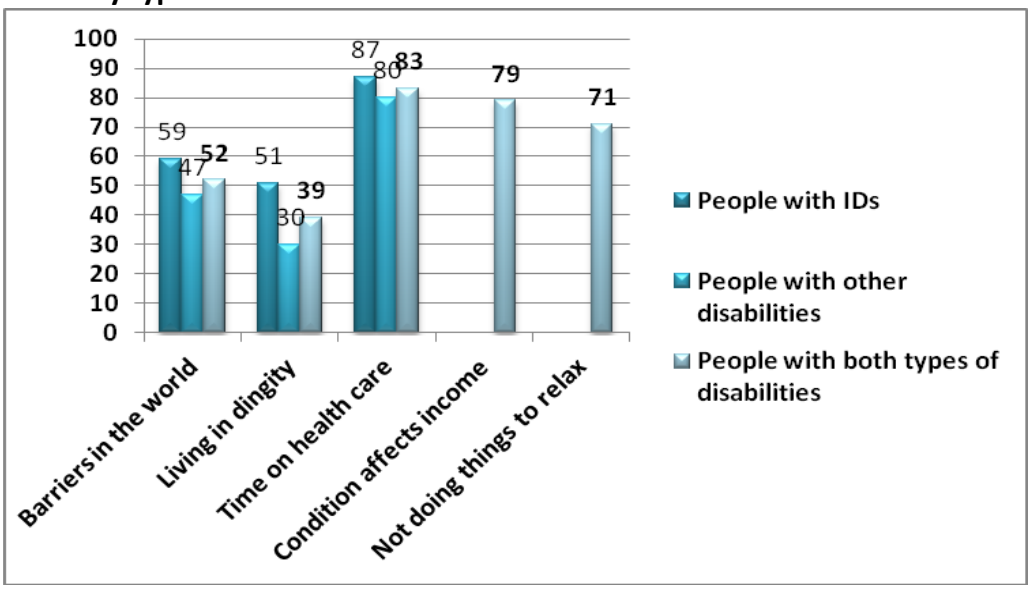


SOCIAL PARTICIPATION/OVERALL WELL-BEING INDICATORS

There were important questions asked focusing on social participation and the overall wellbeing and relation to community and the general living environment of the disabled. People with disabilities or their proxies were asked if they had difficulties participating in society, and the degree to which they were psychologically affected by their health problems. Twenty seven percent of the total disabled responded to at least one of these questions with a "yes." Those answering positively were then asked six more questions. Thus 52% of the disabled who were asked these questions reported that there were barriers in the world around them (coming in their way of living normal life) with significantly more people with IDs reporting this problem at 59% compared to 47% among people with other disabilities, 39% reported that living in dignity was a problem because of the views and actions of others and with significantly more people with IDs reporting this problem at 51% compared to 30% among the other disabled, a high of 83% reported that spending time on health care is a problem with 87% of IDs reporting this

problem compared to 80% among the other disabled, 79% reported that their condition affects their income and the income of their family with no differences between those with disability; and 71% reported problems in doing things to relax and for entertainment with no differences between the disabled (Chart 30).

Chart 30: Selected social participation/well-being indicators — percentage of disability type and total



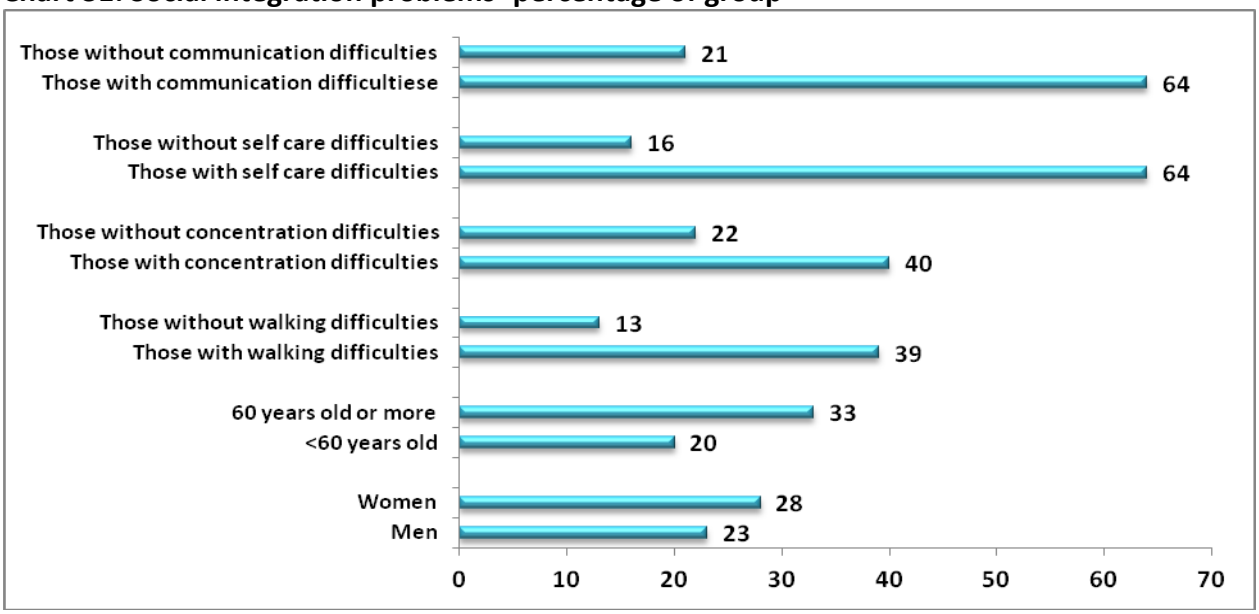
These results demonstrate important difficulties related to the burden of disability especially among IDs but not only, as this includes the burden on the family in dealing with the disability, and its financial and social consequences, all priorities for action.

Combining these questions on social participation, and excluding the question on finances above into one scale, with very good internal consistency (Alpha =0.88), we find that 27% reported 1-6 difficulties, and 40% of people IDs reporting difficulties in

participation compared to 22% among people with other disabilities, and pointing to social integration as an important aspect for future action.

