Ministry of Social Development

1946
2016

unicef

70 YEARS FOR EVERY CHILD

Every child counts: understanding the needs and perspectives of children with disabilities in the State of Palestine

December 2016

Funded by
The Government of Japan

من الشعب الياباني
From the People of Japan

Ministry of Social Development

1946
2016

unicef

70 YEARS FOR EVERY CHILD

Every child counts: understanding the needs and perspectives of children with disabilities in the State of Palestine

December 2016

This report was written by Nicola Jones, Bassam Abu Hamad, Kifah Odeh, Paola Pereznieto, Ola Abu Al Ghaib, Georgia Plank, Elizabeth Presler-Marshall and Mohammed Shaheen.

A special thanks to Jerusalem Princess Basma Centre for their kind cooperation with UNICEF in documenting children with disabilities.

For further information, please contact:
Kumiko Imai
Chief, Social Policy, Monitoring and Evaluation
UNICEF – State of Palestine
Email: kimai@unicef.org

Cover photo: © UNICEF-SoP/Ahed Izhiman
Cover photo caption: Mira, a 4-year old girl from Nablus who is benefiting from physiotherapy sessions at the Jerusalem Princess Basma Centre

Overseas Development Institute
203 Blackfriars Road
London SE1 8MJ

Tel: +44 (0) 20 7922 0300
Fax: + 44 (0) 20 7922 0399

Email: info@odi.org.uk
www.odi.org
www.odi.org/facebook

United Nations Children's Fund - UNICEF
P.O.Box 25141
Shuffat, E. Jerusalem

Tel: +972 (2) 5840 400
Fax: +972 (2) 5830 806

www.unicef.org/opt
www.facebook.com/unicefstateofpalestine

Acknowledgements

We would like to thank both the many participants in our research and our field team.

At MOSD in the West Bank, we appreciate the efforts of Daoud Al-Deek, Ameen Enab and all other staff who provided facilities for the study and took their time to answer our questions.

At MOSD in Gaza, we appreciate the hard work of Riyad Bitar, Itimad Tarshawi, Mohammad Nassar and Ghassan Felfel. We also would like to express gratitude to MOEHE.

As our work would not have been possible without the full support of NGOs supporting those with disabilities, we also thank the staff at the General Union of Disabled Persons, the Palestinian Medical Relief Society and the Palestinian Red Crescent Society.

Thanks go to all governmental, non-governmental and international organisations that participated in the study and contributed to the community validation workshops. Thanks go in particular to the National Society for Rehabilitation and the Palestinian Medical Relief Society for providing access to their databases.

We give special thanks to all the boys and girls and mothers and fathers who gave up their time to help us understand their lives.

And, finally, we thank our field team and translators: in the West Bank, Atheer Asi, Ohoud Khoufash, Shumos Harb, Fardous Salama, Sammar Mahmoud, Fida Abu Turkey, Ayat Al-Jabari and Rana Bani Odi, Rabyha; in Gaza, Riyad Diab, Eman Abu Hammra, Haneen Rasg, Hala Rasg, Dr Amal Sarsour, Dr Sanna Al Najjar, Amal Shanti, Nadia Al-Bayoumi, Nabeel Al Ghoul and Ahmad Rasg.

Acronyms and abbreviations

ADL	Activities of Daily Living
BASR	Bethlehem Arab Society for Rehabilitation
CBR	Community-based Rehabilitation
CPN	Child Protection Network
CRPD	Convention on the Rights of Persons with Disabilities
CWDs	Children with Disabilities
EFA	Education for All
ESDP	Education Development Strategic Plan
EU	European Union
GBV	Gender-based Violence
HH	Household
ICF	International Classification of Functions
ICHR	Independent Commission for Human Rights
ILO	International Labour Organization
M&E	Monitoring and Evaluation
MOEHE	Ministry of Education and Higher Education
MOH	Ministry of Health
MOL	Ministry of Labour
MOSA	Ministry of Social Affairs (renamed as the Ministry of Social Development in 2016)
MOSD	Ministry of Social Development
NAD	Norwegian Association of the Disabled
NFE	Non-formal Education
NGO	Non-Governmental Organisation
OCHA	UN Office for the Coordination of Humanitarian Affairs
ODI	Overseas Development Institute
OPD	Organisations for persons with disabilities
PA	Palestinian Authority
PCBS	Palestinian Central Bureau of Statistics
PDL	Palestinian Disability Law
PHC	Primary Health Care
PLO	Palestinian Liberation Organisation
PNCTP	Palestinian National Cash Transfer Programme
PWDs	Persons with Disabilities
Sida	Swedish Agency for International Development Cooperation
SoP	State of Palestine
TVET	Technical and Vocational Education and Training
UN	United Nations
UNCRC	UN Convention on the Rights of the Child
UNESCO	UN Educational, Scientific and Cultural Organization
UNICEF	UN Children's Fund
UNRWA	UN Relief and Works Agency for Palestine Refugees in the Near East
WHO	World Health Organization

Contents

Tables

Figures

Boxes

Annexes

Executive summary

Children with disabilities (CWDs) are one of the most marginalised and excluded groups of children. Defined and judged by what they lack, rather than what they have, they experience widespread violations of their rights that result not from the intrinsic nature of disability but from the social exclusion that arises from it (UNICEF, 2013). Palestinian CWDs typically face a particularly dire situation, given the levels of cultural stigma directed at disability and the protracted conflict that surrounds them, which has devastated infrastructure, fractured the economy and overwhelmed service providers. This situation analysis and needs assessment, commissioned by UNICEF State of Palestine, adopts a lifecycle approach that captures difference at the individual, family and community levels. Paying attention to differences in age, gender, disability type and family characteristics, our study explores how Palestinian CWDs are marginalised and excluded, the obstacles they face in fulfilling their rights and what mechanisms might be put into place by the government, donors and non-governmental organisations (NGOs), communities and families to better support their development and their rights.

Mixed methods approach

ODI's mixed-methods approach combined an extensive literature review with primary quantitative and qualitative data in seven governorates in Gaza and the West Bank. The literature review, which pulled together national reports about disability in general and CWDs in particular, allowed us to assess the evidence base and design our research instruments to augment the known and address the unknown. Critically, as not all CWDs are registered with the Ministry of Social Development (MOSD), meaning existent reports likely have significant blind spots, our quantitative sample used both government and non-government databases and explicitly aimed to be inclusive of a wide variety of children. The 851 children (and/or their caregivers) who completed our survey comprised boys and girls, children of varying ages and in- and out-of-school children. It also included a wide variety of disability types.

Given that Palestinian culture tends to silence both children and those with disabilities, our qualitative work aimed to capture the unique voices of CWDs. To this end, we used a wide variety of adaptable participatory tools, recruited researchers with extensive experience working with CWDs and brought on board sign language interpreters to reach out to children with speech and hearing difficulties. While we acknowledge that, given limited resources, our research could not achieve full inclusivity, we believe it better captures the diversity of CWDs' experiences and needs than any research in Palestine thus far. In total, our qualitative sample included 62 key informants at local and national levels and individual and group interviews with 241 individuals who were either CWDs or siblings/caregivers of CWDs.

Once the fieldwork was completed—and after the preliminary analysis was available—ODI organised and facilitated a number of regional and central-level participatory workshops in each area (four in Gaza and three in the West Bank) in order to be able to undertake a causal and capacity gap analysis to further enrich research findings. These workshops engaged participants to give their perspective on findings and to generate additional information about the causes of poor access to services and support.

Policy, institutional and legal landscapes for Palestinian children with disabilities

While the Palestinian Disability Law dates to 1999, and ostensibly guarantees Palestinians with disabilities the same rights as those without disabilities, the disability-related legal framework is generally regarded as unspecific and weak. However, the sector strategic plans adopted by the Palestinian Authority since 2011 have begun to operationalise government responsibilities for meeting the rights of citizens with disability. For example, the Ministry of Education and Higher Education (MOEHE) is moving towards inclusive education and the Ministry of Health (MOH) provides all citizens with a disability with a comprehensive set of basic health care services. Critical to understanding both the successes and the failures of these plans is the fragmented way in which services are delivered in Palestine. Basic services are provided by both the government (for non-refugees) and the UN Relief and Works Agency for Palestine Refugees in the Near East (UNRWA) (for refugees), and disability-specific services, ranging from community-based rehabilitation (CBR) to special education, are most often offered by a crowded field of NGOs, usually under contract to the government and UNRWA.

Challenges facing children with disabilities and their caregivers

Given that our sample of CWDs was designed to be more representative than those of previous surveys, as it drew on both MOSD and NGO beneficiary lists, several sample characteristics represent key findings in their own right. For example, while MOSD registries listed less than 10% of CWDs as multiply disabled, we found that 41.8% of CWDs had more than one type of disability. We also found it was very common for families to have more than one PWD. Of all the households included in our study, 41.4% had at least one person with disability (PWD) in addition to the sampled CWD. Driven by high rates of consanguineous marriage and pollution, and made worse by poor antenatal, delivery and newborn care, in most cases (59.4%) the second PWD was another child. Families in Gaza were especially likely to have more than one CWD. As hinted at by our previous research on the Palestinian National Cash Transfer Programme (PNCTP) (Pereznieto et al. 20014), we also found families with CWDs were extremely likely to be poor. Nearly 40% had monthly incomes that were about half of the extreme poverty line.

Children's limited access to services

Both our quantitative and qualitative research found Palestinian CWDs were regularly denied access to the services guaranteed to them by law. For example, while most (53%) live in families that receive some cash assistance from MOSD—which is an artefact of the extreme poverty in which they live—very few receive any sort of disability-targeted assistance or even disability-related education from the ministry tasked with ensuring their well-being. Given the high costs associated with disability, for services and products ranging from transportation to nappies, families of CWDs almost universally reported a hard time making ends meet. Many of the children who required the most expensive support, such as wheelchairs and hearing aids, were simply forced to do without.

Families, especially those in the West Bank, also reported difficulty with accessing quality education for their CWDs—although children with vision and hearing impairments experience relatively less difficulty than children with other sorts of disabilities. Our research found that because the stigma directed at CWDs by their peers—and even their teachers—is pervasive, schools are poorly adapted, transportation to and from school is expensive and specialised learning materials are often not available, CWDs are quite likely to drop out of school before they have completed basic education. The average age at which children in our sample left school was only 11.85. Children with cognitive and multiple disabilities are particularly likely to be denied an education, as are girls once they reach puberty.

While all CWDs are putatively guaranteed free health insurance and access to a range of CBR services, our research also found access to health care was lacking. In addition to the fact that the basic package of available health services is not tailored to address the specific health care needs of those with disabilities, respondents reported that insurance did not cover medication, medical disposables or transport to and from medical appointments, and—critically—the coordination to facilitate follow-up and improve continuity of care is almost completely lacking. Furthermore, while our qualitative work found families were overall quite happy with the care their children received at more specialised institutions, children and caregivers said mainstream medical providers were at times even hostile to CWDs, particularly those born with disabilities rather than acquiring them 'heroically' in conflict.

Respondents reported that a significant factor in children's lack of access to services was the poorly adapted Palestinian environment. Not only are schools and health clinics often unaccommodating to those with special needs, but also specialised transport is essentially unavailable and private homes often un-adaptable, given over-crowding and large family sizes. This often means that home environments challenge even children with vision and hearing difficulties—not only those with mobility constraints.

Family and community life

Our research found that caring for CWDs was a burden born disproportionately by mothers. While fathers sometimes provide complementary care, Palestinian culture does not encourage the day-to-day involvement of fathers—especially with regard to physical care of children and especially girls. Indeed, several girls with disabilities reported that their fathers were actively hostile towards them. Furthermore, the overwhelming majority of mothers in our qualitative sample tended to work extremely long hours with little opportunity for respite. Often, the only 'reward' for their efforts is blame for producing a 'damaged' child. Gender-based violence is common, with both in-laws and husbands emotionally, verbally and physically abusing mothers, and in some cases mothers of CWDs are forced to accommodate co-wives as husbands seek to produce healthy children. Our qualitative research found circumstances were especially fraught for mothers who had more than one CWD.

Families' awareness of the rights and services to which their children are entitled is low. Nearly nine in 10, for example, were unaware there were disability-related forums and nearly half did not know their children were eligible for CBR. Our qualitative work found that in part this was because parents either found it difficult to admit that their children had a disability (most common for fathers) or had been unable to obtain an accurate diagnosis for their children (most common for children who appeared to be on the autism spectrum). It was compounded by many parents' beliefs that their children could be 'cured'. CWDs had relatively more awareness of their rights. However, given their negative experiences at school and with the health care system, they tended to not be only hesitant about demanding access but also adamant that they had fewer rights than their non-disabled peers and siblings.

Our research found the stigma surrounding disability in Palestine was both pervasive and strong. Outside of the home—and sometimes even within it—CWDs tend to encounter very little actual support. Indeed, they are far more likely to encounter hostility and abuse. Over a third of children in our quantitative research reported that they avoided doing things simply because they could not bear the attitudes of those in the community and only 5% said they could always rely on their friends. Our qualitative work found that, for those CWDs who were able to access programming, including schooling that provided support and fostered inclusivity the results could be transformational. It also, unfortunately, found such programming was largely unavailable—particularly for the children with the most severe disabilities, girls and those living in more remote areas.

Barriers to service uptake

As noted above, our gap analysis workshops allowed us to closely explore capacity shortcomings with key disability stakeholders. While responses were many and varied, in part depending on where the stakeholder worked and which services he/she provided, they largely converged around six main themes. Stakeholders were, for example, deeply concerned about the lack of any sort of comprehensive registration system for CWDs. Not only is there no national database to help coordinate and track needs and services, but also, even within sector, there is little attempt to ascertain the size and shape of the population needing service. For instance, government schools do not keep records of which children have disabilities. Stakeholders observed that this lack of coordination was made worse by the highly fragmented provision of disability-related services and agreed that lack of political will to address disability in a coherent, cohesive manner was ultimately more of an issue than budget constraints.

Workshop participants also noted insufficient capacity of adapted infrastructure and staff. Schools and health clinics are often not accessible; even when they are they are often only partially so, leaving children without access to toilets or computers labs. Furthermore, special education teachers are rare and regular classroom teachers do not often have any training or support to teach those with disabilities. Doctors and medical staff are similarly ill equipped. Most primary care providers are not trained to diagnose disability and few have an understanding of the service landscape that could be brought to bear to meet individual children's needs. Indeed, diagnostic capacity is low across sectors. Screenings to detect hearing and vision difficulties, for example, do not take place in infancy and early childhood, but when children enter Grade 1. There is no system in place to 'catch' children with more complex developmental issues such as autism.

Conclusions and recommendations

Our research finds Palestinian CWDs are highly vulnerable. They are very likely to be extremely poor, woefully under-supported to realise their rights to an appropriately tailored education and health care, have very few opportunities to participate in the social activities required for healthy development and poorly protected from abuse and exploitation. Both our quantitative and qualitative work, like the body of more narrowly targeted research that preceded it, finds CWDs' health, schooling and well-being outcomes are markedly worse than those of their siblings and peers without disabilities. Our research finds the families of CWDs—and especially their mothers—are also highly vulnerable. Given the dearth of disability-targeted services and the discriminatory social norms surrounding disability in Palestine, caregivers are not only largely left without respite, even when they have children with severe disabilities or several children with disabilities, but also often marginalised, isolated and abused, even by their own family members. Indeed, even the health care and educational providers meant to provide service sometimes perpetuate such stigma.

The vulnerabilities facing Palestinian CWDs are often overlapping, leaving some children at particular risk. For example, those living in rural areas have far less access to services, because of transportation deficits. Bedouin children appear particularly vulnerable. Not only are their families the least likely to have easy access to services, but also our research finds their communities have especially limited awareness about disability rights and the care needs of CWDs. Adolescent girls with disability are also at heightened risk of neglect and abuse. The restrictive gender norms of the broader community means they are often denied their right to an education and the extreme stigma directed at disability, which plays into notions of family honour and can prevent their siblings without disabilities from finding marriage partners, means they are often hidden even within the family. Risks are also multiplied where families have several CWDs, which we found to be quite common.

Our research finds the social assistance provided to CWDs is grossly inadequate. The PNCTP, laudable at reducing the depth of poverty on a national level, is far from adequate for families burdened by the extra costs of caring for CWDs since benefit levels are not sensitive to disability-related need. Similarly, health insurance, because it is targeted at mainstream populations and takes no account of disability-related health needs, is useful but insufficient. Families of CWDs must purchase nappies and medication out-of-pocket and children all too often must do without the wheelchairs and hearing aids they need—sometimes because their families literally cannot make ends meet and sometimes because their needs are deprioritised as they are seen as less valuable than their siblings without disabilities.

Access to basic social services is also limited, especially for children with severe or intellectual disabilities. Public schools are over-crowded, poorly adapted and largely lacking the specialised teachers and teaching materials that make inclusion possible. Bullying—even from teachers—appears to be rampant, and transportation to and from school very expensive. While our research found children in tailored educational settings generally have better psychosocial outcomes than those at mainstream schools, demand for such education far outstrips supply. Health care too falls short. Prevention efforts are negligible, which is glaring given the high incidence of disability owing to cousin-marriage and birth-injury, and early diagnosis and intervention are comparatively rare, particularly given the high number of children with congenital disabilities.

Critically, our research finds Palestinian CWDs effectively exist in a ‘no man’s land’. While MOSD is ostensibly tasked with overseeing the needs of all citizens with disabilities, it has no particular mandate to serve children, despite the cascading implications of neglect during childhood, and is poorly equipped to drive the cross-sector coordination CWDs need to realise their rights and meet their potential. Indeed, because of the extremely fragmented way in which disability services in Palestine are delivered, with the government and UNWRA sharing space with literally hundreds of NGOs, families seeking services are effectively abandoned to their own devices to map the service landscape and arrange interventions for their children. The end result is CWDs remain largely invisible.

Based on our research, we make the following recommendations to better address the needs of Palestinian CWDs and the families that care for them:

Quick wins

- Raise policy-makers and communities’ awareness of disability by revising the disability law, which is both dated and pejoratively named. The PDL should be revised to better align with international conventions to further progress towards the realisation of disability rights. Donor resources should be channelled towards improving the way information on disability and services for people with disabilities is communicated to service providers and communities.
- Involve PWDs and their families to ensure policies and programmes are better centred around users’ needs. Local governments and MOSD offices could take a lead role in involving families more actively in programme design, monitoring and evaluation, including through establishing feedback and participatory accountability mechanisms (e.g. citizen score card exercises).
- Operationalise the disability law by developing a national strategy for disability prevention, early detection and management. This should include adopting a common working definition of disability with clear indicators for monitoring prevalence, risk factors and outcomes. It should also translate the law into a concrete set of services and support for children with different types of disabilities. The MOSD should seek to revitalise the Coordinating Council for Disabilities and through it facilitate coordination between ministries and service providers to improve capacity, awareness and practice with regard to services for CWDs.
- Invest in strengthened data collection related to CWDs—and minimise both gaps and duplication—by strengthening the registration of CWDs. The government should make immediate efforts to build an accurate database of all children with developmental delays and disabilities, using Gaza’s area-wide survey as a model and drawing on the efforts of Save the Children with MOSD in the West Bank. Data collection should cover prevention efforts, prevalence by age and gender, location of different disability types and access to services.
- Strengthen the disability mandate within government by enhancing coordination. Implementation of the current law is poor in part because MOSD remains under-equipped to drive a cross-ministerial mandate. Disability-related concerns should be handled but at the supra-ministry level to facilitate greater coordination, setting and monitoring of minimum quality standards for all facilities that serve CWDs—including not only those providing disability-related services but also kindergartens, neonatal and delivery centres, etc. One option is to strengthen the mandate of and adequately resource the Coordinating Council for Disabilities so it can oversee and hold ministries accountable for their actions and services.
- Allocate consistent fiscal space for disability-related needs and make longer-term commitments to purchase services from NGOs and the private sector when they are not publicly available. This will allow the government to better meet its existent obligations to CWDs but also stabilise the budgets of non-governmental providers. More systematic information on budget resources will also make it possible to identify crucial funding gaps.
- Step up efforts to prevent disability. Our research suggests many childhood disabilities are preventable, as they result from consanguineous marriage and/or poor antenatal and neonatal health care. Prevention efforts should include investments in pre-marriage genetic testing—using religious leaders and institutions to promote increased uptake, as well as pre-conception counselling and better antenatal care. Efforts also need to be directed towards ensuring hospitals have

the equipment to prevent permanent disability (e.g. incubators) and trained health care professionals capable of following evidence-based guidelines and protocols on neonatal care.