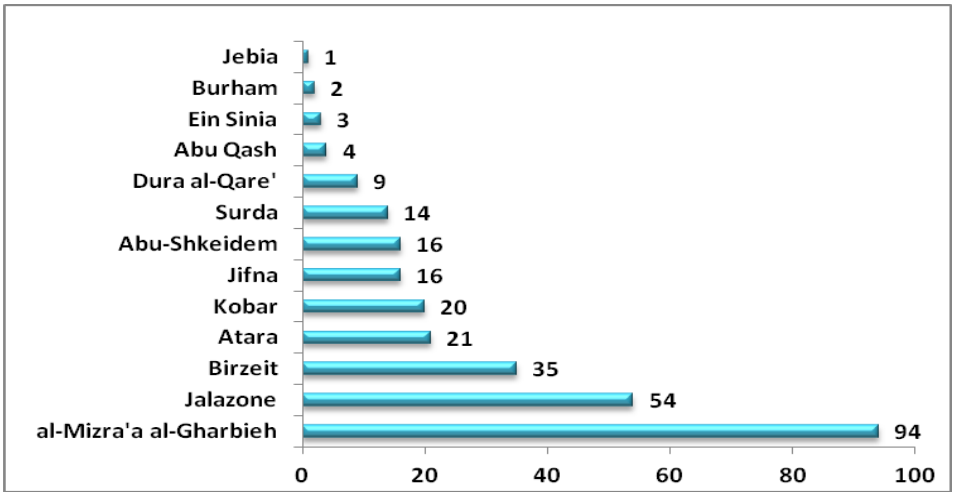
There were significant differences in the level of social participation by the characteristics of the disabled: 28% of women reported participation difficulties compared to 23% of men; 33% of those 60 years or over reported participation problems compared to 20% for the other age groups; 39% of those with walking difficulties compared to 13% for those with no such difficulties; 40% of those with concentration and remembering difficulties compared to 22% with no such difficulties; 64% of those with self-care difficulties compared to 16% among those without such difficulties; and 64% of those with communication difficulties compared to 21% without such difficulties (Chart 31). **The results clearly point to people with IDs and especially women and older people as a priority for action in the area of social integration.**

Chart 31: Social integration problems- percentage of group



Finally, at first glance the number of persons experiencing social participation difficulties appears to be much higher in al-Mizra'a al-Gharbieh compared to the other locales. So we calculated the proportion of those with participation difficulties among all of the population over 3 years old, we find that 2.4% of the people of al-Mizra'a al-Gharbieh report such difficulties, followed by 1.8% for Surda, 1.6% for Jifna, 1.4% for Atara, 1.3% for Birzeit, 1.1% for Abu Shkeidem, 1% for Jibia, 0.9% for Jalazone refugee camp, 0.8% for Dura al-Qare', 0.7% for Ein Sinia, 0.6% for Kobar, 0.5% for Burham, and 0.3% for Abu Qash (Chart 32). Thus the range of social participation/integration difficulties does vary, and requires further investigation.

Chart 32: Number of persons with 1-6 difficulties in social participation by residence

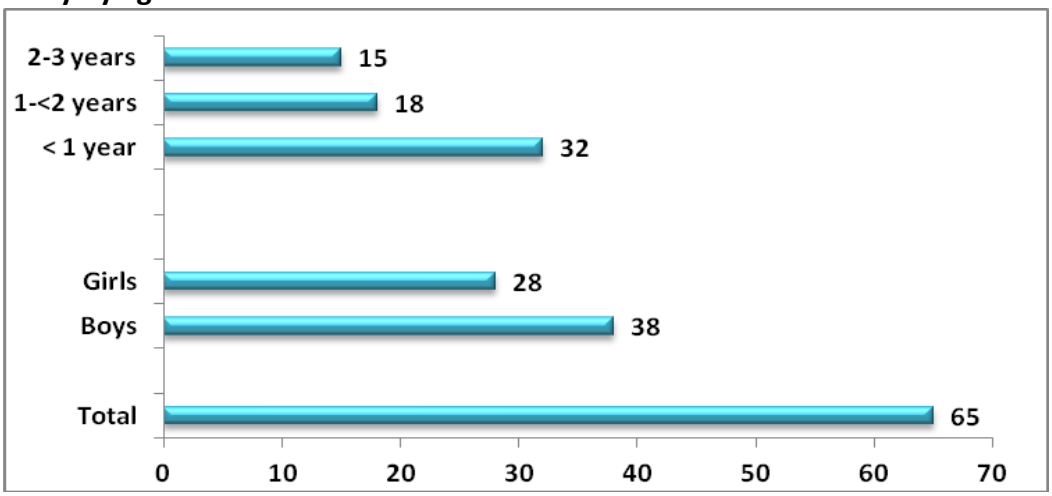


CHILDREN THREE YEARS OLD AND UNDER

Based on the analysis described in the methods above, we found 65 children 3 years old and under with reports indicating possible developmental delays, which require further investigation. Given that there were only 65 children with suspected developmental delays, it was not possible to identify differences among groups. There were slightly more disabled boys at 37 compared to 28 girls, which is expected

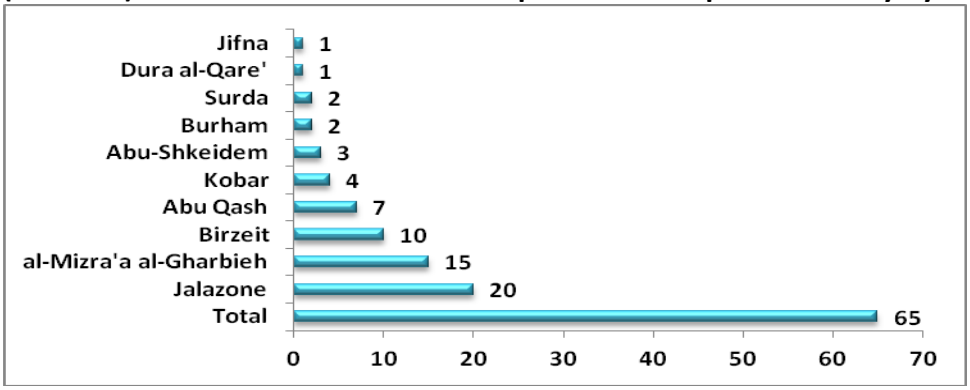
as boys are more prone to disability compared to girls, but the results are not statistically significant because the numbers of developmentally delayed children is too small. 32 of the 65 were less than one year old, 18 were one year and just under 2 years old and 15 were 2-3 years old (Chart 33).

Chart 33: Number of children 3 years and under with suspected developmental delay by age and sex.



Finally, the proportion of possible developmentally delayed children 3 years and under in these communities was 2.9% of the total number of children in this age group found in these communities. This proportion seems to be compatible with the national average (Chart 34).