- Improve early detection and intervention. Train the primary care physicians and nurses who come in contact with infants to assess child development using harmonised standards and instruments and to detect early signs of developmental delay and disability. This should include formal screening tests for all children at key developmental junctures in the first three years of life, as well as informal screens at every point of contact. Consistent referral systems should be built to ensure at-risk children are then seen in a timely manner by experts. Since the most vulnerable children often live in hard-to-reach areas, home visits should be made to those not seen in clinic to ensure their development is on track.
- Educate parents on early detection and support for CWDs. Use well-child visits (whether in clinics or at home) to educate parents on child development and the importance of positive parenting, as well as on how to provide supportive therapies at home. The MOH could support the development of a manual and training of trainers in which hospital staff develop resources for local health providers or social workers to share this knowledge with families of CWDs.
- Implement community- and facility-based early intervention programmes. The MOH working in coordination with the MOSD can play a major role through health and communication for development as well as early childhood development services to support families and practitioners in this area. Focusing on school-age children can often be too late and miss a critical opportunity for appropriate early intervention.
- Support pre-primary and primary teachers to recognise signs of developmental delay and disability and build systems that facilitate their coordination with health care providers and social workers. This can be supported by the case management system currently being developed by Save the Children with MOSD, but information on existing services needs to become available on a website and in printed form so social workers and local service providers—including teachers—can share it with families. A good model could be the UK National Health Service website, which provides clear information on early detection, support needed and services available, and could be adapted to the Palestinian context.
- Invest in community education to reduce stigma. Using both traditional (e.g. mosques) and new (e.g. TV) outreach channels, work to help the broader community understand disability is neither contagious nor a sign of dishonour and PWDs have needs, rights and dreams equal to their own. Consider supporting communication campaigns to talk about ability. Also importantly, incorporate citizenship education that includes sensitisation on equality across different dimensions—particularly disability—into school curricula so children from a young age not only become more supportive of their peers with disabilities but also contribute to changing perceptions in the community. MOEHE can spearhead this initiative. Further, given Palestine's obligations under the CRPD, it is important to improve advocacy with all relevant ministries on behalf of CWDs. The CRPD state party drafting process is currently underway; it is important to be able to show progress on key areas between state reports.

Medium-term goals

- Map and align service providers. Given the fractured nature of service provision in Palestine, with the government, a detailed mapping exercise will help identify gaps and overlaps and allow for a more rational allocation of resources. It will also serve as the backbone of future plans to establish a continuum of care for CWDs, who are very often lost between providers. This activity could be spearheaded by MOSD based on the mapping of services developed recently by Save the Children and some of the information presented in this report.
- Direct more human resources to disability to focus on the fact that CWDS are first and foremost children. Current social work caseloads are more than 10 times higher than they are in the UK (several hundred versus 15) and disability receives no particular focus. Furthermore, not only is there little coordination between schools, health care providers and social workers but also, given the fragmented, NGO-driven nature of the rehabilitation sector, the staff with whom CWDs interact on a regular basis are often trained only on very specific disabilities and not on the broader needs of children. The effort requires more resources, and would benefit from donor grants to train and resource social workers, though their recruitment and salaries should be included in the government's budget to guarantee sustainability over time.
- Improve and tailor social protection for CWDs. Disability can be expensive. Furthermore, stigma means that, even when families are provided resources, CWDs can be left out. We suggest CWDs be provided with categorical, rather than means-tested, support to ensure their disability-specific needs are met—possibly using the PNCTP as a delivery mechanism. This would particularly help the many families that have multiple children with disability or whose children have multiple disabilities. Cash should be provided to mothers until children turn 18—at which point it should be provided directly to the young adult with disability (where developmentally appropriate). We also suggest an in-

kind support package for CWDs that covers medication, transport, adapted educational materials, care and—for older CWDs—economic empowerment programming. Support must be provided in a continuous, predictable manner, CWDs with congenital disabilities must not be not ignored in favour of their peers disabled by accident or conflict and children with 'hidden' disabilities, such as autism or cognitive impairments, must be provided with benefits. In addition to categorical targeting based on disabilities, if families are also within poverty estimates of the PNCTP as per the public targeting, they should also receive the additional benefit to ensure they can meet their needs.

- Rethink the inclusive education approach. Expecting schools in Palestine to serve the needs of CWDs is currently unrealistic, but rather something to work towards in the medium and long term. The lack of resources available for specialised teachers, materials and infrastructure effectively condemns CWDs to poor learning outcomes—especially in primary and secondary schools. Dedicated schools may provide a good alternative in the short to medium term, especially for children with the most complex needs, and must include free transportation.
- Accelerate efforts to make inclusive education a positive experience. This must include efforts to make school buildings, classrooms, play spaces and WASH facilities fully accessible to CWDs but also expanding educational opportunities for teachers. MOEHE should include this as part of its plans to roll out the Inclusive Education Policy, with technical support from agencies such as UNESCO. Disability should also be integrated into school health programmes, with counsellors available to help address CWDs' psychosocial needs and awareness-raising programmes. In addition, citizenship education for all students should be directed at reducing the stigma and hostility all too often meted out to CWDs within the school environment.
- Step up efforts to provide tailored education for the youngest and oldest CWDs. Pre-primary education in Palestine is almost exclusively provided by the private and NGO sectors. The government needs to ensure private spaces, curricula and teaching methods are adapted for CWDs—and schools enrol CWDs and help them achieve good outcomes. Attention also needs to be directed to helping older CWDs transition from specialised schools to public schools and to providing TVET to help CWDs achieve an independent, more financially secure adulthood.
- Expand health insurance to meet the real needs of CWDs. Health legislation needs to be strengthened with respect to PWDs, including specific guidance for CWDs, in order to provide a strong mandate for service providers and to underpin a broader health insurance. We suggest health insurance meet all of CWDs medically related needs—including the provision and maintenance of all assistive technologies required for their optimal development as well as transport to and from medical appointments. This effort needs to be spearheaded by MOH in coordination with OPDs. The costs of disability-related health care must be shifted into annual budgets to eliminate the current system's unsustainable short-term approach. While there are budgetary constraints, the political will to prioritise this issue, plus improvements in the overall efficiency of the health sector budget, could help create fiscal space for such insurance.
- Increase the capacity of OPDs to diagnose and treat CWDs by providing training and exposure to state-of-the-art practices and consistent financial support. The first step is for MOSD to update and publish relevant guidelines, which it has identified as one of its priorities. Particular efforts should be made to learn from, and expand, the good practice models that offer families of CWDs a more holistic, 'one-stop' care experience.
- Adapt physical and information infrastructure for better accessibility. Beginning with providers with a disability mandate (e.g. MOSD, MOH, MOEHE, etc.), and moving on to the broader community, ensure spaces and information are accessible to PWDs. This will include a wide range of concrete adaptations, including ramps, pamphlets in Braille, sign language interpreters at hospitals, etc.
- Provide support for the families of CWDs. Invest, through local governments and CBR, in disability-specific support groups for mothers—possibly led by mothers with older CWDs who have a wealth of experience to share; engage with mothers and fathers—who are often the least supportive; and reach out to Bedouin communities, where stigma is especially high. We also recommend the state provide easily accessible web-based information and diagnostic tools, drawing on good practice from other countries and disability rights NGOs and offer families comprehensive information on child development and care tailored to account for disability—perhaps using social media such as What's App to send regular tips. This should include a comprehensive list of providers and services available, drawing on the mapping exercise above. We also recommend respite care for mothers/families caring for children with severe/multiple disabilities and or multiple children with disabilities, which could entail expanding existing residential services and subsidising community-based respite care options.
- Strengthen the social work network to provide better outreach to CWDs and their families, not only to facilitate access to social services but also to serve as a grievance/complaint mechanism when services are failing, to inform about cases of abuse and negligence and so families feel service providers can be held accountable.

- **Address the gender dimensions of disability and disability-related care.** Girls with disability, sisters of CWDs and mothers of CWDs often face gender-specific vulnerabilities. Adolescent girls with disabilities are especially unlikely to attend school or be allowed to socialise, given the risk of sexual assault and its associated threat to family honour, and those same girls—and their mothers—are at high risk of intra-familial violence. We suggest more community awareness through communication for development and home visiting by nurses, social workers and disability officers, who should be trained to identify those at risk and refer them to adequate services. Emergency shelters should take account of the needs of those dealing with disability. Currently, referral mechanisms in cases of child abuse are lacking, so these need to be developed—with the support of UNICEF—and take specific account of CWD needs.
- **Strengthen the role of international NGOs as champions for CWDs.** INGOs which have been actively engaging on the issue of disabilities - such as Save the Children and Diakonia - could play a key role in the donor/multilateral community, championing the needs and rights of CWDs. They could help coordinate the development of a fit-for-purpose database and management information system, assist with social protection system reforms and facilitate sharing of good practice learning across government agencies and NGOs. Donors could also reach out to the private sector and encourage greater investment in service provision for CWDs (e.g. building on the School for Blind in Hebron model).

1. Introduction

Children with disabilities (CWDs) are one of the most marginalised and excluded groups of children. Defined and judged by what they lack, rather than what they have, they experience widespread violations of their rights that result not from the intrinsic nature of disability but from limited access to supportive services and social exclusion (UNICEF, 2013a). Surrounded by those who do not understand difference, who fear contamination or who hold discriminatory views about the causes of disability—and all too often further restricted by poverty and physical environments that are not adapted to their needs—CWDs are typically forced to live on the margins. Palestinian CWDs face a particularly challenging situation, given that the protracted conflict that surrounds them has devastated infrastructure, fractured the economy and overwhelmed service providers.

This situation analysis and needs assessment, commissioned by the UN Children's Fund (UNICEF) State of Palestine, analyses how Palestinian CWDs are marginalised and excluded, the obstacles they face in fulfilling their rights and participating fully in society and what mechanisms the government, donors and non-governmental organisations (NGOs), communities and families might put in place to better support their development and the fulfilment of their rights. This means the study's objective is to assess gaps in current service provision capacity as well as to identify service providers that can meet their needs; and to identify existing and future policy and programmatic responses to address these bottlenecks and barriers. The terms of reference for the study is included in Annex 1 (available in a separate report online).

We adopt a lifecycle approach that captures difference at the individual, family and community levels. We explore how disability affects children differently depending on the nature and severity of the disability itself (physical, cognitive, etc.), gender, family characteristics (poverty, refugee status, etc.), children's chronological age, children's developmental stage (paying particular importance to transition points), the extent of family and community support and access to services. Seeking to ascertain the shape and determinants of bottlenecks and barriers to equitable outcomes for CWDs, our study combines quantitative survey data from seven governorates from Gaza and the West Bank with the voices of several hundred Palestinian CWDs and those who care for them to paint a more comprehensive and nuanced picture of their realities. The study is organised as follows:

- Section 2 presents the study's methodology.
- Section 3 provides an overview of existing data on Palestinian CWDs, drawing on Palestinian Central Bureau of Statistics (PCSB) data, including on prevalence and types of disability.
- Section 4 presents the policy, institutional and legal landscape for children with disabilities in Palestine.
- Section 5 explains what institutions are in charge of providing services to CWDs at the different levels. It presents some positive examples of organisations that are promoting rights fulfilment of CWDs in Palestine, analysing some of the lessons that can be learnt from these approaches as well as some of the challenges they face. The section also summarises findings from secondary sources about some of the main gaps in the implementation of these policies.
- Section 6 presents our primary quantitative and qualitative data collection and discusses the multiple challenges facing CWDs and their caregivers, and explores some of the common causes of those challenges as well as the specific vulnerabilities confronting particular cohorts of children.
- Section 7 discusses our findings from key informant interviews and stakeholder workshops regarding barriers and bottlenecks to service delivery.
- Lastly, in Section 8, the report lays out our key conclusions and recommendations emerging from our mixed-methods findings.

2. Methodology

Our mixed-methods approach combined an extensive literature review with both quantitative and qualitative data. The literature review, which pulled together national-level reports about disability in general and CWDs in particular, allowed us to ascertain the state of the evidence base and design our research instruments to augment the known and address the unknown. Critically, because not all CWDs are registered with the Ministry of Social Development (MOSD), meaning existent reports have likely had significant blind spots, our quantitative sample pulled from both government and non-government databases and was explicitly designed to be inclusive of a wide variety of disability. Furthermore, given that Palestinian culture tends to silence both children and those with disabilities, our work also aimed to capture the unique voices of CWDs and those of their caregivers. To this end, we used a wide variety of adaptable participatory tools, recruited researchers with extensive experience working with CWDs and brought on board sign language interpreters to reach out to children with speech and hearing difficulties. While, given limited resources, we acknowledge that our research was unable to achieve full inclusivity, we believe it captures the diversity of children's experiences and needs.

It should be noted at the outset that our study was not designed as a prevalence study and as such drew its sample from various rolls of children officially registered as having a disability. We acknowledge that those rolls may be more or less accurate due to difficulties in defining disability in child populations. While the Washington Group questions (see Box 1 below) are designed to facilitate the creation of internationally comparable data by providing standard definitions and methodologies regarding disability, their application to children is problematic. First, it far more difficult to define disability in children than in adults, as different children reach different milestones at different times and because children are in a constant state of flux as a result of development. Furthermore, because the types of disability in children can be different from those in adults—as they include more developmental and psychosocial problems—and because child disability is typically assessed by asking questions about functioning of parents or other adults, the Washington Group questions are not always appropriate for children. The Child Functioning Question Set, which is being developed in conjunction with UNICEF and asks different questions for children aged 2–4 and children aged 5–17, is generally considered more appropriate for children (Washington Group, n.d.). However, because Palestinian statistics are collected using the Washington Group questions, this report simply acknowledges the mismatch rather than attempting to address it.

Box 1: Washington Group questions

This short set of questions asks respondents to rate the amount of difficulty they have with six types of activities. Ratings are given on a four-point scale: no difficulty, some difficulty, a lot of difficulty and cannot do at all. The six questions are:

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

Source: http://www.cdc.gov/nchs/data/washington_group/wg_short_measure_on_disability.pdf

2.1 Quantitative data collection

As noted in Annex 2, because the data sources used to identify households with CWDs were slightly different between Gaza and the West Bank, the sample in each area was modified accordingly. The final sample, as shown in Table 1, of 851 households (451 from Gaza and 400 from the West Bank) was based on the minimum size needed to ensure robust data analysis. The sample included the entire Gaza Strip and three localities in the West Bank: Hebron, Jenin and the central area (Ramallah and Salfit). Within these areas the distribution of the sample was calculated to capture the necessary strata (disability type, locality, sex). The sampling parameters included a 95% confidence level and a 5% confidence interval. (Annex 3 presents the output of the calculated sample for each area) In Gaza, we oversampled children who had recently acquired disability as a result of the 2014 conflict.

Quantitative data were collected at the household level. In the case of children with physical disabilities (mobility, sight,

Table 1: Quantitative sample

Variable	Gaza	West Bank	SoP
Number of participating CWDs	451	400	851
Questionnaire completed by			
CWD	16.2%	2.0%	9.5%
CWD's caregiver	68.5%	66.3%	67.5%
Both CWD and their caregiver	15.3%	31.8%	23.0%
Gender of CWD[i]			
Male	54.1%	56.0%	55.0%
Female	45.9%	44.0%	45.0%
Place of residency			
Urban	74.5	23.3	50.4
Rural	4.0	72.5	36.2
Refugee camps	21.5	4.3	13.4
% of CWDs who are refugees	69.4%	19.8%	46.1%
Age of CWD in years[ii]			
Up to 5 years	12.9%	10.5%	11.8%
6–11 years	44.8%	39.0%	42.1%
12–14 years	19.1%	25.8%	22.2%
15–18 years	23.3%	24.8%	24.0%
Mean age	**10.73**	**11.17**	**10.94**
Type of disability (as characterised by the Washington Group questions)			
Mobility	38.6%	45.8%	42.0%
Vision	18.0%	20.8%	19.3%
Hearing	14.6%	14.5%	14.6%
Communication	36.8%	45.0%	40.7%
Intellectual and learning	25.1%	31.0%	27.8%
Remembering and concentrating	14.6%	35.8%	24.6%
Psychological and mental health	4.4%	10.0%	7.1%
Medical diseases	0.9%	3.0%	1.9%
CWD had more than one type of disability	31.7%	53.3%	41.8%
Parental characteristics			
Mothers of CWDs with secondary school and above	40.3%	36.6%	38.5%
Mothers of CWDs are unemployed	91.8%	92.8%	92.2%
Fathers of CWDs with secondary school and above	45.1	35.6	40.7
Fathers of CWDs are unemployed	25.3%	12.8%	19.4%
HH characteristics			
HH composed of only 1or 2 rooms	23.7%	26.8%	25.1%
HH size is more than 8 members	35.7%	17.5%	27.2%
Mean number of HH members	7.99	6.89	7.48
HH monthly income is less than NIS 1,000	52.8%	24.8%	39.6%

Note: SoP = State of Palestine.

speech or hearing), the enumerators interviewed consenting children aged 12–18 directly. About 10% of CWDs personally completed the entire survey (16.2% in Gaza and 2% in the West Bank). (Caregivers were asked to stay nearby so they could assist the child if required or to provide additional information when necessary.) In the case of cognitively disabled adolescents, who were not able to respond themselves, or in the case of children under the age of 12, the main care-giver responded to the survey. (Details about the characteristics of the research team, the training received and the data collection tools can be found in Annex 4.)

The sample included a good mix of pre-schoolers, school-aged children and adolescents. There is a higher number of children in the age group 6–11 because they have more exposure to injury as they begin to venture outside home while still young, they have a greater exposure to accidents at schools and, also, disabilities are discovered when the child approaches the age of four or five years. While both mothers and fathers in our sample had largely completed basic education (with fathers slightly more likely to have completed at least secondary school), mothers were overwhelmingly likely to be housewives—although fathers' unemployment rate in Gaza was also high, as a result of the blockade. As we discuss in greater detail later, families in our sample were also very likely to be extremely poor. Over 52% of families in Gaza, for example, lived on less than NIS 1,000/month, which is about half of the extreme poverty line[1] and is further exacerbated by the large household size of most CWDs.

2.1.1 Data management and quality control

We developed field manuals for the recruitment of participants and for data collection and management. The team also conducted validation visits and calls. All completed questionnaires for both territories were verified and cleaned in the field and at the central office using the same instructions. They were then coded and data were entered into a database using SPSS. Initial quantitative analysis was conducted immediately in order to further contextualise the qualitative fieldwork.

2.2 Qualitative data collection

Since a key goal of this study was to capture the voices of children with different forms of disabilities directly and provide them with a space to talk about their experiences with services and social support, as well as their experiences of social exclusion, we sought out CWDs with the capacity to share their views. In Gaza, qualitative data collection took place after the quantitative survey had been completed, which, as noted above, allowed us to finely contextualise our questions. In the West Bank, the quantitative and qualitative data collection took place in parallel—but with regularly scheduled time for discussion in order to address emerging issues and fine-tune the research instruments as needed.

2.2.1 Sample

Qualitative data were collected by interviewing a purposive and highly diverse sample of girls and boys and their families. Specifically, our sample included children with:

Table 2: Qualitative research interviewees

	Gaza	West Bank
Localities included	Northern Gaza, Gaza City, middle area, southern Gaza and refugee camps	Ramallah, Hebron, Jenin, the Jordan Valley in Area C and Bedouin communities in East Jerusalem
Key informant interviews with local-level stakeholders	12–3 in each of the 4 localities	6: 2 in each of 3 localities
Focus group discussions with CWDs (boys and girls with different types of disability—divided into younger (10-12) and older (14-17) adolescents)	7 groups of 9 children each	6 groups with 4–8 children each
Focus group discussions with parents of CWDs with cognitive disabilities	2 groups of 12 caregivers	1 group of 6 caregivers
Focus group discussions with siblings of CWDs	2 groups of 9 children (1 of sisters and 1 of brothers)	1 group of 5 sisters
Key informant interviews with high-level stakeholders, including ministry officials, NGOs, international organisations	19	25
Individual interviews with caregivers of CWD	15 (13 females and 2 males)	10 (8 females and 2 males)
Individual interviews with CWDs—and their caregivers—served by disability related services and not served by organisations	38 (23 with girls and 15 with boys)	8 (generally with their caregivers)

---

[1] Families earning less than NIS 2,293/month are regarded as living below the poverty line; those earning less than NIS 1,932/month are below the extreme poverty line (PCBS, 2015b).

- diverse types of disability: vision, hearing, speaking, mobility, memory and concentration, and cognitive
- diverse causes of disability: congenital, diseases, injury, abuse related, conflict related
- diverse demographics: age (between 12 and 17), place of residency (Gaza versus West Bank), educational status, refugee and non-refugee, service user and non-service user

In addition to interviewing CWDs themselves, we also interviewed their parents (or other caregivers) and their siblings, in order to assess care burdens and issues of stigma.

We also interviewed a wide variety of key informants at different levels. These included local NGO representatives, government service providers and community service providers—and also high-level stakeholders from organisations serving persons with disabilities (PWDs), policy-makers from relevant ministries (e.g. the Ministry of Education and Higher Education (MOEHE), MOSD and the Ministry of Health (MOH)), decision-makers and service providers in Gaza City and Ramallah and staff from international organisations, including UNICEF, working in relevant areas (e.g. health, education and social policy). The final list of key informants interviewed can be found in Annex 5.

2.2.2 Ethical considerations

Care was exercised to ensure the rights of participants were well protected. The study design and implementation followed UNICEF guidelines on the ethical participation of children. They also followed the Modified International Code of Ethics Principles (1975) known as the Declaration of Helsinki and permission was sought, and given, from Gaza's Helsinki Committee[2].

To protect the rights of the participants at the household and facility level, each participant received a complete, standardised explanation of the purpose and parameters of the research, and informed consent was sought.

Researchers were trained on techniques for conducting research with children and how to engage ethically with CWDs and their families. They were also trained on child protection.

2.2.3 Participatory workshops

Once the fieldwork was completed—and after the preliminary analysis was available—the Overseas Development Institute (ODI) organised and facilitated seven regional and central-level participatory workshops in each region (four in Gaza and three in the West Bank) in order to be able to undertake a causal and capacity gap analysis to further enrich research findings. These workshops aimed to engage participants so they could give their perspective on findings and to generate additional information about the causes of poor access to services and support. The ODI team, in consultation with UNICEF, invited a range of participants, including decision-makers and service providers (central and local levels), as well as representatives of active NGOs that advocate on behalf of CWDs and the international community and some particularly articulate children and their families.