(Chart 34) Number of children with suspected developmental delay by residence



CONCLUSION

We would like to express our appreciation for the Star Mountain initiative which has allowed us to uncover the needs of people with disability and identify priority groups. Indeed, the oPt is undergoing important demographic and epidemiological transitions, away from high infant mortality rates and communicable diseases, including the diseases of childhood, and moving towards the emergency of non-communicable and chronic diseases. Yet, intellectual and other forms of disability continue to arise at a young age because of a combination of genetic/familial and environmental reasons. However, because such disabilities are not spotted early enough or at all until too late, they end up increasing in severity, sometimes leading to childhood death, but also to permanent disability.

At the same time, the Palestinian population is also beginning to age, bringing in the issues and problems of not only chronic diseases, but other problems related to old age such as dementia, and the various other types of disabilities related to old age. Yet, the country's health and other systems are not ready to absorb the increasing needs of the elderly. This is precisely why this study is so important. We hope that data presented in this report will prioritize those with intellectual disabilities, especially women, and all other people with disabilities as needing assistance in improving their functioning and ability to participate in society. It is hoped that this report will function as a wakeup call to all those concerned about ensuring that the needs of all groups, especially excluded and invisible groups like the mentally disabled, are met.

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Appendix 1: Questionnaire

اسم العاملة الميدانية:.....

V1: رقم العائلة:.....

(يعبأ من قبل العاملة الميدانية حسب تسلسل المقابلات)

للعاملة الميدانية: المقابلة راح تكون مع ست البيت المسؤولة عن العيلة والأولاد وتربيتهم وأكلهم. قولي لست البيت:

مركز جبل النجمة وجامعة بيرزيت، وأنا بشتغل معهم وبالتعاون مع المجالس القروية/البلدية، بدهم يعملوا بحث عن الناس اللي عندهم صعوبات. مثل : البصر، الحركة، الفهم،...الخ. بدنا نعرف هادي الأشياء عشان نشوف كيف جبل النجمة بقدر يساعد هدول الناس اللي عندهم صعوبة حسب إمكانياته.

كل الإجابات راح تكون في تقرير على شكل أرقام وبدون أسماء حتى نحافظ على خصوصية الناس/الأشخاص.

إذا ما عندك مانع، بدنا في البداية نسألك أسئلة عن حالك، وإلك الحق ما تشاركي في هاي الدراسة، وبتقدري تنسحبي واحنى بنعبي في الأسئلة وبتقدري ما تجاوبي على بعض الأسئلة.

هل بتحبي تشاركي؟ 1. نعم 2. لا

إذا كان الجواب لا، عبي ما يلي، واحتفظي بهذه الصفحه للتوثيق :

(تم رفض المشاركة للسبب التالي): (.....)

الجنس: 1. ذكر 2. أنثى

العمر: .....

اسم القرية:.....

تاريخ إجراء المقابلة: ...../ ..... / **2013**

اسم المشرف الميداني: ..... **التوقيع** .....

للعاملة الميدانية: اطلبي من ست البيت انو تجاوب على كل الأسئلة من V2 وقوليلها ما تتردد بالسؤال عن بعض الأسئلة إذا في إشي مش واضح.

رقم الاستمارة (يترك للاستخدام المكتبي)	☐☐☐☐☐
V1. رقم ألعائلة.....	☐☐☐☐☐
V2. اسم رب العائلة.....	
V3. اسم القرية أو البلدة.....	☐☐
V4. عدد غرف البيت دون الحمامات والمطبخ والفرندات المفتوحة	☐
V5a. عدد الأشخاص الساكنين في هادا البيت واللي بشتغلوا بره 20 يوم أو أكثر في الشهر (5 أيام على الأقل في الأسبوع أو أكثر)	☐
V5b. عدد الأشخاص الساكنين في هادا البيت واللي بشتغلوا بره أقل من 20 يوم في الشهر (أقل من 5 أيام في الأسبوع).....	☐
V5c. عدد الأشخاص الساكنين في هادا البيت اللي ما بشتغلوا وبدوروا على شغل.....	☐
V6. حالة اللجوء للعائلة 1. لاجيء مسجل 2. لاجيء غير مسجل 3.ليس لاجئاً	☐
V7. إيش القرابة بينك وبين زوجك؟ 1. إبن عمك أو عمتك لزم 2. إبن خالك أو خالتك لزم 3. ولاد عمام أو خوال مش لزم 4. من الحمولة 5. لا توجد قرابة على الإطلاق	☐
V8. تعليم ربة العائلة 1. أقل من توجيهي 2. توجيهي 3. أكثر من توجيهي	☐
V9. تعليم رب العائلة 1. أقل من توجيهي 2. توجيهي 3. أكثر من توجيهي	☐
V10. هل ربة العائلة بتشتغل؟ 1. شغل مدفوع الأجر 2. شغل حر 3. طالبة 4. ربة بيت 5. متقاعدة 6. عاطلة عن العمل (مشاكل صحية) 7. عاطلة عن العمل (أسباب أخرى) 8. غيره، حدد.....	☐
V11. هل رب العائلة بشتغل؟ 1. شغل مدفوع الأجر 2. شغل حر 3. طالب 4. رب بيت 5. متقاعد 6. عاطل عن العمل (مشاكل صحية) 7. عاطل عن العمل (أسباب أخرى) 8. غيره، حدد.....	☐