2.3 Methodological caveats

We faced a number of challenges collecting data for this research. For example, the lack of a single, unified, consistent database on CWDs proved a real challenge and resulted in significant lost time—as did accessing families living more remote areas (see Box 2). This meant the sample for the quantitative component was taken from databases of organisations serving CWDs. The voices of those who are un-served or not registered were not adequately reflected in the study's quantitative component, though the qualitative part partially addressed this caveat.

Additionally, despite our explanations, some families found it hard to understand that this was a research project. They pressed field workers for financial support and asked for assistance in locating services. Field workers, particularly those collecting qualitative data, found this heart-breaking and needed considerable debriefing at the end of the day.

It must also be noted that disability is so complex and so diverse that it is preferable to study the different types of disabilities in greater depth in studies targeting specific disabilities. Furthermore, the design of research tools could have been strengthened by including CWDs in their design.

Lastly, data collected were reliant solely on self-reported responses. Self-reporting techniques and responses may have been influenced by personality, norms, stigma, emotion and time. We noticed sometimes people tried to avoid mentioning issues related to the cause of disability. For example, they rarely referred to consanguineous marriage, but too often cited oxygen deprivation at the time of delivery. It would be ideal if, in further studies, some of the information on CWDs could be verified or complemented through medical records.

---

[2] The Helsinki Committee in Gaza, formed in the 1980s, is the only available health research ethical body in the country. There is no other body that covers both the West Bank and Gaza. Many researchers from the West Bank seek approval from the Helsinki Committee in Gaza.

Box 2: A note on disability registration in Palestine

A key observation from our research is the need for better disability registration systems. MOSD keeps records of the children it serves, as do NGOs, but there is no single source that includes all CWDs. Data files even within organisations are also often incomplete. For example, they often fail to note the age of the child or the type of disability she/he has and, in some cases, still list children who have died. Addresses are also often wrong. Databases also contain a large number of 'false positives'. In Gaza, for example, 37 CWDs identified by MOSD had no disability according to their families. The Red Crescent Society conducted a household survey on disability in Gaza in 2012 with data hosted at MOSD; those who acquired or were born with a disability after that are not included in MOSD's database.

Additionally, while MOSD and NGO databases categorise children solely by their main disability, we discovered during data collection that many children had multiple disabilities. When the study universe was populated, for example, only 9% of children were identified as having multiple disabilities. During household visits, however, we found that the prevalence of multiple disabilities was especially high in the West Bank (53.3%), particularly in Jenin (60.8%) and Salfit (55.7%). This has tremendous implications for how resources should be allocated—as does the distribution of households with multiple PWDs.

[i] *As Table 1 shows, our sample included slightly more boys than girls (55% versus 45%)—which reflects the fact that boys are more likely to have disabilities than girls in Palestine. This difference is in line with the literature (e.g. Australian Institute of Health and Welfare, 2008), which indicates that, on 33 major birth defects, for many conditions, more males than females were reported to have a congenital anomaly (59% versus 41%). Genetically, females are more protected from the X-linked recessive genetic diseases than boys; they can get an X-linked recessive disorder but this is very rare. Also, because of the stigma, families register male CWDs more than they do females. As such, the difference could be attributed to better identification and documentation of male cases than female cases. Another culturally related point is that boys have greater exposure to the unsafe environment at the street, child labour and risky work than girls, thus they are more exposed to injuries and accidents. While girls stay at home, boys go outside more and are exposed to, for example, road traffic accidents and risky work. The leading cause of death among children under five and older in Palestine is accidents.*

[ii] *We chose to disaggregate adolescence in order to identify emergent gender discrepancies.*

3. Overview of the current status of disability in Palestine

This section sets the scene for the primary data analysis by providing an overview of the situation of PWDs in Palestine based on existing literature and data sources, with a particular emphasis on what is known about CWDs. Most of the statistics draw on the PCSB 2011 disability survey (PCBS, 2012), as well as other PCSB data sources, but where possible we have also included data compiled by other agencies working in the field. Most of the data provided by these sources refer to adults with disabilities (aged 18 or over); only some general statistics on prevalence of disability and educational status/schooling are available for children (aged 0–17). Some—but not the majority—of the data are sex-disaggregated.

The most recent Palestine-wide disability survey, conducted in 2011 using the Washington Group's definitions, found a national prevalence of 2.7% using the 'narrow' definition (a lot of difficulty or cannot at all) and a prevalence of 6.9% using the 'wide' definition (also including some difficulty). In the West Bank and using the narrow definition, disability was most prevalent in Jenin governorate, where 4.1% of all individuals have a disability; this is followed by Hebron with 3.6%. In the Gaza Strip, the highest prevalence was reported in Gaza governorate, with 2.5%, followed by North Gaza, Rafah and Deir Al Balah governorates, with 2.4% each (PCBS, 2012: 19).

The World Bank (2016) notes that these rates are likely to be underestimates. Not only are there cultural and socio-political reasons the underreporting of disability in Palestine, but also there are issues with data collection methodologies and corruption within the disability classification and certification process (p.19). Furthermore, while there was a 2012 comprehensive census of PWDs (including children) in Gaza, the West Bank has never undertaken such data collection.

Critically, from the perspective of this research, the 2011 disability survey was *not* aimed at establishing prevalence of disability in the child population. Because it used the adult-oriented Washington Group questions it likely excluded children with developmental and psychosocial disabilities. The child disability prevalence rate it established—1.5%—is widely considered an underestimate. The survey found child disability was more common in the West Bank than in Gaza (1.6% versus 1.4%) and among boys than girls (1.8% and 1.3 %, respectively) (PCBS, 2012: 35).

Mobility-related impairments are the most common type of disability, making up nearly half of all disability cases in both Gaza and the West Bank. Learning disabilities are the second most common type, accounting for 24.7% of all cases (23.6% in the West Bank and 26.7% in Gaza) (PCBS, 2012: 20). Among individuals under 18 years, communication (speech) disability is the most prevalent type of disability, at 24.4% of all cases, followed by mobility-related impairments at 19.3% (ibid.: 23).

Among the adult population, disabilities are most often the result of illness (37.4%), ageing (13.5%) or congenital conditions (9.6%) (PCBS, 2012: 48). Among children, disabilities are most frequently congenital (29.6%), the result of illness (24%), birth-injury related (15%) or hereditary (12.2%). A small proportion were the result of accidents (5.8%), Israeli actions (1.6%), physical or psychological abuse (1.4%) or post-traumatic stress (0.4%) (PCBS, 2012 35). It should be noted that these survey figures are subject to a considerable margin of error and that other estimates suggest Israeli actions cause 7.6% of all mental health disabilities, 4.6% of mobility disabilities and 4.2% of vision disabilities (PCBS, 2012: 49–52).

PWDs are limited in terms of daily living tasks—in part because their homes are poorly adapted. Findings of the 2011 disability survey indicate that 34.2% of PWDs cannot perform activities of daily living (ADL) (PCBS and MOSD, 2011). The same source indicates that 37.4% of PWDs face difficulties in bathing and washing (especially among females), dressing by themselves (29%) and using the toilet (25.9%) (ibid.). Females also face more difficulties than males in performing ADL. Also, younger CWDs face more difficulties than older ones, and children with multiple disabilities and with mobility-related disability face more difficulties than other groups. In terms of home adaptation, the 2011 PCBS and MOSD report shows that 24.6% of PWDs stated that they needed a ramp at home, 33.7% toilet adaptation, 16.9% kitchen adaptation and 15.4% an elevator in their home.

PWDs have limited access to transportation. The PCBS and MOSD (2011) disability study found that 76.4% could not use public transportation. It also found that 34.7% of individuals with mobility-related disabilities stated that they needed adaptations to transportation in order to reach work, compared with 31.7% of individuals with vision-related disabilities, 20.0% of persons with mental health-related disabilities, 17.6% of individuals with hearing impairment and 12.5% for individuals with communication disabilities.

PWDs' utilisation of medical and rehabilitation care is low: only 7.7% of PWDs have received medical or rehabilitation care, while 83% of respondents would like to receive care (Zaqout and Abu-Hamad, 2013). It is worth noting that mental health institutions providing psychosocial services in Palestine assume PWDs should be served by disability-related organisations (Abu-Hamad et al., 2015).

Palestinian PWDs' educational outcomes are limited. The results of a 2013 study conducted by Zaqout and Abu-Hamad on disabilities covering all age groups in Gaza showed that 31.5% of PWDs had never attended school and that 22.0% had participated but not completed their schooling. The 2011 PCBS and MOSD report shows that only 22.7% of PWDs over 15 years enrolled and graduated, 33.8% enrolled and dropped out and 37.6% were never enrolled.

Both prevalence of disability and the challenges facing PWDs in Palestine have been exacerbated by the ongoing Israeli occupation. In Gaza in 2009 as many as half of the 5,000 Palestinians injured during the first three weeks of the conflict were found to be at risk of permanent impairment (Sida, 2014). The 2012 and 2014 Israeli offensives in Gaza further increased the number of people with disabilities and intensified their vulnerability. Of the 11,200 Palestinians, including 3,400 children, who were injured during the 2014 conflict, 10% suffered permanent disability (OCHA, 2015). The vulnerabilities experienced by Palestinian PWDs are further aggravated by access restrictions and the blockade: they prevent rehabilitation workers from providing early intervention and lead to shortages in medical supplies and assistive devices, as well as scarcity in fuel and electricity needed to operate these devices (Sida, 2014).

4. Policy, institutional and legal landscapes for Palestinian children with disabilities

In order to better understand the situation of CWDs in Palestine, both in terms of the prevalence of different types of disabilities in girls and boys of different age groups but also with respect to the obstacles they face in fulfilling their rights, it is essential to first have a clear picture of the policy, institutional and legal mechanisms that are currently in place. This will then make it possible to analyse the extent to which CWD are able to access and be served by these, and if they are not, to explore the barriers they face in this regard. As such, this section lays out the Palestinian legal, institutional and policy framework for PWDs and CWDs in particular, and then provides an initial overview from secondary sources about some of the barriers preventing the adequate implementation of these laws and policies.

Palestinian laws unequivocally prohibit discrimination against persons with disabilities (MOSD, 2012a):

- The 1999 Palestinian Disability Law (PDL, or Law Number 4 Concerning the Rights of PWDs) provides for the right of PWDs to equality before the law and to non-discrimination, as well as to housing, health care and rehabilitation, travel and work and participation in cultural life. The law identifies MOSD[3] as the government agency tasked with fulfilling these commitments and requires that the ministry coordinate with all relevant and competent bodies to secure the welfare and rehabilitation of PWDs (PLO/PA, 1999). MOSD adopted executive bylaws for the law's enforcement in 2004.
- Article 9 of the 2003 Amended Basic Law provides for the right of all Palestinians to equality before the law and judiciary 'without distinction based on race, sex, colour, religion, political views, or disability'. Article 22 commits the Palestinian Government to providing education services, health and social insurance to vulnerable groups including PWDs.
- Article 3 of the 2004 Palestinian Child Law also prohibits discrimination and provides for CWDs' rights in terms of equal and equitable access to services and to a voice within families and society, as well as their protection as a group at risk of exploitation and abuse.

Palestinian law, however, has many gaps that all too often leave CWDs without access to the rights. For example, the PDL does not explicitly reference children and contains only limited provisions on the responsibilities and accountability of specific institutions (MOSD, 2012b). Furthermore, laws tend to ignore the social aspects of disability in favour of a narrowly medical definition (PCBS, 2015: 22). An ongoing UN Partnership Programme to Promote the Rights of PWDs involving various UN agencies and Palestinian line ministries is seeking to review and revise the PDL to ensure its alignment with international standards, not least those articulated by the CPRD, but this has not yet borne fruit (see Box 3).

It is only since 2011, when the Palestinian Authority (PA) began adopting a number of strategies targeting disability, that real impetus can be observed in translating the PDL into sector-specific strategies, policies and programmes (World Bank, 2016: 21–2). For example:

- The Palestinian National Development Plan for 2014–16 includes among its policy priorities references to improving the social protection, security, access to justice and opportunities of persons with disabilities. It commits itself to providing 'sustainable, high quality,

---

[3] MOSA was renamed as MOSD in 2016. The renaming of the ministry took place after the data collection phase of the study.

Box 3: International frameworks addressing children with disabilities

The UN Convention on the Rights of the Child (UNCRC) makes it clear that CWDs are entitled to all the rights guaranteed to children without disability. For example, Article 2 of the UNCRC specifies that children should never be discriminated against on the grounds of disability and Article 23 emphasises the rights and freedoms of CWDs to maximal independence and enjoyment of life.

In addition, CWDs are specifically cited in the Convention on the Rights of Persons with Disabilities (CRPD). Noting that CWDs have rights and freedoms equal to children without disabilities, the CRPD calls for measures to protect CWDs' rights to education, family life, freedom from violence, opportunities for play, access to justice, birth registration and protection from forced sterilisation.

rights-based, gender-sensitive social services' and specifically lists PWDs among its intended beneficiaries.

- The National Strategic Plan for the Disability Sector, developed under MOSD and adopted in 2012, deals with issues of rights, poverty, policies and access. Key policy directions set out include the 'provision of all basic and vital services for PWD as a right to enjoy a decent living'. However, consultations with the High Council on Disability in 2014 revealed that, at that point, no major steps towards its implementation had been taken, largely owing to the fragile security situation and limited financial resources (Development Studies Centre, 2012). MOSD has a directorate in charge of operationalising, supporting and coordinating actions to advance the PDL and the National Strategic Plan, but its coordinating capacity is weak and it has insufficient resources. This is further discussed in Section 7.
- MOEHE's Education Development Strategic Plan (EDSP) 2014–19 articulates key disability-related objectives, including the development of national policy for inclusive education, professional development in the area of special education and other forms of expanded support to increase and improve the integration of students with disabilities in public schools. While MOEHE introduced its Inclusive Education Programme in 1997, this has lacked mechanisms to ensure accountability and its full implementation. The ministry recently finalised its Inclusive Education Policy, which addresses these shortcomings through a coherent policy that seeks to eliminate environmental, attitudinal and resource barriers to CWDs' education access through a twin-track approach that combines systemic changes with individualised support. For example, the policy prioritises CWDs' access to school infrastructure, giving MOEHE responsibility for both ensuring new buildings are fully accessible and retrofitting older buildings. Priority is also given to the development of inclusion-oriented human resources (by offering capacity-building opportunities for teachers), participatory development of inclusive education settings (by having students with disabilities represented on school health committees and student unions) and opportunities for lifelong learning opportunities from early childhood to vocational, informal and adult education. The plan is for the EDSP to be implemented through a new service delivery structure comprised of seven programmes—with six each addressing a different stage of education and the seventh seeking to introduce results-based and accountability management at ministry level (MOEHE, 2014, 2015)[4].
- MOH's **National Health Strategy 2014–16** states that policies will centre on the provision of a comprehensive network of health care services that ensures safe and affordable access to a variety of services, with a focus on vulnerable groups including PWDs. This does not represent the introduction of a holistic approach to health and rehabilitation services for PWDs but nevertheless represents a significant step forward for CWDs, given that it calls for the development of screening and early detection programmes for disabilities—including learning disabilities—and the development and integration into primary health care (PHC) services of community mental health services. The strategy's aims will be implemented through the development of a National Health Service coverage plan, which will focus on the availability of appropriate infrastructure, with the strategy highlighting the criteria of accessibility to PWDs (World Bank, 2016). It is not clear whether this plan includes a comprehensive strategy for the provision and maintenance of assistive devices for PWDs, which are of crucial importance for their better integration into everyday life.

- Neither the **Ministry of Labour's** (MOL's) current strategic plan (2014–16) nor its **National Strategy for Employment** and its **Technical and Vocational Education and Training** (TVET) **Strategy** explicitly reference PWDs. Clear strategies or policies for the economic empowerment and inclusion of PWDs in the labour market are conspicuously absent, despite more

---

[4] Other relevant policies are the National Plan for the Educational Inclusion of Students with Impaired Vision 2014–19 and the 2012 Policy for Safe and Equitable Access to Quality Education, which identified access gaps for PWD (most notably lack of awareness of education rights, inadequate transport and poor early detection) prior to the development of the more recent EDSP and Inclusive Education Policy.

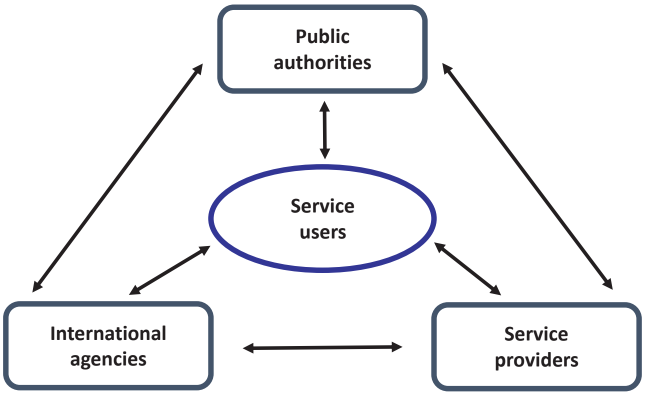
anecdotal suggestions that ministries themselves hire PWDs in order to build visibility.

Implementation of the action plans associated with each of these strategies tends to be hampered by the country's inadequate database, limited financial resources and protracted conflict—as Section 7 explores further. However, it is important to first explain how services for CWDs in Palestine are organised and delivered with the aim of rolling out the policies and laws outlined above, in order to be able later to analyse barriers and bottlenecks to this delivery. The next section draws attention to the way different responsibilities are shared among service providers at the national, intermediate and local levels, highlighting challenges related to existing referral systems. The different types of services are categorised in accordance with Articles 24, 25 and 26 of the UN CRPD: education, health care, habilitation and rehabilitation.

5. Services provided to children with disabilities in Palestine

While there are many actors involved in service provision processes, there are three main categories of actors central to our analysis because of the major roles they assume in providing disability services: public authorities, service providers and international agencies. Public authorities refer to such entities as national ministries, local governorate ministry bodies and municipalities. Service providers include NGOs and the private sector. Service users are children with disabilities and their families as well as the organisations for persons with disability (OPDs) that represent them. Finally, international agencies are international organisations and relevant UN agencies. These different actors operate at three key levels: national, intermediate and local, which we outline in more detail below.

Figure 1: The main providers of disability services in Palestine



The key services for CWDs provided at the national level are health and education, with some social protection support through the Palestinian National Cash Transfer Programme (PNCTP) and health insurance for those with disabilities. Most of the other needed services are supposed to be delivered at the intermediary and local levels, though not all are delivered as they should. Crucially, because of both the ongoing conflict with Israel and the intra-Palestinian divisions, services in Gaza often fall short of the mark.

Health and rehabilitation services for CWDs, like the health services provided to the broader population, are provided by different stakeholders in both the West Bank and Gaza. MOH is responsible for providing general health services, including sexual and reproductive health care, to non-refugees, while the UN Relief and Works Agency for Palestine Refugees in the Near East (UNRWA) provides equivalent services to Palestinian refugees, mostly in Gaza. Furthermore, while MOH provides health care services in hospitals located in central cities, large numbers of private hospitals and NGOs, such as the Palestinian Red Crescent, provide specialised medical care alongside government hospitals. Under the 1999 PDL, all PWDs are entitled to free government health insurance, which can be accessed through two avenues—the PNCTP or a disability certificate provided by the General Union for the Disabled—as well as assistive devices with no more than a 25% co-pay. Thus, in general, government hospitals offer services free of charge if the patient is medically insured under the MOH medical insurance scheme. NGOs and private sector suppliers require out-of-pocket payments unless the patient is covered by private medical insurance or referred by the government for treatment.

Despite intent, however, there are still a considerable number of PWDs without health insurance, primarily owing to the use of a narrow medical definition that excludes those with less severe disabilities. Furthermore, a 2006 health insurance regulation excluded auxiliary medical, assistive and learning aids from the list of products supplied by the health system and, because most of the hospitals in Palestine do not have the technical capacity to perform advanced medical procedures such as cochlear implants (World Bank, 2016: 34–6), many procedures that would improve the lives of CWDs are available only out-of-pocket out-of-country.

Specialised rehabilitation services are provided mainly by national NGOs that are highly qualified and equipped with superior quality medical and rehabilitation facilities.

Their services are covered either privately by patients or through referral by MOH or UNRWA. There are three main rehabilitation centres in the West Bank and three in Gaza. In the West Bank, these centres are Bethlehem Arab Society for Rehabilitation (BASR), Princess Basma Rehabilitation Centre and Abu Raya Rehabilitation Centre. In Gaza, they are Al-Wafa Medical Rehabilitation Centre, Atfaluna Organisation and Al Amal Centre. The main centres provide both in- and out-patient services for occupational and physiotherapy, speech therapy, assistive devices and technical aids. They are situated in central cities and are not easily accessible for families living in remote areas. Except for Princess Basma Rehabilitation Centre, which is mainly for CWDs, the rest of them provide services for adults and children equally.

UNRWA also has a rehabilitation programme in both the West Bank and Gaza for providing rehabilitation services (e.g. assistive devices, home modification, speech and occupational therapy, physiotherapy, home modifications, community- and home-based care) to refugees with disabilities, implemented primarily through NGO-run community-based rehabilitation (CBR) centres and outreach activities, although the agency does have the capacity to deliver some services independently in Gaza. UNRWA usually has waiting lists and is not always able to cover costs entirely, particularly for technical aids and assistive devices (World Bank, 2016: 34–6).

In addition to its poverty-related cash transfer scheme (the PNCTP), the central office of MOSD supports medical care for poor households by providing MOH medical insurance free of charge, and—in rare situations—some money to cover specialised medical support under its emergency support fund.

Within the education sector, opportunities for CWDs vary according to the child's type of disability, his or her family's economic situation and their residence. Through its General Directorate of Special Education, MOEHE is aiming to provide equal opportunities to all school-age CWDs—that is, it is promoting inclusive education. The coverage of the ministry's services is, however, still limited to a small number of schools, and the majority of CWDs who access the formal public education system are those with physical—rather than cognitive—disabilities, which in practice means only those children with mild to moderate physical disabilities (PCBS, 2015c). In addition to providing extra reading, writing and mathematics support for CWDs, the government has three resource centres, in Gaza, Ramallah and South Hebron, staffed by multidisciplinary teams (e.g. social workers, speech therapists, physiotherapists, special education specialists). MOEHE also requires that all new schools be built to accommodate CWDs, and has launched—with nine UN agencies—an Education for All (EFA) package that seeks to ensure the right to quality education for all Palestinian children by improving teacher training. Although mainstreaming and inclusion is the ultimate aim, MOEHE recognises that, in the short and medium term, this is not always possible, so it also supports 15 non-governmental special schools that target children with Down syndrome and visual or hearing impairments.

In the West Bank, MOSD operates two schools for children with visual disabilities (Global Campaign for Education/Handicap International, 2015; World Bank, 2016: 25–7) and also provides some children with needed devices and braille study materials. In addition, about 188 resource rooms are situated in elementary schools across the West Bank in order to provide individual academic and therapy support for children with learning difficulties and those with mild intellectual disabilities. However, the number of the available rooms is very small when situated against a total of 1,800 schools, and in many situations the existing rooms are not well functioning owing to a shortage of experienced staff.

UNRWA, which provides education services for Palestinian refugees, runs 8% of the schools in the West Bank and 50% in Gaza[5]. It launched an Inclusive Education Policy in its schools in 2013 and has since implemented a 14-month training programme on inclusive education for teaching staff but has not collected data on the number of CWDs enrolled in its schools (World Bank, 2016: 27). Furthermore, although UNRWA supports CWDs' access to rehabilitation services and assistive devices through partnering with NGOs, they—like MOEHE—are experiencing a shortage of qualified teachers and are facing challenges in terms of meeting all the needs of CWDs.

5.2 Services provided at the intermediate level

The types of services that should be available at the intermediary level are rehabilitation services, non-formal education (NFE) and TVET, provision of technical aids, education, shelter institutions for severe disabilities, home adaptations, diagnosis and treatment. Not all of these services, however, are provided consistently throughout the Palestinian territory. While the UNRWA, MOH, and MOE provide some intermediate-level services—through primary care centres and schools, for example—NGOs provide the vast majority of services at this level. As very few are supervised/monitored by the related ministries, and almost all are donor-dependent and often running only short-term projects, it is difficult to assess the scope and coverage of services.

With respect to health services, the crowded NGO sector dominates rehabilitation, providing more than 90% of all services (PCBS, 2015: 40; World Bank, 2016, 34–6). A recent World Bank mapping exercise identified

---

[5] In 2010/11, there were 2,653 schools in the Palestinian territory. Of these, 74.4% were public schools, 12.8% were UNRWA schools and 13% private schools (MOEHE, 2011).

55 NGOs in the West Bank and 33 NGOs in Gaza, mostly small, which provide health-related rehabilitation services (ibid.). However, while contracts between MOH and these NGOs are long term, an official referral system is lacking so the *de facto* system is opaque, inaccessible and narrow in scope. The larger NGO-operated rehabilitation centres in Palestine—which include BASR, the Palestinian Red Crescent Society and Abu Raya Rehabilitation Centre in the West Bank and Al-Wafa Medical Rehabilitation Centre, Al-Amal Centre and the Artificial Limbs and Polio Centre in Gaza, as well as Princess Basma Rehabilitation Centre in Jerusalem—have worked to introduce a social rights-based approach through CBR. An evaluation of a CBR programme funded by Diakonia/the Norwegian Association of the Disabled (NAD) found that the programme had empowered individuals and parents, improved basic daily living skills and coping mechanisms, heightened emotional well-being and self-esteem, reduced stigma and isolation and increased social inclusion, with PWDs more visible and respected within their families (Nilsson and Quttina, 2005; Diakonia/NAD, 2011).

In case of education services, there are nearly two dozen NGOs delivering a variety of education programmes for children with various types of disabilities—including 12 special schools for hearing impaired students and 11 for students with visual impairments. While NGOs reported having more technical expertise with disability than government-run schools (World Bank, 2016), and a 2011 study found that over half of visually impaired students preferred NGO-run schools to government schools because the latter were so poorly adapted to their needs, it should be noted that coordination between the government and NGOs is limited. NGO education services do not share common quality standards, and NGO schools often charge user fees of $25–50/month, which, combined with the high cost of transport, renders them financially out of reach for the vast majority of families (ibid.: 29–33).

In Gaza there are two residential programmes run by religious organisations. Sister Delphenia is affiliated with the Christian church and serves 50 children. Mabaret Palestine Society is an Islamic organisation and serves about 100 children.

5.3 Services provided at the local level

During the past two decades, the disability sector in Palestine has begun to depart from the traditional ways of interacting with PWDs, who used to be seen as the object of charity and religious obligation, to a newer model based on equal rights and opportunities. While basic health care centres provide some care to PWDs, most specialised services are provided through CBR programmes.

PHC centres, which provide both diagnostic and referral services to PWDs, have increased in number by 65% since 1994 (from 454 to 750 centres). They are offered by various providers across Gaza and West Bank, including MOH—which operates over 60% of all PHC centres, NGOs, UNRWA, Palestinian Red Crescent Society and Palestinian Medical Relief Society. In some cases, depending on local initiative and funding availability, municipalities have worked to make PHC centres more accessible, by building ramps for example, but in many cases they remain all but unusable to PWDs.

CBR programmes, which are provided by NGOs, are also available at the local level. CBR programming was established in the early 1990's as 'a strategy within general community development for rehabilitation, equalization of opportunities, and social inclusion of all people with disabilities implemented through the combined efforts of people with disabilities themselves, their families and communities, and the appropriate health, education, vocational, and social services' (ILO et al., 2004). In Palestine, CBR services have evolved in the past few years beyond simple medical and rehabilitation services. While still in the early stages, they now equally address other aspects in the CBR matrix as endorsed by the World Health Organization (WHO) in 2010—such as social inclusion, empowerment and livelihood options.

The main CBR programme covers four regions and operates under different NGOs:

- CBR Central, covering Ramallah and Jericho, is now in the process of acquiring independent status as an NGO.
- CBR North (Jenin and Nablus) operates under the umbrella of the Palestinian Medical Relief Society.
- CBR South (Bethlehem and Hebron) operates though the Bethlehem Arab Society.
- The Gaza Programme is operated through the Palestinian Medical Relief Society.

There are concerns about the effectiveness of having different CBR programmes, given the poor coordination among them and inadequate referral mechanisms to other service providers. Still, most respondents interviewed—including practitioners and donors—were very supportive of the CBR as one of the most effective and useful approaches, so it is one that needs resources and support so it can better serve its important functions.

Besides the main CBR programme actors mentioned above, other parallel programmes are run either by UNRWA (for refugees) or by other NGOs, such as the Health Work Committees and Qader for Community Development. Coordination between programmes is limited and, while the CBR programme covers 45% of all local communities in Palestine, the total number of CWDs served is comparatively limited. In 2015, only 1,412 people were enrolled (Diakonia, 2015).

Outreach services are also offered by some service providers that aim to reach PWDs who are living in remote areas.

5.3.1 Role of organisations for persons with disabilities (OPDs) in promoting service access for CWDs

OPDs, particularly at the local level, do not yet meet their potential as civil society actors in promoting the inclusion of PWDs, especially in development processes—for two main reasons. First, they have very limited participation within existing monitoring mechanisms, such as the Higher Council of Disabilities. Second, many of them still need to advance their skills and knowledge in monitoring disability rights and services. That said, at the national level, a number of OPDs—including the General Union for Persons with Disabilities, Stars of Hope Society, Aswat Society, the Deaf Union and Al Basera—are advocating for inclusive policies and services. While most focus mainly on capacity-building, awareness and advocacy, a handful, such as the Deaf Union, provide direct services for CWDs.

5.4 The role of international organisations and UN agencies in supporting services for children with disabilities

International organisations, including donors and UN agencies, play a major role in influencing the availability and quality of services offered to Palestinian CWDs. While they primarily provide technical and/or financial support to relevant ministries and NGO service providers, in some cases—mainly humanitarian but sometimes also in the case of child abuse and gender-based violence (GBV) (see Box 4)—they also directly implement services in partnership with national and local-level actors. Involvement by international organisations on disabilities includes the European Union's engagement with MOSD to improve social service for persons with disabilities at regional directorate levels; UNICEF's engagement with MOSD to strengthen child sensitive social protection, the promotion of the rights of CWDs and, in the case of health, promoting early detection; the UN Educational, Scientific and Cultural Organization (UNESCO) has been working closely with MOEHE to develop standards for inclusive education, and WHO has provided support to MOH on issues related to disability assessment and services. Coordination among UN agencies on work on disabilities has been weak, partially reflecting the weak coordination between government agencies in this area. The new push by MOSD, working closely with the EU and UNICEF, to promote interagency coordination may improve the situation going forward, and will likely result in more strategic and effective work in this area.

In the case of education, both UNICEF and UNESCO, along with a number of international NGOs—most notably Terres des Hommes, Save the Children and Diakonia/NAD—support inclusive education through financial and technical support to MOEHE planning, implementation and monitoring. They also provide direct support to public and NGO-operated schools (World Bank, 2016: 28–9).

Save the Children and Diakonia are two particularly key players who have been working to support the government to improve institutions, systems and services for CWDs.

5.4.1 Diakonia

Diakonia has been supporting disability work in Palestine since the early 1990s, focusing mainly on establishing and supporting the CBR programme. It also supports some of the national specialised rehabilitation centres. Leading up to the launch of the National Strategic Plan on Disability in Palestine in 2012, Diakonia actively worked with MOSD on its development. It has recently shown more interest in supporting OPDs and provides important financial support to different organisations working with PWDs, including for example the Union of PWD. It has also provided financial support to the development of the Inclusive Education Policy, as the organisation believes it is very important to ensure the effective implementation of the commitments made by the ministry.

5.4.2 Save the Children

Save the Children has played a key role in strengthening legislation and institutions in Palestine in favour of the rights of CWDs. Importantly, it has been providing financial and technical support to MOSD in the development of a case management system for CWDs, as well as on the development of child rights-based indicators—including on disability. It provided technical support to the development of the Inclusive Education Policy as well as conducting training of trainers in its rollout, and has worked with MOH to increase the visibility of disabilities in MOH's public health legislation. Save the Children has also provided technical assistance and training on reporting on the rights of CWDs to the Independent Commission for Human Rights (ICHR) in Palestine. Save the Children is also chairing an inter-agency group of NGOs and UNRWA working on CWDs.

5.5 Coordination mechanisms

In 2004, a Presidential Decree was issued calling for the establishment of a Higher Council for the Affairs of Persons with Disabilities under MOSD to oversee the implementation of the PLD, as well as other legal provisions relating to disability. This was only really activated in 2012. One of its roles was the implementation of a Disability Card, based on the basket of services that a PWD is entitled to. However, high turnover of MOSD ministers and weak coordination and resourcing of the Council have meant it is not fully functional and work towards implementation of the law has stalled (Sida, 2014).

The Council meets occasionally, sometimes once per year or once every 18 months. One of the challenges identified in the sector is that NGOs, ministries and

Box 4: Child protection and protection against GBV services

Child protection services are largely provided by the NGO sector—and fail to meet the needs of many CWDs. A recent EU (2015) mapping exercise of local social service resources in three pilot governorates, for example, found that the community at large was targeted for two-thirds of all services and that, where services are targeted to individuals and families, most are provided in an out-patient institutional setting, with home-based and residential care quite rare (9.9% and 5.3%, respectively). On the other hand, a second exercise—conducted across all five of Gaza's governorates (Al Far et al., 2012)—mapped 279 child protection agencies (broadly conceived) and found that, while children with physical disabilities were relatively well served (by 140 of the total of 587 activities), children with mental disabilities were included in only 37 activities (ibid.). The highest number of activities targeted at CWDs was being carried out in Gaza City (99, of which 74 were for children with physical disabilities and 25 were for children with mental disabilities) and the least in Khan Yunis (12), indicating considerable disparity in the distribution of services (ibid.: 16).

UNRWA is tackling GBV for Palestinian women and girls, including those with disabilities—in Gaza, the West Bank, Jordan, Lebanon and Syria—via the implementation of a referral system that enables victims to access appropriate services including physical safety and shelter, legal, health and social services and counselling. In addition, in Gaza, UNRWA is developing a 'one stop shop' in health centres, where victims receive counselling, legal aid and social support. In the West Bank, MOSD has established Child Protection Networks (CPNs) comprised of key service providers (government and NGOs) in four localities (Ramallah, Jenin, Hebron and Bethlehem) to promote inter-agency coordination in child protection service delivery. There is, however, little evidence of the accessibility and impact of these services for CWDs. A referral system for child protection and GBV and abuse is not available for the wider population beyond that served by UNWRA or outside the localities with CPNs, which represents an important challenge for the protection of child rights in general and in particular for that of CWDs, for whom there is evidence of particularly high levels of abuse and neglect.

institutions working with PWDs are not committed to the objective of coordination and sharing of information. There are some models where regional coordination can be established around some types of disabilities, such as mental disabilities, with four or five organisations establishing a connection, but these are not the norm. This is partly the result of a competitive relationship in relation to the provision of services for PWDs between MOSD, NGOs and the private sector in general. Often, MOSD's endorsement is sought only in name but not to involve the ministry as an active player or leader in the field.

The reactivation of the Council requires good policies to fill the different gaps in coordination and communication among the different players, as well as resources to support effective policy implementation. There needs to be more commitment and political will between ministries to work in a concerted manner so they can each meet their obligations and existing challenges with respect to PWDs and CWDs in particular. For coordination to work effectively, there is a need to spell out the operational roles of each ministry through a plan of action that makes institutions accountable for their duties.

Some initiatives to coordinate actions within ministries have started to emerge. For example, in May 2016 MOSD established, with international support, an online coordination system that allows organisations to register the PWDs they are serving and make note of what particular services they are providing. The aim is to reduce duplication. Furthermore, in MOH, a ministerial-level technical committee has been established that includes members of all of the ministry's directorates, to oversee implementation of the disability policy; each directorate has to integrate the corresponding parts of the policy into its directorate plan, which is expected to be completed by the start of 2017. The plans result from extensive preparations, including meetings with internal and external stakeholders including donors. In the case of education, a committee has been established, including MOEHE and headed by UNESCO that aims to help integrate inclusive education into the school system. In addition, Handicap International has recently begun building coordination networks at the government level between disability-related organisations.

5.6 Examples of high-quality services provided to children with disabilities

This section presents examples of organisations that have positive models of service delivery for children with different types of disabilities. These range from national-level organisations to small CBR centres, which through their different approaches address some of the needs facing CWDs throughout Gaza and the West Bank. These are all organisations visited for this study, so this is not a comprehensive mapping of CWD service providers. Rather, it illustrates how select organisations respond to demands from families and CWDs and make specific adjustments to improve their service delivery capacity, tailoring aspects of their model to meet the needs of their beneficiary population.

While there is a basic premise in fulfilling the rights of CWDs to provide them with inclusive services—that is, mainstreaming CWDs into existing services and ensuring they receive adequate and effective support so they can integrate with other children—some of the services featured are specialised. This reflects the current reality in which services available for CWDs are weak and CWDs still lack the support they need to benefit equitably from mainstream services (this is further discussed below and in Sections 6 and 7). Until this gap is effectively bridged, it is important for CWDs and their families to have access to specialised services that provide them with the care and support they require.

The tables below provide basic information about organisations providing high-quality services for CWDs. It is followed by an analysis of what makes these organisations stand out or have the potential to become reference centres for other organisations. These organisations nevertheless face similar challenges to those of other service providers in improving and extending their services. This analysis of areas for improvement is found in Section 7.

Table 3: National level, Gaza and the West Bank

Name of organisation	Key features and services provided	Strengths	Areas for improvement
Palestinian Medical Relief Society	• Catchment area is wide—around 480,000. • Runs a specialised centre that provides physiotherapy and devices for PWDs (e.g. wheelchairs, crutches, etc.) and implements outreach programmes. • Provides other supportive services (e.g. general health clinic, pharmacy, health education, women's health, youth programme, mobile clinics).	• Wide coverage and deals with all kinds of disabilities. • CBR approach focuses on community involvement and participation. • Provides high-quality service and has committed staff. • Works in areas that are not served by other. • Coordinates well with other providers: leads 32 community-based organisations in disability. • Has a database of PWDs served. • Advocacy through the Palestinian NGO network and direct activities.	• Financial sustainability is not guaranteed. • Monitoring and evaluation (M&E) requires strengthening. • Advocacy and prevention components could be enriched.
Palestinian Red Crescent Society	• In 2015 reached about 2,500 people, of whom about 1,500 were children. • Offers both CBR and outreach—in 2015, the disability programme served about 120 under-5s as well as older children and adults with different disabilities. • Provides training in rehabilitation—trained 100 providers in 2015. • Offers support programmes at its health facilities. • Runs a school for CWDs—served 114 children in 2015. • Provides early childhood development programme— integrating CWDs with others without disabilities—serves around 100 children. • In West Bank also specific school for the hearing impaired and raises money to buy them hearing aids. • Offers CBR programme for children with intellectual disabilities or complex disability cases.	• High commitment to disability, around 30% of budget goes to disability services. • Long legacy effect; Palestinian Liberation Organisation (PLO)-affiliated with commitment to the injured. • Focused on capacity-building and has technically competent staff. • PWDs occupy important staff positions and serve as good role models. • It is developing a database of CWDs. • Demonstrated successes such as sending students on to university are important for community education. • It uses international best practice models in the services provided.	• Needs to increase coverage. • Should strengthen governance and accountability. • Limits itself to providing services and does not take advantage of space to advocate for PWDs. • Good knowledge base, but not working with the government to disseminate good practices. • Faces important financial constraints.
Princess Basma Hospital for Children with Disabilities	• Founded 50 years ago as a regional centre. • Provides comprehensive rehabilitation process for children with physical disabilities and autism. • Has dormitory for parents to stay with children for the duration of treatment. • Offers inclusive school—pre-school to primary—with 164 out of 500 children with disabilities. • Offers out-patient clinic for adults with disabilities. • Provides training for service providers working with PWDs. • Cost of services for those children insured through MOH is free—with even mothers' boarding costs often covered through externally raised.	• Uses multi-disciplinary rehabilitation model that allows for different therapies (e.g. sensory room, music therapy, hydra therapy, etc.). • Inclusive school recognised as international model: prepares many children to return to public school. • Outreach programme with mobile clinics that give support for diagnostics and rehabilitation throughout the West Bank, partnering with CBR. • Positions families as partners by providing training to mothers (at the centre and through outreach) so they can continue children's rehabilitation at home. • Certified internationally and many providers train in top Israeli universities.	• Jerusalem location means that difficult for children to obtain permits for treatment—especially from Gaza. • Transport costs often prohibitive, even though treatment is subsidised. • Capacity constraints mean children can only stay for 2–3 weeks at a time. • Offers no medical treatment, only rehabilitation. • Owing to resource constraints, does not work with children with other intellectual disabilities other than autism.

Table 4: Gaza, intermediate level

Name of organisation	Key features and services provided	Strengths	Areas for improvement
National Society for Rehabilitation	• Implements CBR approach for 1,300 PWDs (active files) using 25 providers. • Serves CWDs through the community means/resources and outreach programmes. • Leads networking and referrals. • Offers limited financial empowerment support to PWDs and their families.	• Covers most of the Gazan area, except the north and Khan Younis East villages. • Pioneer in CBR programming, which has well-respected track record of success. • Applies a well-grounded model of care according to WHO standards. • Has a promising practice of forming self-support groups. • Chairs referral network, which helps it synergise and be synergised by broader CBR activities. • Maintains database of PWDs receiving services.	• Highly dependent on external funding. • Could invest more in self-support groups and then help them market their success in order to inspire PWDs. • Given experience, should invest in becoming a focal point for care-coordination of CWDs. • Needs to invest more in advocacy activities and community mobilisation for disability prevention. • M&E function is limited and database is under developed.
Al Amal Rehabilitation Society –Rafah	• Since inception has served about 64,000 children with 64 staff members. • Offers diagnostic clinic for hearing problems, speech therapy, assistive devices and outreach programme. • Provides pre-school for the hearing impaired and offers their parents training. • Has an income generation programme for adults.	• Very experienced and has good coordination with other organisations. • Focuses on early intervention. • Has strong outreach capacity and connections with the community.	• Funding streams are variable. • Needs to increase prevention work with community and step up efforts to provide holistic services. • Needs better coordination with sister organisations (e.g. agree on school curriculum with Atfaluna). • Should improve staff technical training • No systemic M&E.
Deir Al Balah for Rehabilitation	• Serves approximately 300 children with physical disabilities and 180 with hearing impairments. • Offers diagnosis, education services and assistive devices. • Has outreach programming. • Runs advocacy through Fiorsan Alirada radio-for PWDs.	• Very experienced and has good coordination with other organisations. • Radio-based advocacy programming for community fills important need. • Combines psycho-social support activities and livelihood support to leverage its programme. • PWDs are represented in its management, which strengthens outreach.	• Activities and programmes are highly dependent on external funds. • Does not have the capacity to offer the breadth of services it would like to. • Community mobilisation is weak—especially with regard to prevention. • Limited M&E.