(للعاملة الميدانية) : بدي أسألك عن جميع أفراد العيلة

V13	V13	V14	V15	V16	V17	V18	V19	V20	V21
رقم الفرد المتسلسل	اسم الشخص (الاسم الثلاثي)	ما هي علاقة (الاسم) برب الأسرة؟ 1. رب الأسرة 2. زوج/زوجة 3. ابن/ بنت 4. أب / أم 5. أخ/أخت 6. جد/جدة 7. حفيد/حفيدة 8. زوجة ابن/زوج بنت 9. أقرباء آخرون	الجنس 1.ذكر 2. أنثى	العمر بالسنوات الكاملة سجل/ي (00) إذا كان العمر أقل من سنة 98: إذا كان العمر 98 سنة	الالتحاق بالتعليم 1.ملتحق حاليا 2.التحق وترك 3.التحق وتخرج من المدرسة 4. التحق وتخرج من الجامعة 5. لم يلتحق	إذا التحق وترك المدرسة/الجامعة، في أي عمر ترك؟.....	عدد سنوات الدراسة التي أتمها الفرد بنجاح بالتعليم النظامي ..... سجل/ي (00) إذا كانت سنوات التعليم اقل من سنة 98: لا اعرف	نوع العلاقة بقوة العمل 1. عمل مدفوع الأجر 2. عمل حر 3. طالب 4. ربة بيت 5. متقاعد 6. عاطل عن العمل (مشاكل صحية) 7. عاطل عن العمل (أسباب أخرى) 8. غيره، حدد:.....	الحالة الزواجية 1.لم يتزوج ابدا 2. متزوج/ متزوجة 3.مطلق/ مطلقة 4.أرمل/ أرملة 5.منفصل/ منفصلة
01		☐	☐	☐☐	☐	☐☐	☐☐	☐	☐
02		☐	☐	☐☐	☐	☐☐	☐☐	☐	☐
03		☐	☐	☐☐	☐	☐☐	☐☐	☐	☐
04		☐	☐	☐☐	☐	☐☐	☐☐	☐	☐
05		☐	☐	☐☐	☐	☐☐	☐☐	☐	☐
06		☐	☐	☐☐	☐	☐☐	☐☐	☐	☐
07		☐	☐	☐☐	☐	☐☐	☐☐	☐	☐
08		☐	☐	☐☐	☐	☐☐	☐☐	☐	☐
09		☐	☐	☐☐	☐	☐☐	☐☐	☐	☐
10		☐	☐	☐☐	☐	☐☐	☐☐	☐	☐
11		☐	☐	☐☐	☐	☐☐	☐☐	☐	☐
13		☐	☐	☐☐	☐	☐☐	☐☐	☐	☐
13		☐	☐	☐☐	☐	☐☐	☐☐	☐	☐
14		☐	☐	☐☐	☐	☐☐	☐☐	☐	☐
15		☐	☐	☐☐	☐	☐☐	☐☐	☐	☐
16		☐	☐	☐☐	☐	☐☐	☐☐	☐	☐

V13	V13	V1						
			هل (الاسم) يعاني من أي من صعوبة في التالية:					
رقم الفرد المتسلسل (من صفحة 3)	**اسم الشخص (الاسم الثلاثي)** **(في حال وجود أطفال بعمر أقل من 3 سنوات، لا يتم سؤال الصعوبات لهم بل يتم تعبئة أسئلة تطور الطفل الخاصة بالأطفال). صفحة رقم 19)**	رقم العائلة	**1. صعوبة في النظر حتى مع لبس النظارات؟** 1.لا توجد صعوبة 2.نعم، بعض الصعوبة 3. نعم، صعوبة كثيرة 4. ما بقدر يشوف بالمرة	**1.1 سبب الصعوبة** 1. مرض 2. منذ الولادة 3. حادث 4. إصابة حرب 5. من الله 6. غيره، حدد.....	**2. صعوبة في السمع حتى مع استخدام سماعة؟** 1.لا توجد صعوبة 2.نعم، بعض الصعوبة 3. نعم، صعوبة كثيرة 4. ما بقدر يسمع بالمرة	**2.1 سبب الصعوبة** 1. مرض 2. منذ الولادة 3. حادث 4. إصابة حرب 5. من الله 6. غيره، حدد.....	**3. صعوبة في المشي أو طلوع الدرج؟** 1.لا توجد صعوبة 2.نعم، بعض الصعوبة 3. نعم، صعوبة كثيرة 4. ما بقدر يمشي بالمرة	**3.1 سبب الصعوبة** 1. مرض 2. منذ الولادة 3. حادث 4. إصابة حرب 5. من الله 6. غيره، حدد.....
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		☐	☐	☐	☐	☐	☐	☐
		☐	☐	☐	☐	☐	☐	☐

V13	V13	V1						
			هل (الاسم) يعاني من أي من صعوبة في التالية:					
رقم الفرد المتسلسل (من صفحة 3)	**اسم الشخص (الاسم الثلاثي)** **(في حال وجود أطفال بعمر أقل من 3 سنوات، لا يتم سؤال الصعوبات لهم بل يتم تعبئة أسئلة تطور الطفل الخاصة بالأطفال). صفحة رقم 19**	رقم العائلة	**4. صعوبة في إنه يتذكر أو يركز؟** 1.لا توجد صعوبة 2.نعم، بعض الصعوبة 3. نعم، صعوبة كثيرة 4. . ما بقدر يتذكر بالمرة	**4.1 سبب الصعوبة** 1. مرض 2. منذ الولادة 3. حادث 4. إصابة حرب 5. من الله 6. غيره،حدد....	**5. صعوبة إنو يدير باله عحاله مثل إنو يتحمم ويلبس أواعيه؟** 1.لا توجد صعوبة 2.نعم، بعض الصعوبة 3. نعم، صعوبة كثيرة 4. ما بقدر يتحمم أو يلبس أواعيه بالمرة	**5.1 سبب الصعوبة** 1. مرض 2. منذ الولادة 3. حادث 4. إصابة حرب 5. من الله 6. غيره، حدد.....	**6. صعوبة التواصل مثل انو يفهم أو يفهموا الناس عليه؟** 1.لا توجد صعوبة 2.نعم، بعض الصعوبة 3. نعم، صعوبة كثيرة 4. ما بقدر يفهم بالمرة	**6.1 سبب الصعوبة** 1. مرض 2. منذ الولادة 3. حادث 4. إصابة حرب 5. من الله 6. غيره، حدد.....
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V22. عدد الافراد (أطفال وكبار) اللي دايما ساكنين في الدار وباكلوا وبستعملوا نفس المطبخ ☐☐

(للعاملة الميدانية: عدي الأشخاص من جدول أفراد العائلة الأول وتأكدي من العدد مع ست البيت)

V23. هل العائلة 1. نووية 2. ممتدة ☐

أسئلة WHODAS 2 (13+24)

بحب أعرف عن بعض الصعوبات اللي بواجها الناس بسبب وضعهم الصحي. فرجي البطاقة رقم 1 (ماذا نعني بالوضع الصحي والصعوبة في عمل النشاط) لربة البيت أو للشخص اللي عنده الصعوبة. نقصد بالوضع الصحي المرض أو مشاكل صحية اللي بتستمر لفترة قصيرة أو طويلة، مثل الاصابات أو مشاكل نفسية.

قولي لربة البيت أو الشخص انهم يفكروا بكل المشاكل الصحية اللي عندهم عن الشهر الماضي خلال فترة المقابله.

لما بسألكم عن صعوبات في عمل نشاط بعني (فرجي البطاقة رقم 1)

- إنك تزيد/ي من الجهد اللي بتعمل/ي فيه النشاط
- تعمل/ي النشاط وإنت مش مرتاح أو متوجع
- تعمل/ي النشاط ببطء
- بتضطر تغير في طريقة عملك للنشاط عشان تنجزه

قولي لربة البيت أو الشخص إنهم يفكروا بآخر شهر لما يجاوبوا ويتذكروا الصعوبة اللي واجهتهم خلال عمل النشاط اللي بعملوه بالعادة.