Table 5: Gaza, specialised services

Name of organisation	Key features and services provided	Strengths	Areas for improvement
Atfaluna Society for Deaf Children	• Specialises in diagnosis and treatment (including assistive devices) of hearing impairments and serves more than 2,500 PWDs each year. • Provides pre-school and primary school for 400 children with hearing difficulties. • Provides vocational training and support for income generation.	• Provides active screening and early intervention. • Leads rehabilitation cluster in the Palestinian NGO network and has good coordination and referral network. • Large and well-trained staff (90 full-time and 150 part-time)—embedded in stable management structure. • Contributes to advocacy. • Most services are computerised. • Core funding is secured by CBM-Germany.	• Need to transfer learning to MOH and UNRWA—especially with regard to early screening and intervention. • Should strengthen psychosocial services. • Should invest in evidence-based practice and support robust M&E. • Should continue computerisation and further strengthen funding.
Physically Disabled Association	• Serves around 12,000 PWDs with outreach, home visits, and assistive devices. • Has a school for 180 children with physical disabilities.	• Good coordination with MOH and UNRWA and other NGOs. • Wide coverage and long experience. • Good range of services provided—physical, recreational and health.	• Funding streams are highly variable. • Clinics are not especially well adapted for use by PWDs. • Lack of case management system means follow-up falls short. • Weak M&E.
Future Palestine	• Specialises in cerebral palsy and serves 150 children/day. • Has a school. • Trains 120 university students annually.	• Offers early diagnosis and tailored treatment. • Prioritises CWDs and females with disability.	• While meant to serve all of Gaza, effectively serves only Gaza City owing to transport issues. • As most employees are on the PA payroll, needs stable funding stream—should consider cooperating with MOEHE.
Right to Live	• Specialises in Down syndrome and autism. • Runs a preschool and special education programme for 400 children with Down syndrome. • Provides vocational training and medical and dental. • Collaborates with UNRWA and the PA and gets half of its staff paid by them.	• Tighter focus means higher-quality services. • Because children of staff attend preschool with CWDs, offers the community a model for inclusion. • Includes adolescent girls in the vocational programme.	• Services largely available only in the north of Gaza. • Staff need ongoing training to keep up with evolving best practices. • Need to transfer knowledge to other organisations.
Wafa Rehabilitation Hospital	• Services to children include in-patient care, education, play and recreation, physiotherapy, occupational therapy, etc. • Has advanced diagnostic services not available in other places.	• Provides individual case management with a focus on multifaceted care.	• Serves few children. • Needs stable funding source and better referral system.
Rafi secondary school for children with hearing impairments (MOEHE-run)	• Serves 80 girls and 50 boys by adapting the national curriculum to meet the needs of the deaf. • The dropout rate for girls is zero and for boys only 5%. • Has committee to develop sign language for new words.	• Teachers are well trained, transportation is provided (through MOEHE) and—since students take national exams—their access to university is good.	• Still under0resourced in terms of computers, smart-boards, recreational opportunities, counselling staff. • Physical space is not safe
Al Noor Centre for visually impaired children (UNRWA-run)	• Provides basic education, rehabilitation, psychosocial support, recreation and assistive devices to children in 3 programmes: pre-school (18 children), primary school (114 children) and an integration programme (333 children).	• Provides comprehensive services	• Under-resourced. • Teachers need training—especially on meeting the needs of children with multiple disabilities.

Table 6: West Bank, intermediate level

Name of organisation	Key features and services provided	Strengths	Areas for improvement
BASR	• Provides diagnostic, outreach and referral services for children in remote areas. • Offers local community centres that include children with and without disabilities. • Builds capacity of preschools that serve CWDs.	• Is the main source of information, support and referral for PWDs in the West Bank.	• Uncertain funding stream. • Faces competition from NGOs that provide poorer-quality services but are more conveniently located.
Star Mountain Rehabilitation Centre	• Provides rehabilitation services for children with intellectual disabilities and Down syndrome. Serves 83 children from 12 villages. • Offers early diagnosis and works closely with families on appropriate care-giving and disability rights. Develops development plans for children with parents. • Provides community outreach—working on disability rights and stigma.	• Follows international best practice models and recognises that children at different developmental stages can have very different needs. • Early diagnosis, outreach and advocacy fills important need. • Builds strong partnerships with parents.	• Limited finances limit the scope of operations—especially with regard to transport—receives no government support. • Enrols more boys than girls because families are more reluctant to enrol girls. • Charges an annual fee—which it sees as the families' co-responsibility for engagement—but may be too high for some families. • Unable to refer abuse cases because there are no government referral mechanisms.
Ladies of Selwad Charitable Assembly for Disabled Children	• Provides rehabilitation services with intellectual disabilities—including Down syndrome, muscular atrophy and learning and speech difficulties. • Provides training to parents on how to support CWDs. • Offers community outreach for mothers unable to bring their children to the centre. • Works with local social workers. • Helps some children integrate into local schools to provide social opportunities.	• Good support from local elites and the broader community. • Outreach and advocacy programmes fill key need. • Good coordination with other local actors.	• Serves a small number of children. • Funding from local community means resources are minimal. • Little support from MOSD and MOEHE.
Alfawar Rehabilitation Centre in Dura, Hebron	• Provides CBR in Dura refugee camp—includes referrals for specialised care, educational programmes for mothers on appropriate care-giving and advocacy to reduce stigma. • Offers inclusive pre-school and teaches children with mild intellectual disabilities. • They coordinate with other local organisations helps address more specialised needs. • Receives regular training and support from Princess Basma Hospital's mobile clinics.	• Outreach for mothers fills important need in the community, given the number of families that do not take their children to the centre. • Runs summer camps for CWDs that include support groups for mothers. • Involvement of community members in the centres' operations that increases trust from families in the camp. • Good model of good CBR services.	• Serves a relatively small number of children. • Limited to UNRWA funding, which means it focuses on satisfying only the 'minimum' needs of patients. • Families must pay small fee, which may further limit uptake.
Institute of Childhood, An-Najah University, Nablus	• Provides rehabilitation and educational services to 18 children with different forms of intellectual disabilities. • Uses case management system to develop individual plans for each child. • Provides capacity-building for kindergarten teachers, including on early diagnosis.	• Case management system is child-focused. • Good coordination with other early childhood actors.	• Very high demand and limited funding has resulted in long wait lists. • Limited relationships with the government: variable with MOH and none with MOEHE.

Table 7: West Bank, specialised services

Name of organisation	Key features and services provided	Strengths	Areas for improvement
Al-Nahda Women's Association	• Provides services for the intellectually disabled—including Down syndrome, as well as for the hearing impaired. • Teaches language skills, self-care, sensory activities, etc. • Has vocational component for older CWDs.	• Teachers are well trained. • Older CWDs can generate their own income at the centre through a woodwork workshop.	• Small programme—with limited funding—with long wait list.
Jasmine Charitable Society, Ramallah	• Established by families of CWDs, provides rehabilitation and support to challenging cases.	• Provides services to difficult/complex cases that other organisations do not treat.	• Funding constraints mean demand far outstrips supply.
School for the blind (charity-run), in Ramallah	• Provides high-quality, free day and residential school for blind children—serves 45 girls and 20 boys between the ages of 5 and 15. • Offers education to parents to help them support their children to achieve independence.	• Even transport is included for free. • Working with parents helps children succeed. • Students who transition to university become role models for success.	• MOEHE does not adequately support students to do well on the high school final exam. • Children must complete secondary school at government-run schools, which are not prepared to meet their needs. Dropout rates at this point are high—and many children who do transition do not do well on their final school exams because of lack of specialised support. • No community outreach to provide information to potential students. • Funding stream uncertain and shrinking.

Through these examples we can understand the landscape and use the information for an analysis of what works and what challenges remain for improving the provision of service for children with different disabilities who have different levels of economic and social support in their homes. It also serves as a resource to share information with other organisations throughout Palestine that might be looking for support or partnerships to improve their practice or to make referrals. Additionally, it should be a reference point for the relevant ministries—in particular MOSD, MOH and MOEHE—which have the mandate to serve the population of CWDs, to learn about what organisations are doing what, so they can extend to them their commitment and support.

5.7 Lessons from positive practices

There is important variation in the positive practice examples presented above, from geographical coverage, to size, scale and scope of work. Some organisations work with various forms of disability; others work with children who experience only one type. There are, however, several important positive commonalities that suggest that there is good work being done for CWDs, for which further financial and institutional support is needed so they can expand their services and increase their impact:

Strong child- and family-focused service provision: Most of the good practice organisations identified provide rehabilitation services. However, in many cases the crucial element of their success is not the services they provide directly to CWDs but working with caregivers to support them to learn about appropriate caring practices for their children at home—from rehabilitation to psychosocial support—ultimately enabling CWDs to become better integrated in family and community life. Many of the good practice examples also provide training or education for children or adolescents, through inclusive schools in some cases or via occupational therapy or training in traits that can provide them with income-generating opportunities. These are important services, especially in locations where CWDs have no access to other service providers. Examples of organisations that do this include Princess Basma Rehabilitation Centre and Star Mountain and, at the local level, the Alfawar Rehabilitation Centre.

Community outreach: Community outreach is important for two reasons. First, it enables more distant families—and those that lack transportation—to obtain some form of support, in some cases diagnoses and in other cases rehabilitation. Second, and similar to the point above, most outreach schemes include a focus on caregivers. Some run support groups; others teach caregivers how to provide disability-specific care at home. Many engage with communities to promote an understanding of PWDs' rights to reduce stigma. The Princess Basma Rehabilitation Centre is a particularly good example of this type of programme. It runs mobile clinics that provide support to caregivers and offer rehabilitation to CWDs. It also offers early diagnoses in more remote areas and provides training to local service providers.

Referral mechanisms and coordination with other organisations: Given that there is no established referral system for CWDs in Palestine, the agencies with the most success are often those that have forged their own links to various ministries and built networks with other agencies. In some cases, even quite small agencies have established good coordination mechanisms with other relevant local organisations that can provide more specialised services for the most complex disabilities.

Community engagement—through volunteering and donations: In the absence of systematic financial and policy support from the state through relevant ministries, community engagement to support local initiatives is often central to good practice. For some of the organisations we visited, much of their funding comes from committed wealthy individuals, small local enterprises or Zakat annual contributions. In other cases, local volunteers support the operation of some of the smaller centres, which increases their ability to provide services. One salient example of this support is the Ladies of Selwad Charitable Assembly—a rehabilitation centre in a village outside Ramallah, set up by local volunteers and financed largely through private donations.

Training and capacity-building of local community members: Some of the larger centres are providing in-service training for new service providers, building local capacity and expanding service options in order to better serve CWDs and their families.

A focus on independence: As noted above, some of the centres we visited work with older adolescents and young adults—providing them with basic skills that allow them to generate their own income. In some cases, the centres themselves even employ some of their own graduates (e.g. the Al-Nahda Women's Association in Ramallah). While the pay they offer varies according to the level and type of disability, and can be quite low, these jobs not only contribute to the partial independence of some older CWDs but also demonstrate to the wider community that PWDs are able to engage in meaningful work.

6. Primary findings regarding the challenges facing children with disabilities and their caregivers

Our quantitative survey and our qualitative fieldwork uncovered significant vulnerabilities and related service deficits for Palestinian CWDs. While approximately half of families with CWDs are receiving some sort of assistance from MOSD, rates of extreme poverty are very high (see Box 5) and very few families have access to any sort of psychosocial support, or even information about what types of services are available to their child. Access to education and health services—and participation in community life—is similarly limited. Schools and health facilities lack early detection and are usually not equipped to meet the needs of CWD. Further, children face stigmatisation from peers and even the providers meant to be 'on their side'. These factors, compounded by transport shortages, cause CWDs to drop out of school early and all too often give up on obtaining the rehabilitation services that could improve the quality of their lives, leading them to live lives of social isolation. CWDs' mothers, who not only bear the brunt of care-giving but also are blamed for producing 'defective' children, are marginalised and abused, even by their own husbands and families. Outcomes for Palestinian CWDs, in terms of health, education and overall well-being, are predictably poor.

Box 5: Sample characteristics

Given that our sample of CWDs was designed to be more representative than those of previous surveys, as it drew on both MOSD and NGO beneficiary lists, several sample characteristics represent key findings in their own right (see Table 8). For example, while MOSD registries listed less than 10% of CWDs as multiply disabled, we found 41.8% of CWDs had more than one type of disability (based on parental report). We also found it was very common for families to have more than one PWD. Of all the households included in our study, 41.4% had at least one PWD in addition to the sampled CWD. In most cases (59.4%), the second PWD was another child. Families in Gaza were especially likely to have more than one CWD. As hinted at by our previous research on the PNCTP (Pereznieto et al., 20014), we also found families with CWDs were extremely likely to be poor. Nearly 40% had monthly incomes that were about half of the extreme poverty line. Despite this, only about half were receiving cash or in-kind assistance from MOSD or UNRWA and about 10% were not even covered by health insurance.

Table 8: Emergent characteristics about the population of Palestinian PWDs

Variable	Gaza	West Bank	SoP
HH monthly income is less than NIS 1,000	52.8%	24.8%	39.6%
Source of income—more than one option			
Employment of parents	66.7%	78.5%	72.3%
Assistance from MOSD	52.3%	51.5%	51.9%
Assistance from UNRWA	56.3%	2.8%	31.1%
Service use			
Receiving cash assistance	55.4%	53.3%	54.4%
Receiving in-kind assistance	74.5%	31.5%	54.3%
Not covered by health insurance	10.9%	9.3%	10.1%
Not registered as PWD at any organisation	31.0%	11.5%	21.9%
CWD had more than one type of disability	31.7%	53.3%	41.8%
Percent of HH with more than one PWD	41.2%	41.6%	41.4%
Identity of PWD in HH			
Children	65.6%	52.4%	59.4%
Adults	21.0%	30.1%	25.3%
Both	13.4%	17.5%	15.3%
Mean number of CWDs in the HH, other than the sampled child, is 1.5, the maximum is 7			
Mean number of adult PWDs in the HH, other than the sampled child, is 1.3, the maximum is 4			

6.1 Social assistance and its limitations

Although our survey found that the majority of CWDs receive some form of social assistance from MOSD (see Table 8), significant gaps remain, with the vast majority reporting that they need far more assistance than they are receiving. For example, as Table 9 shows, while 19.5% of CWDs in Gaza and 49% of CWDs in the West Bank are receiving health insurance, a further 11% and 9.5%, respectively, indicate they need it. Similarly, 37.3% of CWDs in the West Bank reported a need for cash assistance and 47.5% of CWDs in Gaza a need for financial support to purchase assistive devices.

As Table 9 also indicates, disability-specific services are the most needed and the least available. For example, while 79.6% of respondents indicated that they would like information about the package of services available for CWDs, only 0.2% had received such information. Similarly, only 2.1% of families nationwide had access to a duty-free car with which to transport their CWD—despite legal provisions. Taken together, the data indicate that, while MOSD may be legally tasked with supporting CWDs and their families, it is failing to do so. While resource constraints are perpetual, and MOSD currently lacks the funding to provide assistive devices or emergency assistance, some of the most glaring service gaps would be comparatively inexpensive to plug. For example, providing information about legal rights and services could be done quite cheaply. Providing this information is currently one of the main activities for which the Palestinian Union of Persons with Disabilities is responsible, but its reach is very limited. Based on interviews with the Union this study found that, while it typically provides information to those who seek out their services (including the health insurance card), it does not reach out to those who are not aware of it or the services it provides, who are likely to be the most vulnerable.

The inadequacy of social assistance for children with disabilities also emerged as a strong theme in the qualitative work. Families receiving the MOSD cash transfer acknowledged that it was a help but far from adequate to cover the multiple additional needs CWDs face. One mother of two children with cerebral palsy in Nusirat Al Jadeed Camp, Gaza, explained,

> *'Once I take MOSA cash, I purchase nappies in large amounts and store them to use them when needed. When they finish, my husband buys from the supermarket through debits, we have no other choice. MOSA cash is not enough even for their nappies and sometimes it doesn't come each three months, sometimes there are more frequent delays.'*

Indeed, during interviews with MOSD in Ramallah, officials confirmed that the PNCTP is still using the old

Table 9: Distribution of responses regarding services received from MOSD

Variable	Gaza		West Bank		SoP	
	Received	Needed/not received	Received	Needed/not received	Received	Needed/not received
Health insurance	19.5%	11%	49.0%	9.5%	33.4%	10.3%
Cash assistance	52.8%	38.4%	53.3%	37.3%	53.0%	37.8%
In-kind assistance	7.8%	20.4%	22.0%	57.3%	14.5%	37.7%
Financial support to purchase assistive devices	0.4%	47.5%	1.5%	54.8%	0.9%	50.9%
Sponsorship of the CWD	0.7%	82.5%	0.8%	55.8%	0.7%	69.9%
Economic empowerment for HH	0.2%	84.0%	5.3%	76.8%	2.6%	80.6%
Economic empowerment for CWD	0.0%	21.5%	0.5%	51.4%	0.2%	35.5%
Duty-free cars	0.0%	6.7%	4.5%	68.5%	2.1%	35.7%
Emergency assistance programme (utilities, adaptation of HH, financial aid, medical transfers)	1.1%	75.6%	1.0%	64.0%	1.1%	70.2%
Pay a fee to enrol in special centres (purchase of service)	0.4%	49.2%	4.3%	62.9%	2.2%	55.6%
Psychosocial services	0.4%	63.2%	1.0%	63.8%	0.7%	63.5%
Counselling and guidance	0.2%	69.2%	1.0%	74.0%	0.6%	71.4%
Information about community resources available for CWD	0.2%	80.3%	0.3%	83.8%	0.2%	81.9%
Information about package of services for CWDs	0.2%	79.6%	0.5%	85.0%	0.4%	82.1%
Information about bill of rights guaranteed by law to CWDs	0.0%	79.8%	0.3%	88.5%	0.1%	83.9%

formula, which does not give special weight to CWDs in the appraisal process. This is despite the fact that the officials in charge of disabilities have sent multiple requests for the formula to be amended recognizing that families with members with disabilities have many additional financial requirements, without success.

Furthermore, in a number of cases, families complained that, because of the proxy means test formula used by the PNCPT, their assistance had been discontinued, even though support should be a right for CWDs according to both national and international legislation. One father from a village in Ramallah, who has both his own disability (mobility) as well as a six-year-old daughter with mobility and neurological disabilities, noted,

> *'I am fighting a lot with MOSA. I don't feel shy and do not fear anyone to ask about my rights and the rights of Sheema [his daughter]… I said you are not a social worker—your role is to be a social worker and to focus on marginalised people and their rights—but you are a reporter and suspect the people. Your office is just ignoring us!'*

Similarly, a mother from Yatta, who has an extraordinarily difficult care burden because her husband is out of work and five of her children have disabilities, explained,

> *MOSA cut off the cash transfer because I am janitor in governmental school so that means I am governmental l employee. I visited them to ask for return back our file, I submitted new file, I wait… I benefited from the cash transfer for seven years then a month ago they cut my benefit off, my older boy 19 years married a girl 16 years old, and to make matters even worse my house was badly burned last month.*

In other cases, families of CWDs had not lost MOSD support, but had simply never been adequately included owing to limited outreach and follow-up. Without active champions such as social workers, a number of very impoverished families had resigned themselves to a lack of support for their child—even when they were clearly very pained by their children's suffering. As one Bedouin mother of an older adolescent boy with advanced muscle dystrophy near Ramallah explained,

> *Sometimes the other kids drop him as the wheelchair is not great. He has a lot of pain in his legs—so he doesn't sleep well. He cannot extend his legs because he doesn't do physical therapy. We don't have any pain medicine for him. When he sleeps on his side and the legs the same, he is uncomfortable—he calls me to be turn him over at night. We have not been to the doctor for three years—if he has flu we just get something from the pharmacy. For pain, just put oil on his legs or warm them up. We can't afford anything else and there is no one to provide support. Do you know how I can relieve pain from the legs—physical therapy and doctor. Physical therapy is close in Anata—each session needs a private car to take them—and so it is so difficult.*

We also found, in interviews with social workers at the sub-governorate level, very limited disability-related capacity. Few have knowledge of how to manipulate the social assistance database (which is in a simple Excel format), for example, and in some cases they have not even visited households with CWDs. This appeared to be especially the case in the Jordan Valley and in Yatta, where villages are more scattered—although by international standards the distances are actually quite short and the roads generally accessible. For example, while the MOSD office head in Yatta estimated that there 'might be about 500 cases of people with disabilities' receiving MOSD support, she was unsure what proportion of these were children. Furthermore, she explained 'MOSA is not helping all of these… I can't tell how many exactly.'