فرجي البطاقة رقم 2 واطلبي من ربة البيت أو الشخص إنهم يجاوبوا باستخدام الخيارات التالية: 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة

كعاملة ميدانية، اتأكدي بأنو ربة البيت أو الشخص بقدروا يشوفوا البطاقة رقم 1 ورقم 2 خلال المقابلة.

القسم الأول (للعاملة الميدانية: اسألي الأم عن جميع أفراد العيلة اللي عمرهم أكبر من 3 سنوات)

خلال الشهر الماضي، هل أدى وضع الفرد الصحي بسبب مرض أو إصابة أو مشاكل نفسية إلى صعوبة في إنه يعمل نشاطاته اليومية بطريقة مختلفة مثل "زيادة جهد في عمل النشاط أو يعمل النشاط وهو مش مرتاح أو متألم أو يقوم بنشاطاته ببطء أو تغيرت طريقته في عمل النشاط"؟ شو الصعوبة اللي واجهها خلال الشهر الماضي في هذه النشاطات؟

للعاملة الميدانية: (إذا كانت الإجابة في هذا القسم غير **أبداً** لسؤال **واحد على الأقل (عنده صعوبه)** كملي تعباية الاستبيان في القسم الثاني.

V13	V1	V13	S1	S2	S3	S4	S5
رقم الفرد المتسلسل (من صفحة 3)	**رقم العائلة**	**اسم الشخص (الاسم الثلاثي)**	**هل لاقى صعوبة في الوقوف لفترة طويلة مثل 30 دقيقة؟** 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	**هل لاقى صعوبة في الاهتمام بمسؤوليات البيت؟** 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	**هل لاقى صعوبة في تعلم اشي جديد، مثل إنو يتعلم كيف يوصل لمحل جديد؟** 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	**هل لاقى صعوبة إنو يشارك في نشاطات مجتمعية (مثل أفراح،عزى أو نشاطات دينية أوغيرها من الأنشطة) بنفس الطريقة اللي بقدر أن يقوم فيها شخص ثاني؟** 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	**قديش تأثر نفسياً بمشاكله الصحية؟** 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق
			☐	☐	☐	☐	☐
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بقدر أحكي مع الشخص اللي عنده صعوبة وأساله عن هاي الصعوبات (للأشخاص اللي بتزيد أعمارهم عن 13 سنة واطلبي من الأم إنها تجاوب عن الأشخاص اللي بزيد عمرهم عن 3 وبقل عن 13).
في حال عدم استطاعة الشخص فوق 13 سنة الإجابة عن نفسه اطلبي من الأم الإجابة ولا داعي لتوقيع الموافقة أدناه. حيث انها وافقت على المشاركه في بداية المقابلة).

قولي التالي للشخص اللي عنده الصعوبات(في حال أن الشخص سوف يجاوب عن نفسة):
برغب مركز جبل النجمة وجامعة بيرزيت وبالتعاون مع المجالس القروية/البلدية بعمل مسح ميداني عشان نعرف إذا عندك صعوبات، على سبيل المثال: البصر، الحركة، الفهم،...الخ. بدنا نعرف هادا الاشي عشان نشوف كيف بقدر المركز يساعدك ضمن إمكانياته. بدنا نسألك أسئلة عن حالك، وبالتأكيد الك الحق إنك ما تشارك في هذا المسح، وبتقدر تنسحب اذا بتحب واحنى نعبي بالاستبيان وبحق إلك ما تجاوب على بعض الأسئلة.

هل بتحب/ي تشارك/ي؟ 1. نعم 2. لا
إذا كان الجواب نعم: (اسم العاملة الميدانية التي حصلت على الموافقة: .....)

إذا كان الجواب لا، عبي ما يلي:
(تم رفض المشاركة للسبب التالي):
(.....)

الجنس: 1. ذكر 2. أنثى
العمر: .....
إسم القرية:.....

يتم تعبئة المعلومات التالية ولآخر الاستبيان للأشخاص الذين يعانون من صعوبات فقط.

القسم الثاني

(إذا كانت الإجابة في القسم الأول غير **أبداً** لسؤال **واحد على الأقل**، كملي تعباية الاستبيان للقسم الثاني).
خلال الشهر الماضي، هل أدى وضعك الصحي بسبب (مرض أو إصابة أو مشاكل نفسية إلى صعوبة في إنك تعمل نشاطاتك اليومية مثل "زيادة جهد في عمل النشاط أو تعمل النشاط وانت مش مرتاح أو متألم أو تقوم بنشاطاتك ببطء أو بتغير طريقتك في عمل النشاط")؟
شو الصعوبة اللي واجهتها خلال الشهر الماضي في الآتي؟

(قابلي الشخص نفسه إذا كان عمره أكثر من 13 سنة إذا ممكن. اطلبي من الأم إنها تجاوب عن

V13	V13	V32	S6	S7	S8	S9	S10	S11	S13
رقم الفرد (من صفحة 3)	اسم الشخص	مين جاوب 1.الأم 2.الشخص نفسه	هل لقيت صعوبة إنك تركز على عمل إشي لمدة عشر دقائق؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا	هل لقيت صعوبة إنك تمشي لمسافة طويلة مثل كيلومتر؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	هل لقيت صعوبة إنك تحمم جسمك كله؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	هل لقيت صعوبة إنك تلبس أواعيك؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	هل لقيت صعوبة إنك تتعامل مع أشخاص ما بتعرفهم؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	هل لقيت صعوبة إنك تحافظ على علاقة صداقة/صحابك ؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	هل لقيت صعوبة إنك تعمل أعمالك اليومية؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. ل 7. ا ينطبق
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الأشخاص اللي بزيد عمرهم عن 3 وبقل عن 13).

للعاملة الميدانية: كملي الاستبيان بتحديد المجالات كما يلي:

إذا كانت الإجابة هي (2-5) للأسئلة من S1 إلى S13	**روحي**	**رقم المجال**
S3 أو S6 (الإدراك)	←	مجال 1 صفحة رقم 11
S1 أو S7 (ألحركة)	←	مجال 2 صفحة رقم 13
S8 أو S9 (العناية بالنفس)	←	مجال 3 صفحة رقم 13
S10 أو S11 (التواصل)	←	مجال 4 صفحة رقم 14
S2 أو S13 (نشاطات يوميه)	←	مجال 5 صفحة رقم (15-16)
S4 أو S5 (المشاركه)	←	مجال 6 صفحة رقم 17

D1.6	D1.5	D1.3	D1.2	V32	V13	V13

القسم الثالث

المجال رقم 1 (الإدراك)

(للعاملة الميدانية: إذا كان هناك صعوبة عند الشخص في تعلم اشي جديد أو التركيز لمدة عشر دقائق، إسأليه الأسئلة التالية)

بدي أسال بعض الأسئلة عن الفهم والتواصل

خلال الشهر الماضي، هل أدى وضعك الصحي بسبب (مرض أو إصابة أو مشاكل نفسية إلى صعوبة في إنك تعمل نشاطاتك اليومية مثل "زيادة جهد في عمل النشاط أو تعمل النشاط وانت مش مرتاح أو متألم أو تقوم بنشاطاتك ببطء أو بتغير طريقتك في عمل النشاط")؟ شو الصعوبة اللي واجهتها خلال الشهر الماضي في الآتي؟

رقم الفرد المتسلسل (من صفحة 3)	اسم الشخص	مين جاوب 1.الأم 2.الشخص نفسه	هل لقيت صعوبة تتذكر أشياء مهمة لازم تعملها؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	هل لقيت صعوبة تلاقي حلول لمشاكل الحياة اليومية؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	هل لقيت صعوبة في إنك تفهم إيش الناس بتحكي بشكل عام؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	هل لقيت صعوبة في إنك تبدأ وتكمل إشي بدك تحكي فيه مع حدى ثاني؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق
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المجال رقم 2 (الحركة)

(للعاملة الميدانية: إذا كان هناك صعوبة عند الشخص في الوقوف لمدة 30 دقيقة أو يمشي مسافة كيلومتر، إسأليه الأسئلة التالية):

بدي أسألك عن صعوبات في الحركة

خلال الشهر الماضي، هل أثروضعك الصحي بسبب (مرض أو إصابة أو مشاكل نفسية) إلى صعوبة في إنك تعمل نشاطاتك اليومية مثل "إنك تزيد جهدك في عمل النشاط أو تعمل النشاط وانت مش مرتاح أو متألم أو تقوم بنشاطاتك ببطء أو بتغير طريقتك في عمل النشاط")؟
شو الصعوبة اللي واجهتها خلال الشهر الماضي في هاي الأشياء

V13	V13	V32	D2.2	D2.3	D2.4
رقم الفرد المتسلسل (من صفحة 3)	اسم الشخص	مين جاوب 1.الأم 2.الشخص نفسه	هل لقيت صعوبة في إنك توقف بعد ما تكون قاعد؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	هل لقيت صعوبة تتحرك داخل البيت؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	هل لقيت صعوبة إنك تطلع من البيت؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق
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المجال رقم 3 (العناية بالنفس)
(للعاملة الميدانية: إذا كان هناك صعوبة عند الشخص في أنو يحمم حاله أو يلبس لحاله، إسأليه الأسئلة التالية):
بحب أسألك عن صعوبات في إنك تدير بالك عحالك.
خلال الشهر الماضي، هل أثروضعك الصحي بسبب (مرض أو إصابة أو مشاكل نفسية) إلى صعوبة في إنك تعمل نشاطاتك اليومية مثل "إنك تزيد جهدك في عمل النشاط أو تعمل النشاط وانت مش مرتاح أو متألم

D3.4	D3.3	V32	V13	V13

أو تقوم بنشاطاتك ببطء أو بتغير طريقتك في عمل النشاط")؟
شو الصعوبة اللي واجهتها خلال الشهر الماضي في هاي الأشياء؟

رقم الفرد المتسلسل (من صفحة 3)	اسم الشخص	مين جاوب 1.الأم 2.الشخص نفسه	هل لقيت صعوبة في إنك تاكل لحالك؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	هل لقيت صعوبة إنك تكون لحالك في البيت لأيام قليلة؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق
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المجال رقم 4 (التواصل مع الناس)

(للعاملة الميدانية: إذا كان هناك صعوبة عند الشخص في إنو يتعامل مع أشخاص ما بعرفهم أو يحافظ على صحابه، إسأليه الأسئلة التالية):

بحب أسألك عن صعوبات في التواصل مع الناس.

خلال الشهر الماضي، هل أثروضعك الصحي بسبب (مرض أو إصابة أو مشاكل نفسية) إلى صعوبة في إنك تعمل نشاطاتك اليومية مثل "إنك تزيد جهدك في عمل النشاط أو تعمل النشاط وانت مش مرتاح أو متألم أو تقوم بنشاطاتك ببطء أو بتغير طريقتك في عمل النشاط")؟
شو الصعوبة اللي واجهتها خلال الشهر الماضي في هاي الأشياء؟

V13	V13	V32	D4.3	D4.4	D4.5
رقم الفرد المتسلسل (من صفحة 3)	اســـــــــم الشخص	مين جاوب 1.الأم 2.الشـــخص نفسه	هل لقيت صعوبة في التواصل مع الناس القريبين منك؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	هل لقيت صعوبة في إنك تعمل أصحاب جداد؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	هل لقيت صعوبة في علاقتك الزوجية الحميمية؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق
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المجال رقم 5 (النشاطات اليومية)

5 (1) النشاطات المنزلية

(للعاملة الميدانية: إذا كان هناك صعوبة عند الشخص في إنو يهتم بمسؤوليات البيت أو الأعمال اليومية، إسأليه الأسئلة التالية):

بحب أسألك عن نشاطات بتخص بيتك وفي إنك تدير بالك على الأشخاص اللي بعيشوا معك.

خلال الشهر الماضي، هل أثروضعك الصحي بسبب (مرض أو إصابة أو مشاكل نفسية) إلى صعوبة في

D5.4	D5.3	D5.2	V32	V13	V13

إنك تعمل نشاطاتك اليومية مثل "إنك تزيد جهدك في عمل النشاط أو تعمل النشاط وانت مش مرتاح أو متألم أو تقوم بنشاطاتك ببطء أو بتغير طريقتك في عمل النشاط")؟

شو الصعوبة اللي واجهتها خلال الشهر الماضي في هاي الأشياء؟

رقم الفرد المتسلسل (من صفحة 3)	اســـــم الشخص	مين جاوب 1.الأم 2.الشـــــخص نفسه	هل لقيت صعوبة في عمل أهم واجباتك المنزلية جيداً؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	هل لقيت صعوبة إنك تقوم بكافة أعمالك المنزلية المطلوبة منك؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	هل لقيت صعوبة في إنك تقوم بكافة أعمالك المنزلية بالسرعة المطلوبة؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق
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إذا كانت إحدى الإجابات على الأقل أو كلها للأسئلة D5.2 إلى D5.4 ليست أبداً، إسألي السؤال التالي:

المجال 5(2) نشاطات العمل أو المدرسة

إذا كان الشخص بشتغل (شغل مدفوع الأجر، غير مدفوع، شغل حر) أو بروح على المدرسة، كملي سؤال الأسئلة D5.6 إلى D5.10، عدا ذلك ما تسألي.