Illustrating this lack of detailed follow-up by MOSD, one of the mothers we interviewed in Yatta—who had a five-year-old son with multiple and severe mobility and neurological disabilities—noted,

> *It took about seven months before they [MOSD] came to visit… They left very quickly—they didn't hear everything I had to say about my son—I said I needed more support in knowing how to care for him. But they came so quickly and just left. They came twice and now we get NIS 750 per month but nothing else.*

A father of two CWDs in the Jordan Valley noted,

> *I know it is our right to ask—I know the government should be responsible—I tried to ask MOSA—but they didn't give any attention to my children. Here in Palestine—Arabs believe—as long as you have a car or work you don't need any help. Unless you are a beggar… It is about dignity—I asked once and I will never ask again. If they don't ask me again then I won't chase. It makes me feel like a beggar.*

Similar gaps in MOSD's outreach were observed in our fieldwork in Gaza. The mother of a 15-year-old girl with a physical disability living just east of Gaza City told us,

> *'If you reached our name from ministries and organisations' databases, then they know that we are in need and we have CWD, why don't they come and see our difficult situation why there is no support?'*

While social workers noted that there were some additional rehabilitation support services available, there is no systemic approach to identifying which children should have access to these. Furthermore, it appears provision is determined largely by which families know about them—and can make direct demands from MOSD. A social worker from Jericho explained,

> *We can only do it case by case. There is no guidance. It is just based on the evaluation and recommendations of social workers… It is also about the capacity of the specialised centres and what they can manage. We face lots of challenges as there usually isn't the capacity to include most cases—often we simply can't add more. Obviously we don't welcome this situation—but that's what we have.*

Table 10: Distribution of reported difficulties CWDs or their family experience in accessing services because of the disability

Variable	Locality	Very difficult	Average difficult	Not difficult	% of mean	P value
Financial difficulties because of expenses related to disability	Gaza	71.6%	18.6%	9.3%	89.5%	.006
	West Bank	81.0%	11.8%	6.3%		
	SoP	76.0%	15.4%	7.9%		
Difficulties in securing needed disability-related assistive devices	Gaza	40.9%	14.2%	13.6%	83.5%	.003
	West Bank	50.3%	10.6%	7.3%		
	SoP	45.3%	12.5%	10.6%		
Difficulties in securing needed medications	Gaza	33.7%	11.5%	33.3%	73.8%	.000
	West Bank	42.4%	13.8%	9.5%		
	SoP	37.8%	12.6%	22.1%		
Difficulties in securing transportation	Gaza	36.6%	17.3%	45.9%	70.3%	.000
	West Bank	48.7%	15.1%	16.8%		
	SoP	42.3%	16.3%	32.3%		
Difficulties in securing rehabilitation services	Gaza	40.6%	26.8%	25.9%	76.2%	.000
	West Bank	45.3%	20.5%	9.8%		
	SoP	42.8%	23.9%	18.3%		
Difficulties in securing maintenance services for disability-related devices	Gaza	15.1%	6.7%	18.6%	74.2%	.000
	West Bank	29.8%	10.5%	5.0%		
	SoP	22.0%	8.5%	12.2%		
Difficulty in staying in school	Gaza	17.1%	11.8%	38.6%	61.2%	.000
	West Bank	31.0%	15.0%	31.8%		
	SoP	23.6%	13.3%	35.4%		
Difficulty in securing recreational activities	Gaza	27.1%	24.4%	48.3%	64.1%	.000
	West Bank	32.9%	28.6%	23.6%		
	SoP	29.8%	26.4%	36.7%		
Total mean of difficulties Gaza	1.86 out of 3 (62%)					
Total mean of difficulties West Bank	2.08 out of 3 (69.3)					
Total mean difficulties SoP	1.967 out of 3 (65.5%)					

6.2 Difficulties accessing services for children with disabilities and their family

Our survey also found CWDs were underserved by mainstream public services such as education, health care, psychosocial support and rehabilitation—leaving more than three-quarters of Palestinian families with CWDs reporting it to be 'very difficult' to make ends meet because of costs related to disability (71.6% in Gaza and 81% in the West Bank). As Table 10 shows, 45.3% of surveyed households reported that it was very difficult to obtain assistive devices, 42.8% found it very difficult to obtain rehabilitation services and 23.6% considered it very difficult to stay in school. Indeed, on average, Palestinian families with CWDs—especially those in the West Bank—reported that they experienced a 'high'[6] level of difficulty in accessing basic public services.

Unsurprisingly, given available services, children with vision and hearing-related disabilities reported the least

---

[6] To calculate the average percentage of difficulties facing CWDs and their families, scores were assigned to variables/items reflecting difficulties faced, with 3 indicating very difficult, 2 average difficult and 1 not difficult. Then the mean level of difficulties was calculated; the higher the score, the more reported difficulties. The overall level of difficulties was 1.96 out of 3 (65.5%), indicating that the magnitude of difficulties facing CWDs and their families is high.

Table 11 Differences in the difficulties scores by selected variables

Variable		Mean	Factor	Value	Sig
Area	Gaza	1.8614	t	-9.442	.000
	West Bank	2.0856			
Gender	Male	1.9603	t	-.574	.566
	Female	1.9747			
Age	5 years and less	1.9828	F	.424	.736
	6–11 years old	1.9736			
	12–14 years old	1.9413			
	15–18 years old	1.9706			
	Total	1.9668			
Type of disability	Multi-disabilities	2.1364	F	22.717	.000
	Vision	1.7343			
	Hearing	1.8506			
	Communication	1.8890			
	Mobility	1.8612			
	Remembering and concentrating	1.9032			
	Intellectual and learning	1.8964			
	Psychological and mental health	2.0345			
	Diseases	1.9978			
	Total	1.9668			
Governorates	North Gaza	1.7741	F	15.018	.000
	Gaza	1.9119			
	Deir Al Balah	1.9799			
	Khanyounis	1.8112			
	Rafah	1.9291			
	Jenin	2.0353			
	Ramallah	2.1454			
	Salfit	2.0718			
	Al Khalil	2.1108			
	Total	1.9668			
Locality	Rural	1.9272	F	20.355	.000
	Urban	2.0646			
	Camp	1.8513			

difficulty accessing services (see Table 11). CWDs with multiple disabilities and those with cognitive disabilities reported more barriers—likely because most NGOs provide services targeted to only a single form of physical disability. There is likely a confluence of reasons for differences between Gaza and the West Bank. First, there is easier physical access to services in Gaza, which is overall more urban. Gaza also has a broader network of NGOs and the active support of UNRWA. Differences may also reflect different expectations, with people in Gaza having more modest expectations because of the blockade. Interesting, no statistically significant differences in difficulties accessing services were noticed between boys and girls or different ages, which means all are facing difficulties.

6.2.1 Education access and outcomes

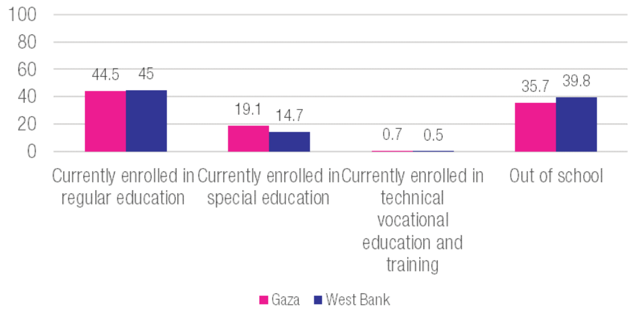
While education is a basic right of all children—and inclusive education is broadly recognised as ideal for most CWDs because of the way it fosters social cohesion and reduces stigma (Nordic Consulting Group, 2012)—Palestinian CWDs in our survey were very likely to face restrictions in this domain. As Table 12 and Figure 2 show, nearly 38% of children in our quantitative sample are out of school entirely and less than 45% are enrolled in regular education. These figures are remarkable given that national enrolment rates are approaching 100% for children between the ages of 6 and 14 and are over 80% for adolescents between the ages of 15 and 17(PCBS, 2013c). Nearly two-thirds of CWDs in the West Bank said their disability limited their access to education (versus 38.7% in Gaza), with only about a quarter feeling their school was supportive of CWDs and a third saying educational tools were not adapted to their needs. The average age at which Palestinian CWDs in our study leave school is only 11.9 years.

As Table 13 shows, our survey found some CWDs were significantly more likely to be out of school than others.

Table 12: Distribution of responses by education related variables

Variables	Gaza	West Bank	SoP	P Value
Enrolment in education				
Currently enrolled in regular education	44.5%	45.0%	44.7%	
Currently enrolled in special education	19.1%	14.7%	17%	
Currently enrolled in vocational training	0.7%	0.5%	0.6%	
Not enrolled in education	35.7%	39.8%	37.6%	.224
The disability affects or limits access of CWD to education	38.7%	64.3%	50.6%	.000
CWD stopped learning against his/her desire	7.7	11.8	9.9	
CWD needs in order to follow his/her education and exams but unavailable				
Personal computer	16.2%	24.4%	20.0%	
Personal assistant	7.0%	19.1%	12.6%	.000
Adaptation of curricula	11.0%	9.8%	10.4%	
Reading materials such as a line amplifier, zoom lens	7.2%	6.2%	6.7%	
Sign language interpreter	1.6%	3.9%	2.6%	
Support at schools				
The pre-school/school is supportive of CWD	22.7%	24.7%	23.6%	.300
School teacher is supportive of CWD	45.5	50.5	47.8	
Peers at schools/pre-schools are supportive	42.7	46.5	44.5	
Selected not adapted school resources				
Resource centres such as computer lab not adapted	50.0%	48.5%	49.3%	
Educational tools not adapted	27.8%	37.9%	33.0%	
Transportation not adapted	27.8%	39.3%	33.1%	
Classrooms not adapted	19.6%	27.3%	23.2%	
Toilet not adapted	30.8%	20.0%	25.0%	
Roads leading to schools not adapted	34.8%	26.5%	29.8%	
Mean age and schooling-related variables				
Mean of total years CWD spent studying	6.42	6.08	6.26	
Mean age of CWD when started pre-school	4.71	4.62	4.67	
Mean age of CWD when started primary school	6.32	6.42	6.37	
Mean age of CWD when finished school	12.18	11.57	11.85	

Figure 2: Proportions of CWDs by their enrolment status in education



For example, while boys and girls are equally likely to be out of school (37.8% versus 37.4%), pre-schoolers and secondary-aged children are far more likely to be out of school than primary-aged children (30.2% versus 62.7% and 48.5%, respectively). This is primarily because pre-school in Palestine is provided almost entirely by NGOs—many of which do not accept CWDs at all—and older students typically require far more adaptions in order to be academically successful, given the more strenuous content they are expected to master. Another important reason for children dropping out of school at secondary level is that the 1999 Disability Rights Law

Table 13: Out-of-school children by important variable

Variable		%	Value X^2	Sig
Area	Gaza	35.7%	1.498	.224
	West Bank	39.8%		
Gender	Male	37.8%	4.936	.177
	Female	37.4%		
Age	5 years and less	62.7%	46.808	.000
	6–11 years old	30.2%		
	12–14 years old	29.1%		
	15–18 years old	48.5%		
	Total	37.6%		
Type of disability	Multi disabilities	57.6%	180.117	.000
	Vision	4.3%		
	Hearing	6.1%		
	Communication	23.1%		
	Mobility	28.1%		
	Remembering and concentrating	50.0%		
	Intellectual and learning	46.7%		
	Psychological and mental health	50.0%		
	Medical diseases	36.4%		
Location	City	36.1%	11.715	.069
	Village	39.6%		
	Camp	38.4%		
Governorates	North Gaza	38.6%	15.544	.049
	Gaza	36.7%		
	Deir Al Balah	46.9%		
	Khanyounis	27.1%		
	Rafah	27.3%		
	Jenin	35.5%		
	Ram Al Allah	47.9%		
	Salfit	31.9%		
	Al Khalil	44.0%		

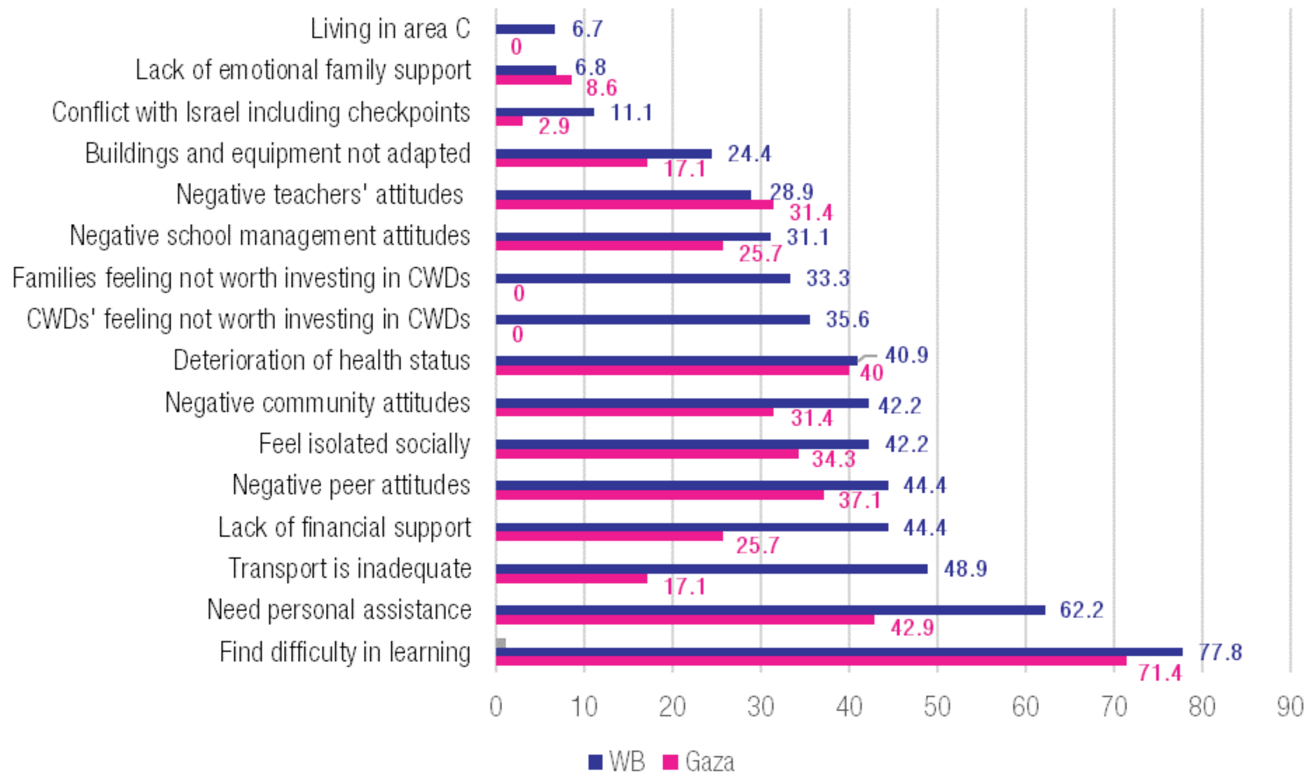


Figure 3: Reasons behind stopping education

requires children in specialised schools to be integrated into 'inclusive' schools at secondary level (from Grade 11); in fact, many special schools provide services only up to grade 10. However, as noted earlier, given the real dearth of capacity and resources available for secondary schools to provide inclusive education (discussed further in Section 7), many children end up dropping out rather than transitioning to secondary level. Further, at secondary level, CWDs may also face more stigma, given adolescent social posturing. Differences in access also have to do with the type of disability facing the child. Longstanding options for children who are visually impaired or hard of hearing mean these CWDs are more likely to be enrolled in school, especially compared with those with multiple disabilities, 57.6% of whom are out of school.

CWDs who were out of school gave different reasons for dropping out of school. As Figure 3 shows, the most common reason was that they found it difficult to learn. This was followed by unmet needs in terms of personal assistance, transportation and financial support. Stigma or discrimination against those with disabilities is also a key reason for school dropout. In the West Bank, for example, 33% of CWDs reported that their families were not supportive of their education—mostly because they felt education was unlikely to translate into a job. In Gaza, over 31% of out-of-school children listed negative teacher attitudes as a reason for dropping out of school.

Our qualitative interviews also highlighted that access to education for CWDs is very limited—and especially so for young children and children with intellectual disabilities, for whom there are very few specialised education providers; these are thus far away and inaccessible. As noted, government schools do not yet have the capacity to provide inclusive education services for the most challenged cases. As one mother of a nine-year-old boy with Down syndrome in a village in Ramallah lamented,

> *There has been a class for four years for special needs students and they were supposed to hire specialist teachers but instead the school has been trying to close this class. Now the class is used just for low performance students… When my son was in this class the teacher advised to just keep in home and to teach religious texts—she was burning with indignation that she even had to teach students like him… This teacher is not encouraging me—rather she was treating me as ignorant. Her goal was to close the door of that class as soon as she could… The social worker knows but she hasn't been able to bring about any change.*

Other caregivers of children with intellectual disabilities explained that the learning and support at the schools their children could attend was so poor that it made no sense to send them. Bullying and stigmatisation were also a challenge for children attending 'inclusive' schools, since no support or sensitisation is provided to other students on how to treat CWDs. Parents of four children with intellectual disabilities in a village near Ramallah explained that their two older children (now aged 16 and 15) had started attending a government school but had faced severe bullying so they had had to pull them out. They then took them to a specialised centre for children with speech and hearing disabilities that included occupational therapy but took them out since they saw no progress. Now none of the four children with disability attend school; the one child without a disability (aged 10), does attend a regular government school. The father explained,

> *'More than money, we need services for our children. I have gone to the municipality a number of times to ask for a special school or at least a teacher for special education, but nothing has happened.'*

Parents of four girls with microcephaly in Dura, Hebron, explained that they did not know of any special schools close by where they could take their daughters. Some centres provide physical rehabilitation but no support for learning. They would willingly take them to a more distant centre if they had access to transport, but this is unavailable to them.

For parents with children with less well-understood developmental and intellectual disabilities—such as autism—securing their children's right to an appropriate education is even more challenging. A number of caregivers of children who appeared to our fieldworkers to be on the autism spectrum reported that they had struggled to find any helpful diagnosis —let alone options for schooling. This is especially the case for families residing in the West Bank outside of major urban centres. Even if they had attended initial sessions in the quest for a diagnosis, expenses, as well as distrust born of stigma and a sense of futility, had led them to give up—and retreat home to wait for some sort of support. Only the most persistent, and usually better educated, are eventually able to obtain services for their children (Box 6).

For children with vision and hearing disabilities, our research found that, while urban areas have better educational services than rural areas, supply is still insufficient to meet demand—especially at the upper secondary level (including those attending the Red Crescent Centre for the Hearing Impaired in Ramallah, for example), at which point most children must be mainstreamed into the regular school system. For families living in more remote areas, and for those who lack the financial resources to pay for private school and private transport (especially those in Yatta, the Jordan Valley and Ramallah villages in the West Bank), access to schooling is limited even at the primary level. Furthermore, the quality of education is often poor. For instance, our sign language interpreters noted that children could express themselves only at the most basic level.

Box 6: Support for children with autism is very rare

The mother of an autistic son, living in the Jordan Valley, told us support for autism was extremely limited.

> *It was difficult at first. He is improving now. But there are still lots of challenges… He was very shocked (as we already had two other boys with disabilities). It was very difficult. All the centres I visited, doctors, hospitals, the Red Crescent—they all didn't know what was wrong with him and said he didn't have autism. I am dealing with him as though he has—although there are no specific papers demonstrating this. I took a short course in autism in Amman where I learned about the factors—clear factors—that characterise a child with autism—certain words, movements, sudden violence. That such children are not affectionate. This is my son—and he feels noise acutely. He also obsesses about certain games. He really likes circles. He is blind but also very clever. He heard verses from the Koran just once and was able to recite back all 23 verses. But where to educate him is still my challenge. He is now at the Community Centre under Jericho municipality, which is not a great match for his needs but it is something.*

Many children and caregivers in our qualitative work also noted that teachers were unsupportive and even abusive (see Box 7). Other parents observed that teachers simply did not invest in their CWDs—and instead directed their efforts to non-disabled children. As one Gazan father of a son with a hearing impairment explained,

> *'He missed class and was absent from his school many times for more than four days and there was no teacher to call and ask about him. If he was without disability, the teacher would have called directly to know the reason but they knew his case.'*

Similar concerns were echoed in the West Bank, as this mother of a 17-year-old son with a hearing impairment in Yatta explained:

> *Yatta is not good community. When he was in school he was absent for two months without my knowledge. He went to school daily but he regularly escaped from the school yet no one told me. Only when my house burned down did people come to the house and then the teacher told me my son did not come to the school for two months. He spent his time on the street and no one cared to call me. The teachers just assumed I was a careless mother because he had only finished Grade 4 but was in his mid-teens. But they were beating him all the time on his hands, and sometimes with plastic pipes, because he couldn't read or write.*

In addition to unsupportive and untrained teachers, accessibility of schools is another very important challenge reported by many of the children interviewed. Schools—which are supposed to be inclusive—are not adapted to receive children with different disabilities. This poses an important challenge when moving children from specialised schools to general schools that are not ready—without adequate transitions and resource centres. This was reported as a cause for dropping out of school in many cases. Interviews with MOEHE confirmed that, indeed, despite its recent efforts to extend training on disability to teachers throughout Palestine, the scale of the initiative had been limited because of a lack of resources and staff capacity, although efforts are continuing.

While most of the cases of CWDs interviewed illustrate the challenges of accessing a school that meets their special needs, we also interviewed a few CWDs who have been able to access a special or inclusive school with positive outcomes

Box 7: A common refrain about unsupportive teachers

> *There is a bottle of water inside the class only for the teacher and she doesn't allow us to drink, but sometimes if I feel very thirsty and don't know what to do, I put my head on the desk and start crying, sometimes I reject participating in the class or reading. Only when I do this, the teacher brings me water; otherwise, she will not respond. (adolescent girl with cerebral palsy and severe cognitive delays, Gaza)*
>
> *He always comes crying and tells me that he hates school and wants to leave it (Mother of 10-year-old boy with multiple disabilities, Gaza)*
>
> *They punish her when she doesn't memorise something or if she forgets her book. Her father came to school to take her to the hospital for monthly check-ups, and recently he found she was being punished outside her class. Her teacher punished her because she didn't memorise her lesson. Eman told me her teacher asked her to stand up all the class time in spite of her leg pain which she suffers from a lot. Sometimes it is even to the extent that she is screaming in pain (Mother of 11-year-old girl with multiple disabilities, Gaza)*
>
> *I went with my dad to register in the school, but the director refused and said, 'Sorry I couldn't register you,' I said 'What?!', she said, 'No, I can't accept you in my school.' I said, 'But why? I really need to know why?!' She said, 'I can't take responsibility for any handicapped persons in this school.' I was shocked and I told my parents, 'Let's go home, why did you bring me to her. To be insulted!' My father told me, 'NO, they told us in the Future Palestine Society that you have the right to be merged in the school…' Yes, unfortunately! These are our schools! I suffered from the first day of the merge till I finished the secondary level. If my teachers supported me, I would not mind all the insults of my classmates, but unfortunately I did not find any support and encourage from my teachers. Teachers themselves refused to support me (24-year-old woman with cerebral palsy, Gaza)*
>
> *One day, the teacher of my class was absent. Another beautiful one came, she had a photo with me and was very nice unlike my teacher (10-year-old boy with physical disability)*

in terms of education, development and self-confidence. While these cases are in the minority, it is important to highlight them as they illustrate the huge potential involved in supporting high-quality education for CWDs.

In Selwad village, for example, Noor, a 16-year-old girl with spina bifida, enjoys school and works hard to perform well; she has high aspirations for her future: '*I hope to be a school principal and achieve my dreams.*' A few factors contribute to this positive story: her parents are well educated—her father is a university professor—and very supportive, and they have resources that facilitate her mobility. She has a modern electrical wheelchair that she can operate and they have a private car to transport her to school.

A 13-year-old girl with a minor disability in Hebron who is in Grade 7 explained, '*I like school, learn how to read and write and when we learn, we help society.*' She walks to school with difficulty, but has the support of some friends who help her carry her bag. Teachers at school have also been supportive and enable her to participate in different activities including sport, which encourages her.

These two cases illustrate that, despite the challenges facing children with mobility disabilities, they have more opportunities to access regular schools than children with learning or intellectual disabilities, who are more severely excluded from education.

6.2.2 Health care access and outcomes

The Palestinian health system faces significant challenges that affect both its efficiency and its effectiveness (MOH, 2014). While MOH is legally mandated to provide health services to all citizens—including PWDs—and UNWRA provides services to the refugee population, the basic package of available services is not adequately tailored to address the specific health care needs of those with disabilities, particularly the youngest children. Early diagnosis and intervention, which are crucial to supporting positive developmental trajectories, are absent or of low quality. Children are therefore often diagnosed later in childhood, which means critical windows for intervention are missed, and the specialised services that many CWDs require are either unavailable or unaffordable.

For example, as Table 14 shows, less than half of all children with vision-related disabilities in our quantitative sample were diagnosed before the age of five—even though nearly 63% of those disabilities were attributed to congenital/hereditary causes. Similarly, while hearing impairments can be detected at birth, there is no routine newborn screening in Palestine. Atfaluna Society initiated a pilot in 2011 and screened children at two UNRWA clinics, with excellent results. However, this was never taken to scale. Additionally, neonatal resuscitation services are weak, with a high rate of asphyxia reported for newborns. In fact, during the qualitative research, many parents reported that their children's disability was a result of oxygen deprivation at birth. As such damage is nearly entirely preventable, this illustrates a need to revisit the newborn health care protocols followed in neonatal intensive care units.

Screening and diagnosis are not the only services in short supply. For example, 26% of households would like access to speech and language therapy for their CWD but are unable to obtain it and 26.9% want access to specialised medical care. Of those who have accessed the former, over half paid out of pocket. Critically, for most respondents, nappies and dressings are almost entirely self-supplied. Over 90% of families pay for them out of pocket. Finally, over 16% of children with mobility-related disabilities who need a powered wheelchair do not have one and over a third of hard-of-hearing children lack hearing aids. Notably, while people from the West Bank purchase services and products out of pocket more often than those in Gaza, this does not mean those in Gaza are receiving help from providers. Rather, given the blockade and the extremely high unemployment rate in Gaza, it simply means these CWDs go without. Limited counselling and information for families with CWDs generally results in poor decisions that result in children not having the services or attention they should receive.

Table 14: Distribution of responses by health-related variables

Variable		Gaza	West Bank	SoP
Age of CWD when diagnosed with having disability				
Vision	0–4 years	54.3%	45.2%	49.7%
	5–12 years	24.7%	19.0%	21.8%
Hearing	0–4 years	90.9%	59.6%	76.4%
	5–12 years	7.6%	10.5%	8.9%
Communication	0–4 years	95.8%	67.0%	80.9%
	5–12 years	2.4%	5.0%	3.8%
Share of respondents who reported the following disabilities as being congenital / hereditary				
Vision		64.0%	61.2%	62.6%
Hearing		73.8%	54.4%	64.8%
Communication		68.6%	57.1%	62.7%
Mobility		56.8%	49.4%	53.0%
Remembering and concentrating		64.6%	59.6%	61.2%
Intellectual and learning		60.2%	58.1%	59.1%
Psychological and mental health		23.8%	51.3%	41.7%
Diseases		83.3%	47.4%	56.0%
% of CWD who received the following services in past year		64.0%	61.2%	62.6%
Speech/language therapy		11.8%	14.3%	12.9%
Occupational therapy		4.7%	11.3%	7.8%
Physiotherapy		14.2%	16.0%	15.0%
Provision of disposables such as dressings, nappies		10.9%	12.5%	11.6%
Medications		31.9%	32.5%	32.2%
Specialised medical care		18.0%	30.0%	23.6%
Medical follow-up		24.2%	34.8%	29.1%
Audiology services		6.2%	6.3%	6.2%
Orthopaedic/prosthetic therapy		1.1%	1.0%	1.1%
Psychosocial/mental health		8.4%	3.8%	6.2%
Assistive devices		7.8%	12.3%	9.9%
Other rehabilitation services		12.6%	7.3%	10.1%
Proportions of CWDs and families who paid out of pocket for medical care				
Speech/language therapy		39.6%	67.9%	54.1%
Occupational therapy		33.3%	51.1%	45.5%
Physiotherapy		14.8%	62.5%	39.5%
Provision of disposables such as dressings, nappies		88.6%	94%	91.5%
Medications		59.2%	67.7%	63.2%
Specialised medical care		60%	75.9%	69.4%
Medical follow-up		49.5%	75.8%	63.6%
Audiology services		44.4%	76%	59.6%
Orthopaedic/prosthetic therapy		20%	75%	35%
Psychosocial/mental health		13.2%	42.9%	21.2%

Distribution of responses by health-related variables (continued)

Variable	Gaza	West Bank	SoP
Assistive devices	22.9%	65.2%	46.9%
Medical care CWD would like to receive but unable to			
Speech/language therapy	26.2%	25.8%	26.0%
Occupational therapy	9.3%	15.8%	12.3%
Physiotherapy	10.6%	21.8%	15.9%
Provision of disposables such as dressings, nappies	9.5%	10.3%	9.9%
Medications	10.2%	20.0%	14.8%
Specialised medical care	26.4%	27.5%	26.9%
Medical follow-up	24.6%	28.5%	26.4%
Audiology services	4.2%	7.5%	5.8%
Orthopaedic/prosthetic therapy	2.4%	4.8%	3.5%
Psychosocial/mental health	35.0%	13.3%	24.8%
Assistive devices CWDs would like to use to help with day-to-day activities but that s/he currently doesn't have			
Walking aid for children with multiple disabilities	5.6	8.5	7.3
Walking aid for children with mobility-related disability	7.5	15.8	10.7
Power wheelchair for children with multiple disabilities	10.5	7	8.4
Power wheelchair for children with mobility-related disabilities	15.8	17.1	16.3
Commode chair for children with multiple disabilities	7	5.2	5.9
Commode chair for children with mobility-related disability	5.8	11.8	8.2
Hearing aid for children with hearing impairment	29.4	41.2	35
Artificial limb	2.5	2.6	2.6
Medical mattresses for children with multiple disabilities	8.4	7.5	7.9
Medical mattresses for children with mobility-related disability	6.7	9.2	7.7
Assistive technology for children with vision impairment	8.5	17.8	12.1
Therapeutic bags for mental disabilities that contain colours and learning cards	25.2	18.8	21.5

As Table 15 shows, while the bulk of respondents in our quantitative sample believe the health care their CWD receives is at least decent—if not actually good—a significant proportion report that the quality of care is poor. For example, one in five households report that the availability of comprehensive health care services for CWDs is poor. Similarly, while half of households believe the information they are given on caring for CWDs is good, 17% believe the continuity of care for rehabilitation services is poor. Families with CWDs are particularly unhappy with the provision of medical disposables—with access to nappies and dressings appearing over the course of our research over and over again. While there were no differences in terms of satisfaction between families with girls versus boys or by disability type, there were significant differences at the governorate level. CWDs from Jenin, Ramallah and North Gaza were more satisfied with the quality of care than those from Hebron (which was the lowest) and Khan Younis.

Overall, our qualitative interviews found significantly lower levels of satisfaction with health care services than did our quantitative survey. On the one hand there were high levels of satisfaction with specialised disability services providers such as Princess Basma in Jerusalem and specialised services at Wafa Rehabilitation Hospital and Atfaluna in Gaza. As one 17-year-old Gazan boy with a physical disability noted,

> *I travelled to Israel before for treatment. I had lots of fun there. They have adaptations everywhere. There, I felt like I do exist. And that I am only a normal human being without feeling inferior or insignificant. The first thing I'd like to achieve is to study medicine in order to treat people with disabilities. I don't want them to live the same experience I've had when the doctors neglected me. Also, I want to treat myself. Sometimes I see myself treating people. It'd be great to help them and give them the medicine needed.*

Table 15: Perceptions about quality of health services

Item		Very poor	Poor	Neither good nor bad	Good	Very good
Quality of health care provided	Gaza	4.5%	15.5%	4.9%	58.0%	10.2%
	West Bank	11.8%	11.0%	4.9%	57.8%	4.9%
	SoP	8.3%	13.2%	4.9%	57.9%	7.5%
Measures taken at the premises to promote access	Gaza	6.9%	11.8%	4.5%	42.9%	4.9%
	West Bank	9.5%	9.5%	9.1%	27.0%	1.5%
	SoP	8.3%	10.6%	6.9%	34.6%	3.1%
Organisation of care provided	Gaza	6.5%	15.9%	8.2%	55.1%	8.6%
	West Bank	11.4%	10.3%	11.8%	51.3%	2.7%
	SoP	9.1%	13.0%	10.0%	53.1%	5.5%
Staff interactions with the CWD	Gaza	3.7%	12.2%	6.1%	62.0%	11.4%
	West Bank	7.2%	8.0%	3.8%	66.9%	4.2%
	SoP	5.5%	10.0%	4.9%	64.6%	7.7%
Outcome of the medical care	Gaza	4.9%	18.0%	6.5%	55.9%	7.3%
	West Bank	9.9%	16.0%	11.4%	47.1%	5.7%
	SoP	7.5%	16.9%	9.1%	51.4%	6.5%
Availability of comprehensive health services for the CWD	Gaza	6.5%	21.6%	4.5%	42.4%	5.3%
	West Bank	8.7%	19.4%	13.3%	38.4%	3.0%
	SoP	7.7%	20.5%	9.1%	40.4%	4.1%
Continuity of care for CWD medical and rehabilitation services	Gaza	10.6%	17.6%	4.1%	49.4%	6.9%
	West Bank	10.6%	16.7%	14.4%	35.0%	3.0%
	SoP	10.6%	17.1%	9.4%	41.9%	4.9%
Availability of medications for the CWD	Gaza	9.0%	20.8%	3.3%	31.4%	3.3%
	West Bank	12.2%	12.2%	3.4%	33.2%	0.4%
	SoP	10.7%	16.4%	3.4%	32.3%	1.8%
Availability of counselling services for the CWD	Gaza	4.9%	19.8%	4.9%	49.0%	4.9%
	West Bank	8.0%	9.2%	11.5%	40.1%	1.1%
	SoP	6.5%	14.3%	8.3%	44.4%	3.0%
Information received explaining the case and status of the CWD	Gaza	3.3%	18.0%	4.9%	60.0%	5.3%
	West Bank	4.2%	8.0%	9.5%	48.9%	2.3%
	SoP	3.7%	12.8%	7.3%	54.2%	3.7%
Information received about the management plan for the CWD	Gaza	3.3%	18.4%	4.9%	57.6%	5.7%
	West Bank	3.8%	7.6%	6.8%	51.3%	1.9%
	SoP	3.5%	12.8%	5.9%	54.3%	3.7%
Degree of involvement in the management plan for the CWD	Gaza	6.9%	23.3%	6.1%	49.8%	4.9%
	West Bank	4.2%	9.9%	6.8%	47.5%	2.3%
	SoP	5.5%	16.3%	6.5%	48.6%	3.5%
Provision of information related to care for the CWD	Gaza	3.3%	21.2%	3.7%	56.3%	4.5%
	West Bank	4.6%	8.0%	7.3%	50.8%	1.1%
	SoP	3.9%	14.4%	5.5%	53.5%	2.8%

Perceptions about quality of health services (continued)

Item		Very poor	Poor	Neither good nor bad	Good	Very good
Availability of medical disposables (dressing, oxygen, tubes, catheter)	Gaza	6.1%	7.3%	2.0%	5.7%	1.6%
	West Bank	2.3%	4.6%	1.9%	6.8%	0.8%
	SoP	4.1%	5.9%	2.0%	6.3%	1.2%
Availability of assistive devices for the CWD	Gaza	9.4%	11.4%	1.2%	19.6%	4.5%
	West Bank	4.9%	7.6%	3.4%	19.4%	1.1%
	SoP	7.1%	9.4%	2.4%	19.5%	2.8%

Note: 1 Very poor. 2 Poor. 3 Neither good nor bad. 4 Good. 5 Very good. All scores were calculated from 1 to 5.

A father of a child with multiple disabilities, living in the Jordan Valley, added,

> *The centre (in Jerusalem) was very helpful—there were many specialists—focused on rehabilitation but we faced some difficulties as the transportation was very expensive—especially as it was during the Intifada—and my wife and daughter stayed for one month, with me back here taking care of the rest of the children. But the centre provided for all my daughter's health needs and provided my wife guidance on how to help her speak, move, swim and play. The support was excellent but we couldn't continue as we had other small children who needed their mother's support. The training we got at the centre was excellent. The centre was focusing also on the parents—how parents can deal with the care needs. It was really helpful. If she could have continued going there for a longer time it would be much better.*

On the other hand, however, outside of the handful of specialised services, many caregivers and children alike complained about inadequate and non-empathetic health care providers. As one 18-year-old girl with vision difficulties in Gaza explained,

> *'I want to complete my education and wish to be a nurse to help myself as I get older because no one helped when I was young, so I want to be the one who cares about myself and to need no one.'*

A visually impaired 15-year-old girl from Gaza had similar ambitions. She said,

> *'I dream of being a surgeon in the future, so that I can treat children with disabilities like me who don't have any hope. The doctors are useless, they don't provide us with any support.'*

Many parents also complained of the undermining attitudes of medical professionals in the process of seeking medical help for their children. One mother in Ramallah villages, for instance, recalled that when her son was first diagnosed with Down syndrome the doctor not only was not supportive but also was blatantly insulting towards her son:

> *After my son was three months we went to the doctor because he had a chest infection. His father remarked to the doctor that, 'We have increased one child in the family tree and we are proud of this,' but the doctor replied, 'No this child is not considered from the family tree.' At that I fell in shock and was crying—for some time I didn't want to continue my life and everything seemed closed—I realised what society's attitude towards my child was going to be like [very negative].*

We also encountered several instances of parents who had been taken advantage of by 'quacks' in Hebron governorate—that is, doctors who professed to have some knowledge of a child's disability but then provided dangerous 'treatment', including over-medication, and medications to impoverished families at considerable cost. A mother of a daughter with an intellectual disability in Jenin, for example, explained,

> *'We took our daughter to a private doctor in Ramallah because there was no one here who understood her condition. The doctor gave her medication but it was not good for her so she is not taking it anymore.'*

Indeed, interviews with MOH confirmed that governmental health care services were not equipped to deal with mental illness in terms of qualified personnel, available guidelines and equipment.

Gender issues also emerged as a theme in CWDs' access to health care, with parents reporting that medical professionals did not see their daughters with disabilities in the same way that they would see girls without a disability. For example, the mother of a 14-year-old Gazan girl with cerebral palsy and severe cognitive delays told us,

> *Palestine Future usually uses male physiotherapists and sometimes they bring male volunteers from universities*

> *who come for practical training. They use Rasha as an example for their training while she is lying on the bed, so she feels very shy and didn't want to continue the sessions… I finally visited them two weeks ago and told them that my child feels she became an adult. She can't be exposed like this among male volunteers and they recorded all this, but they didn't respond so far.*

Our survey found that CWDs' lack of access to health care had significant implications for their quality of life. As Table 16 shows, over a quarter of Palestinian CWDs are judged by themselves or their caregivers to have a bad or very bad quality of life. Less than 20% are judged to have a very good quality of life. Furthermore, as Figure 4 shows, a fifth of respondents reported that their quality of life or that of their CWD was declining. To further explore CWDs' perceptions about their health status, they were asked to determine the number of days—out of the previous 30—that they had felt well versus unwell. As Table 16 notes, the average Palestinian CWD reported feeling unwell in terms of their physical health for 5.6 days of the previous month and their psychosocial/mental health for 6.6 days. These numbers are higher than what is reported by the general population in Gaza (Al-Bayoumi, 2014) by two days and in the US by three days (CDC, 2009).

CWDs' nutritional and growth status is also worrisome. As Table 16 indicates, CWDs are quite likely to receive less food than their non-disabled siblings. In Gaza, for example, 32.5% of respondents said the CWD took in less food than other children in the family and overall nearly 13% of Palestinian families reported the nutritional status of their CWD as bad. This has knock-on implications for children's growth. Nearly a third of CWDs were reported as being too small for their age. While our research did not explore why CWDs were receiving inadequate nutrition, explanations may be linked to some of the following probable causes. First, some families feed their non-disabled children more simply because their value their CWD less. Second, some CWDs, especially those with more complex needs, have difficulty feeding—making it very time consuming to get adequate calories into them. Third, for children who require special diets, cost is a very significant problem given the high poverty rates of families with CWDs.