5 (2) نشاطات العمل أو المدرسة. بحب أسألك بعض الأسئلة عن نشاطات العمل أو المدرسة خلال الشهر الماضي.

V13	V13	V32	D5.6	D5.7	D5.8	D5.9	D5.10

V7	V13	V32	D5.01
رقم الفرد المتسلسل (من صفحة 3)	اسم الشخص	مين جاوب 1.الأم 2.الشخص نفسه	خلال الشهر الماضي، كم يوم اللي قللت أو طنشت فيها أعمالك المنزلية بسبب وضعك الصحي؟ (سجلي عدد الأيام)
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رقم الفرد المتسلسل (من صفحة 3)	اســـــــم الشخص	مين جاوب 1.الأم 2.الشــخص نفسه	هل لقيت صعوبة في إنك تقوم بأهم واجباتك المدرسية/العمل جيداً؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	هل لقيت صعوبة إنك تقوم بكل أعمالك اللي لازم تعملها؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	هل لقيت صعوبة في إنك تقوم بكل أعمالك بالسرعة المطلوبة؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	هل اضطررت للعمل/الدراسة بمستوى أقل بسبب وضعك الصحي؟ 1. لا 2. نعم	هل حصلت على مال أقل بسبب وضعك الصحي؟ 1. لا 2. نعم 3. لا ينطبق
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إذا كانت إحدى الإجابات على الأقل أو كلها للأسئلة D5.6 إلى D5.10 ليست أبداً، إسألي السؤال التالي:

المجال رقم 6 (المشاركة)

(للعاملة الميدانية: إذا كان هناك صعوبة عند الشخص في المشاركة في النشاطات المجتمعية أو متأثر نفسيا

V13	V13	V32	D5.01
رقم الفرد المتسلسل (من صفحة 3)	اسم الشخص	مين جاوب 1.الأم 2.الشخص نفسه	خلال الشهر الماضي، ما هي عدد الأيام التي تغيبت فيها عن الشغل لمدة "نصف يوم على الأقل" أو أكثر بسبب وضعك الصحي؟ (سجلي عدد الأيام)
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بمشاكله النفسية، إسأليه الأسئلة التالية):
بحب أسألك عن مشاركتك في المجتمع وتأثير المشاكل الصحية عليك وعلى عائلتك، ركز على آخر ثلاثين يوم وإنت تجاوب. وتذكر تجاوب على هاي الأسئلة وإنت بتفكر بمشاكلك الصحية: الجسدية أو النفسية.

V13	V13	V32	D6.2	D6.3	D6.4	D6.6	D6.7	D6.8
رقم الفرد المتسلسل (من صفحة 3)	اســـــم الشخص	مين جاوب 1.الأم 2.الشــخص نفسه	قديش واجهت مشاكل بسبب معيقات من العالم حولك؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو بقدر بالمرة 6. لا ينطبق	كم واجهت مشاكل في سبيل إنك تعيش بكرامة بسبب آراء وأعمال من قبل الآخرين؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	كم من الوقت إحتجت عشان تتعامل مع وضعك الصحي أو نتائجه؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	ما مدى تكلفة وضعك الصحي على مصادر الرزق إلك ولأسرتك؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	قديش واجهت عائلتك مشاكل بسبب وضعك الصحي؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق	قديش المشاكل اللي واجهتها عشان تعمل أشياء لحالك بهدف الراحة والاستجمام؟ 1. أبداً 2. قليلاً 3. متوسطاً 4. كثيراً 5. كثيراً جداً أو ما بقدر بالمرة 6. لا ينطبق
☐		☐	☐	☐	☐	☐	☐	☐
☐		☐	☐	☐	☐	☐	☐	☐
☐		☐	☐	☐	☐	☐	☐	☐
☐		☐	☐	☐	☐	☐	☐	☐
☐		☐	☐	☐	☐	☐	☐	☐

للعاملة الميدانية: الرجاء تعبئة الجدول التالي للأشخاص الذين وجد لديهم أي نوع من الصعوبات بشكل عام خلال الشهر الماضي:

V13	V13	V32	H1	H2	H3
رقم الفرد المتسلسل (من صفحة 3)	اسم الشخص	مين جاوب 1.الأم 2.الشـــــخص نفسه	بشكل عام، خلال الشهر الماضي كم يوم كانت الصعوبات موجودة؟ (السؤال يشمل أي نوع من الصعوبات التي كانت موجودة) (سجلي عدد الأيام)	بشكل عام، خلال الشهر الماضي كم يوم كنت غير قادر تماماً إنك تقوم بنشاطاتك المعتادة أو شغلك بسبب أي مشكلة صحية؟ (سجلي عدد الأيام)	بشكل عام، خلال الشهر الماضي بدون اعتبار الأيام التي كنت فيها مش قادر بالمرة، كم يوم اضطررت إنك تقلل أو تختصر نشاطاتك الاعتيادية أو الشغل بسبب أي مشكلة صحية؟ (سجلي عدد الأيام)
☐		☐	☐☐	☐☐	☐☐
☐		☐	☐☐	☐☐	☐☐
☐		☐	☐☐	☐☐	☐☐
☐		☐	☐☐	☐☐	☐☐
☐		☐	☐☐	☐☐	☐☐

للعاملة الميدانية:

ملاحظات تودين إضافتها:

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<u>أسئلة تطور الطفل</u>

اسألي الأم عن وجود أطفال في البيت اللي تتراوح أعمارهم بين 0 إلى 3 سنوات، في حال وجودهم إسألي الأسئلة التالية. وفي حال وجود توأم أو أكثر أو في حال وجود عائلة ممتدة لديها أطفال بنفس العمر تضاف الخانات كما هو موضح على يسار الجدول (يرجى كتابة رقم الفرد لكل الافراد في حال وجود اكثر من فرد في الخانة المخصصة):

V24. إذا كان عمر الطفل أقل من 3 شهور **V1. رقم العائلة .....** **V13. رقم الفرد .....**		**V13** **(رقم الفرد)**	**V13 (رقم الفرد)**	**V13 (رقم الفرد)**	**V13 (رقم الفرد)**
☐	V24.1. بتمدد على بطنه وبحرك راسه من وقت لآخر 1. نعم 2. لا	☐	☐	☐	☐
☐	V24.2. بركز نظره على أمه وهي بترضعه 1. نعم 2. لا	☐	☐	☐	☐
☐	V24.3. بخاف أو بسكت للصوت العالي 1. نعم 2. لا	☐	☐	☐	☐
☐	V24.4. بهدى إذا حملته أمه 1. نعم 2. لا	☐	☐	☐	☐
V25. إذا كان عمر الطفل ما بين 3 شهور وأقل من 6 شهور **V1. رقم العائلة .....** **V13. رقم الفرد .....** **(إذا كانت كل الإجابات لا يرجى سؤال الأسئلة للفئة العمرية السابقة)**		**V13** **(رقم الفرد)**	**V13 (رقم الفرد)**	**V13 (رقم الفرد)**	**V13 (رقم الفرد)**

☐	V25.1. بسكت أو بدير راسه لما بسمع صوت 1. نعم 2. لا	☐	☐	☐	☐
☐	V25.2. بتابع لعبة ملونة على مسافة 15–30 سم 1. نعم 2. لا	☐	☐	☐	☐
☐	V25.3. بتمدد على بطنه وبرفع راسه 1. نعم 2. لا	☐	☐	☐	☐
☐	V25.4. بتفاعل بانبساط مع اللعب والغنى 1. نعم 2. لا	☐	☐	☐	☐
V26. إذا كان عمر الطفل ما بين 6 شهور وأقل من 9 شهور **V1. رقم العائلة .....** **V13. رقم الفرد .....** **(إذا كانت كل الإجابات لا يرجى سؤال الأسئلة للفئة العمرية السابقة)**		**V13 (رقم الفرد)**	**V13 (رقم الفرد)**	**V13 (رقم الفرد)**	**V13 (رقم الفرد)**
☐	V26.1. لما بتمدد على بطنه برفع راسه وصدره وهو مرتكز على إيديه 1. نعم 2. لا	☐	☐	☐	☐
☐	V26.2.إذا حطيت خورخيشة في إيده بمسكها لعدة دقائق 1. نعم 2. لا	☐	☐	☐	☐
V27. إذا كان عمر الطفل ما بين 9 شهور وأقل من 13 شهر **V1. رقم العائلة .....** **V13. رقم الفرد .....** **(إذا كانت كل الإجابات لا يرجى سؤال الأسئلة للفئة العمرية السابقة)**		**V13 (رقم الفرد)**	**V13 (رقم الفرد)**	**V13 (رقم الفرد)**	**V13 (رقم الفرد)**
☐	V27.1. بمسك لعبة في كل إيد وبضربها في بعضها 1. نعم 2. لا	☐	☐	☐	☐
☐	V27.2. بنتبه للموسيقى والأغاني اللي بتطلع من التلفزيون أو الراديو 1. نعم 2. لا	☐	☐	☐	☐
☐	V27.3. بقلد تصفيق اليدين 1. نعم 2. لا	☐	☐	☐	☐
V28. إذا كان عمر الطفل ما بين 13 شهر وأقل من 18 شهر			**V13 (رقم**	**V13 (رقم**	

V1. رقم العائلة ..... **V13. رقم الفرد .....** **(إذا كانت كل الإجابات لا يرجى سؤال الأسئلة للفئة العمرية السابقة)**		**V13 (رقم الفرد)**	**الفرد)**	**الفرد)**	**V13 (رقم الفرد)**
☐	V28.1. بفهم معنى كلمة لا 1. نعم 2. لا	☐	☐	☐	☐
☐	V28.2. بحب أنو يكتشف كل اللي حوليه 1. نعم 2. لا	☐	☐	☐	☐
☐	V28.3. برفع حاله وهو متمدد وبحاول يقعد 1. نعم 2. لا	☐	☐	☐	☐
V29. إذا كان عمر الطفل ما بين 18 شهر وأقل من 24 شهر **V1. رقم العائلة .....** **V13. رقم الفرد .....** **(إذا كانت كل الإجابات لا يرجى سؤال الأسئلة للفئة العمرية السابقة)**		**V13 (رقم الفرد)**	**V13 (رقم الفرد)**	**V13 (رقم الفرد)**	**V13 (رقم الفرد)**
☐	V29.1. بمشي لحاله 1. نعم 2. لا	☐	☐	☐	☐
☐	V29.2. بجر وبسحب لعب كبيرة 1. نعم 2. لا	☐	☐	☐	☐
☐	V29.3. بمسك كاسة بايديه الاثنتين وبشرب 1. نعم 2. لا	☐	☐	☐	☐
☐	V29.4. بساعد في لبسه مثل انو يرفع إيديه لفوق 1. نعم 2. لا 2.	☐	☐	☐	☐
V30. إذا كان عمر الطفل ما بين 24 شهر وأقل من 36 شهر **V1. رقم العائلة .....** **V13. رقم الفرد .....** **(إذا كانت كل الإجابات لا يرجى سؤال الأسئلة للفئة العمرية السابقة)**		**V13 (رقم الفرد)**	**V13 (رقم الفرد)**	**V13 (رقم الفرد)**	**V13 (رقم الفرد)**
☐	V30.1. بسمي صورة أو شكل مألوف مثل القطة 1. نعم 2. لا	☐	☐	☐	☐
☐	V30.2. بطلع الدرج واقفاً بدون مساعدة أحدى 1. نعم 2. لا	☐	☐	☐	☐

☐	V30.3. بغرف أكله بالملعقة وبطعمي حاله 1. نعم 2. لا	☐	☐	☐	☐
☐	V30.4. بلعب ألعاب فيها تمثيل مثل أن يكون شرطي أو تكون طبيبة 1. نعم 2. لا	☐	☐	☐	☐
V31. إذا كان عمر الطفل 36 شهر **V1. رقم العائلة .....** **V13. رقم الفرد .....** **(إذا كانت كل الإجابات لا يرجى سؤال الأسئلة للفئة العمرية السابقة)**		**V13 (رقم الفرد)**	**V13 (رقم الفرد)**	**V13 (رقم الفرد)**	**V13 (رقم الفرد)**
☐	V31.1. بروح لحاله للحمام 1. نعم 2. لا	☐	☐	☐	☐
☐	V31.2. بحكي قصص عن اللي صار معه خلال اليوم 1. نعم 2. لا	☐	☐	☐	☐