Figure 4: Perceptions about the change in quality of life

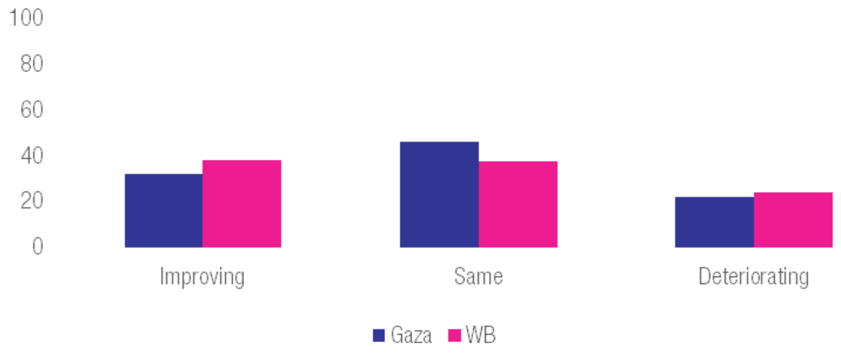


Table 16: Quality of life and growth of CWDs

Variable	Gaza	West Bank	SoP
Perceptions about quality of life of CWD in general			
Very good	17%	18.7%	17.8%
Good	53.4%	56.5%	54.8%
Bad	24.9%	21.5%	23.3%
Very bad	4.7%	3.3%	4.1%
Changes in quality of life of CWD			
Improving	31.8%	38.3%	34.9%
The same	46%	37.8%	42.2%
Deteriorating	22.2%	23.9%	23%
Evaluation of food intake of CWDs in comparison with other children similar in age (without disability)			
Similar	53.6%	56.3%	54.8%
CWD receives less than others	32.5%	28.1%	30.5%

Quality of life and growth of CWDs (continued)

Variable	Gaza	West Bank	SoP
CWD receives more than others	13.7%	15.3%	14.5%
Nutritional status of CWD			
Good	59.9%	62.0%	60.8%
Fair	27.8%	24.4%	26.2%
Bad	12.3%	13.4%	12.8%
Growth and development of CWD			
Good	55.4%	54.6%	55.0%
Fair	25.3%	29.1%	27.1%
Bad	19.3%	16.2%	17.9%
Perceptions about CWD's size (weight)			
Too little	32.3%	30.6%	31.5%
Normal	63.7%	63.5%	63.6%
Too big	4.0%	5.9%	4.9%
Number of meals CWD eats per day			
Up to twice	21.1%	19.7%	20.5%
Three and more	66.6%	69.7%	68.1%
When asked	12.3%	10.5%	11.5%
Perceptions about healthy days			

		N	Mean	t	Sig.
Physical health: how many days during the past 30 days was his/her physical health not good?	Gaza	446	5.4709	-.526	.599
	West Bank	390	5.7256		
	SoP	836	5.5897		
Psychosocial/mental health, which includes stress, depression and problems with emotions: for how many days during the past 30 days was his/her psychosocial health not good?	Gaza	446	6.0516	-1.762	.078
	West Bank	390	7.2128		
	SoP	836	6.5933		
During the past 30 days, for about how many days did poor physical or mental health keeps the CWD from doing his/her usual activities, such as self-care, schooling or recreation?	Gaza	445	4.2674	-2.219	.027
	West Bank	388	5.4330		
	SoP	833	4.8103		

Table 17: Differences in the difficulties score in ADL by characteristic variable

Difficulty		No difficulty	Some difficulty	A lot of difficulty	Can't at all	% mean
Dressing by him/herself	Gaza	49.10%	21.10%	13.50%	16.40%	50.5
	West Bank	46.80%	18.20%	15.60%	19.40%	
	SoP	48.00%	19.70%	14.50%	17.80%	
Feeding by him/herself	Gaza	71.50%	12.80%	6.50%	9.20%	40.3
	West Bank	65.50%	12.30%	8.20%	14.10%	
	SoP	68.70%	12.50%	7.30%	11.50%	
Getting in and out of bed	Gaza	74.00%	9.00%	5.20%	11.90%	40.9
	West Bank	66.80%	8.70%	8.40%	16.10%	
	SoP	70.60%	8.80%	6.70%	13.90%	
Going and using the toilet	Gaza	64.80%	10.30%	9.60%	15.20%	45.05
	West Bank	61.50%	9.50%	10.50%	18.50%	
	SoP	63.30%	9.90%	10.00%	16.70%	
Bathing/washing	Gaza	45.30%	19.10%	16.40%	19.30%	54.02
	West Bank	42.70%	14.60%	19.20%	23.50%	
	SoP	44.10%	17.00%	17.70%	21.30%	
Moving about in the home	Gaza	74.20%	10.80%	5.20%	9.90%	39.6
	West Bank	68.50%	10.20%	5.90%	15.30%	
	SoP	71.60%	10.50%	5.50%	12.40%	
Moving about outdoors	Gaza	61.20%	13.20%	13.90%	11.70%	45.15
	West Bank	60.10%	12.30%	9.20%	18.40%	
	SoP	60.70%	12.80%	11.70%	14.80%	
Getting in and out of a motor vehicle (car, van or bus)	Gaza	63.00%	11.20%	11.00%	14.60%	46.2
	West Bank	59.10%	7.90%	12.00%	21.00%	
	SoP	61.20%	9.70%	11.50%	17.60%	
Total mean Gaza = 1.74 out of 4 (43.5%)						
Total mean West Bank = 1.88 out of 4 (47%)						
Total mean SoP= 1.81 out of 4 (45.25%)						

Note: Higher percentages indicate more difficulties on a scale from 0 to 100.

Unsurprisingly, given the range of types of disabilities included in our survey, CWDs and their caregivers reported significant variation in what CWDs could and could not do. As Table 17 shows, most CWDs do not experience significant difficulty with daily living activities such as dressing themselves and toileting. On the other hand, over 20% are completely unable to bathe themselves and nearly 18% are completely unable to dress themselves and nearly 15% to move about outside of their own homes.

As has been found by other studies (PCBS and MOSD, 2011), our survey found that CWDs in West Bank were statistically more likely to experience difficulty with daily living tasks than those in Gaza and girls and younger children faced more difficulties than boys and older children (see Table 18). Children with mobility-related disabilties and multiple disabilities face the highest level of difficulty.

Table 18: Differences in the difficulties score in ADL by characteristic variable

Variable		Mean	Factor	Value	Sig.
Area	Gaza	1.7429	t	-2.092	.038
	West Bank	1.8866			
Gender	Male	1.7501	t	-1.947	.052
	Female	1.8843			
Age	5 years and less	2.4732	F	22.619	.000
	6–11 years old	1.8628			
	12–14 years old	1.5966			
	15—18 years old	1.5919			
	Total	1.8105			
Type of disability	Multi-disabilities	2.1522	F	18.720	.000
	Vision	1.1719			
	Hearing	1.0827			
	Communication	1.4479			
	Mobility	1.9409			
	Remembering and concentrating	1.8375			
	Intellectual and learning	1.4056			
	Psychological and mental health	1.4792			
	Diseases	1.4113			
	Total	1.8105			
Governorates	North Gaza	1.6373	F	1.637	.111
	Gaza	1.9163			
	Deir Al Balah	1.7452			
	Khan Younis	1.7449			
	Rafah	1.6276			
	Jenin	1.8374			
	Ramallah	2.0739			
	Salfit	1.8009			
	Al Khalil	1.8796			
	Total	1.8105			
Locality	City	1.7914	F	2.346	.096
	Village	1.8918			
	Camp	1.6622			

6.2.3 Environmental adaptation and transportation

CWDs lack of access to their environments is less about disability itself and more about the lack of environmental adaptation. With appropriate adaptions, most CWDs can be included in the daily lives of their families and communities. Our study, however, found Palestinian environments were rarely adapted to meet the needs of CWDs. Transport, for example, is a significant issue for many. As Table 19 shows, about a third of CWDs in our sample face a great deal of difficulty with transportation. Many of the remainder face some difficulty.

Figure 5 highlights the types of difficulties CWDs face regarding their use of transport. Most, for example, find it difficult to transfer from one form of transport to another or to get in or out of the vehicle. Over 40% find the cost to be too high or lack someone to accompany them. In the West Bank, over 14% of CWDs lack access to transport entirely.

Table 20 highlights the many ways in which homes are not adapted to CWDs needs. For example, nearly 10% of children included in our survey need—but do not have—adaptations to the roads to their homes, to their home entrances, to their stairs, to their bathrooms and to their corridors. While several organisations help families with adaptations, including the National Society for Rehabilitation, the Qatar Crescent Society and the YMCA, demand far outstrips supply. Notably, this study found a lower demand for adaptation than did the 2011 PCBS and MOSD study—likely because children are physically smaller and easier for adults to move about. Demand is anticipated to increase with age.

Figure 5: Reported reasons for facing difficulties in using public transportation

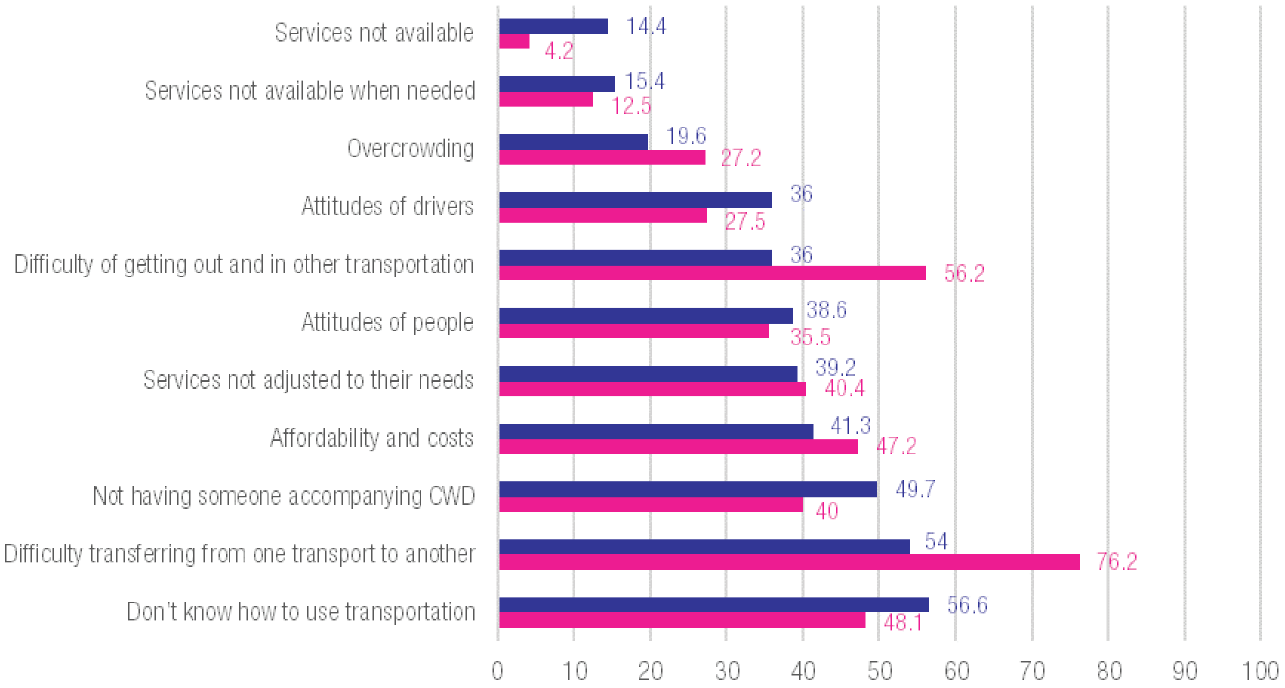


Table 19: Distribution of responses by difficulties in using transportation

Item		NA	Yes to high extent	Somewhat	Not at all
CWDs have difficulties being a passenger in a private car as a result of their disability	Gaza	92.7%	2.9%	1.3%	3.1%
	West Bank	19.8%	27.3%	14.3%	38.8%
	SoP	58.4%	14.4%	7.4%	19.9%
CWD have difficulties in using public transportations in the following cases					
Taxi	Gaza	0.9%	34.6%	23.1%	41.5%
	West Bank	18.8%	31.8%	13.0%	36.5%
	SoP	9.3%	33.3%	18.3%	39.1%
Public bus	Gaza	3.1%	32.8%	21.3%	42.8%
	West Bank	18.8%	32.0%	12.8%	36.5%
	SoP	10.5%	32.4%	17.3%	39.8%
Public van	Gaza	12.4%	28.2%	17.3%	42.1%
	West Bank	23.5%	29.0%	11.0%	36.5%
	SoP	17.6%	28.6%	14.3%	39.5%

Note: NA = No answer

Our qualitative work also found that poorly adapted homes, schools and communities were an issue for CWDs. Of the many homes the research team visited to carry out interviews, only a small minority had been adapted to the needs of children with wheelchairs. Often it was an expense the parents simply could not afford. So, while securing a wheelchair was often considered an important breakthrough in the care of children with physical impairments, as it opened up access to the broader community, because there was little attempt to ensure children were given wheelchairs that physically fit their homes (i.e. were especially small to accommodate narrow doorways) many children were effectively confined to a single room of their home. Furthermore, very few children had ramps to help them access their homes. In most cases the terrain was very challenging, because of hills, a lack of pavement or—in the case of children we visited in the H1 area of Hebron—risky to navigate given nearby checkpoints and Israeli settlements.

Lack of physical adaptations are also challenging to children with other sorts of disability. In the case of children with visual impairments, for example, families are often unable to make appropriate adjustments because of large families and over-crowding. One Gazan mother of two visually impaired children explained,

> *I always try to teach my sons how to be self-dependent and make everything by themselves as they grow up. But sometimes they can't do it by themselves, especially Mohamed. He starts searching for his books and clothes and couldn't find them. Our economic situation is very poor, so we have only two rooms. All my children sleep in one room, which is very messy as you can see. It is, therefore, difficult for Basam to find his things among this mess… All the house is damaged and it's in a very bad situation as you see. It just needs a rocket that completely destroys it so that we may get rid of it. It is so terrible and we are living in a very miserable situation. Nothing is made specially or adapted to suit their disabilities.*

Another key concern that emerged from the qualitative fieldwork, especially in the West Bank, was a dearth of affordable and accessible transport to access medical and social work support services. This is particularly the case in

Table 20: Distribution of CWD who need—and cannot obtain—adaptations to their homes

Adaptations needed but can't be obtained	Gaza	West Bank	SoP
Slide stairs at home	9.8%	6.2%	8.2%
Adapted bathrooms	8.9%	7.6%	8.3%
Adapted kitchen	5.1%	3.9%	4.6%
Electric elevators	9.0%	2.3%	5.9%
System of visual alerts	1.1%	1.6%	1.3%
Adapted house entrance	10.4%	8.3%	9.4%
Adapted roads leading to the house	10.8%	7.0%	9.0%
Adapted corridors	9.7%	6.2%	8.1%

rural areas surrounding Hebron and Yatta and in the Jordan Valley. The mother of a hearing-impaired girl in the Jordan Valley observed, for example,

> *'The school in Ramallah is very good but it requires very expensive transport each week. NIS 700 every month. My daughter needs a car to take her to a bus stop, then a taxi taking her to school.'*

According to the mother of a nine-year-old boy with physical and neurological impairments in the Jordan Valley,

> *My son couldn't walk before he went to the centre. He went for two years. We had to stop because of the economic situation—then he returned. He stopped for two to three months then returned to school. We had to take a taxi because the centre is in Jericho. It is very expensive to get a taxi. So now he is just at home.*

The father of a six-year-old girl with physical and neurological impairments in a village in Ramallah said,

> *We can't go to the Red Crescent for physical therapy—it requires three sessions per week—NIS 70 per session—because of transport. For public transportation it is NIS 22, in addition to the session cost. Moreover, all the time away from the house means the home chores will be destroyed—no work there—you will destroy the home.*

While distances to services are usually less of a problem in Gaza, transport costs are still quite problematic. For example, one Gazan father of a 10-year-old girl with muscular dystrophy explained that,

> *'I stopped sending Aisha to the school for physically disabled children as I can't afford to pay the transportation fees (NIS 100 per month). Most of my salary and MOSD cash goes to my debts because of my son's marriage when he was 19 years old.'*

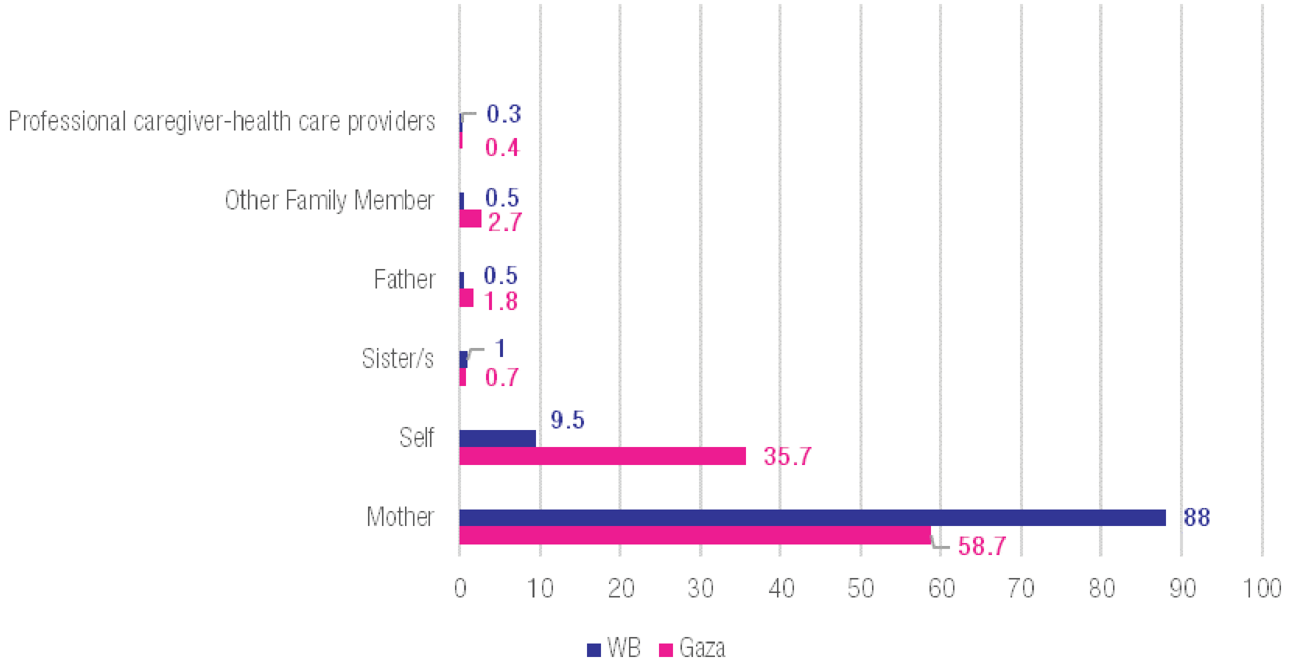
Among children with hearing impairments, lack of adapted community infrastructure is also a significant concern. As one hearing-impaired 15-year-old boy from Gaza underscored,

> *'At school everything is perfect, but the problem is in the community; it needs big efforts to communicate with them. Not all people understand me. It would be better if there are specialised signs for people with hearing disabilities in all streets, markets, health centres and entertainment places.'*

A girl of the same age, also from Gaza and also hearing impaired, explained poetically,

> *Look at those houses; I draw them far away from each other because people in our community have difficulty in communicating and supporting each other, so they are far away from each other… For instance, if I want to go to Gaza it is hard to communicate with people. For example, if I want to visit my friend how can I contact the taxi driver!? This is annoying!*

Figure 6: Main person responsible for daily help of CWDs in ADL



6.3 Family and community life

6.3.1 Family caregiving

As Figure 6 shows, in our quantitative sample mothers are the primary caregivers for CWDs. Mothers are the primary care for nearly 90% of CWDs in the West Bank and nearly 60% of CWDs in Gaza. Complementary care, which the figure does not reflect, is most often provided by fathers and sisters (25%).

Our qualitative work also underscored that families in general—and mothers in particular—bear the overwhelming brunt of care-giving. One Gazan mother summed up the situation:

> *'MOSD needs to reconsider, mothers do everything for the children and take care of expenses while father do nothing.'*

While there were examples of very supportive fathers in our sample, overall it appeared these were few and far between. For example, a father in Alfawar Refugee Camp near Hebron has a 10-year-old daughter with brain damage that resulted from a fall during infancy. Despite the family's economic constraints the father works to provide support, medical assistance and assistive devices for his daughter, who receives some, insufficient, benefits from Alfawar Rehabilitation Centre. The interaction between father and daughter was clearly one of trust and closeness, evidence of the father's caring for her. The mother was not at home during the interview and the girl's father and elder brothers were assisting her. The father explained,

> *'We no longer send her to a special school in Hebron as it is too far away and she does not like to be away from her parents, she gets desperate, so we support her at home.'*

However, our qualitative research did come across a number who were uncaring or even abusive. As one 18-year-old Gazan girl with a visual impairment lamented,

> *'My father used to call me bad nicknames like "Hoola", "Owra" and "Amyaa".7 I hate that, he really hurts me a lot.'*

In the case of a seven-year-old Bedouin boy with a limp, his mother said she only able to take her son to the doctor in secret, as her husband refused to allow care.

> *He takes the cash transfer but not for my son—he always says, "He is not my son." I have been worried about Daoud from when he was little—when he was three years he fell over—I bound up his hand to cover the blood, crying and wanted to protect him as I knew what his father's attitude would be. I have a heavy burden in my heart because of this. He needs special shoes—the NIS 1,100 we receive from MOSD is his right but his father refuses. The only way I can get something for him is to ask my brother and my mother—my sister was disabled and she was never allowed outside, never allowed to see a doctor. There was simply no relationship between her and my father.*

Many of the mothers included in our qualitative fieldwork have large families and no respite care. They spend 24 hours a day, seven days a week, caring for their children. One mother of five children, three of whom have muscle dystrophy (see Box 8), from Ramallah pointed out the residence of her natal family–about 100 m from her home. She explained that she was rarely able to visit her parents, who effectively live next door, because of the never-ending care demands of her children. A mother of a child aged 11 years old with multiple disabilities in Khan Younis explained, '*He takes up so much of my time that I can't care about myself; sometimes I don't even have time to comb my hair.*'

---

7 These are all derogatory terms for persons with vision disabilities: 'Hoola' is an insult for a person with a squint; 'Owra' is a blind woman, singled eyed; 'Amyaa' is also a woman who doesn't see.

Box 8: Families with multiple PWDs

As noted in Table 21 (as well as in section 2), it was surprisingly common for families to have more than one PWD. Over 40% of households in both Gaza and the West Bank had more than one member with a disability. In 60% of cases, families had at least two CWDs. In 25% of cases they had both a CWD and an adult with disabilities. In 15% of cases they had more than one CWD and at least one adult with disabilities. Rafah and Ramallah governorates reported the highest level (50%) while Salfit (31%) and Gaza governorate (34%) reported the lowest. Having several PWDs in a family vastly complicates financial and care-giving burdens—particularly for mothers and older sisters.

Table 21: Families with more than one PWD in the household

Variable	Gaza	West Bank	SoP
Having other HH members with disabilities	41.2%	41.6%	41.4%
Identity of other HH members with disabilities for the 352 HH with more than one disability			
Children	65.6%	52.4%	59.4%
Adults	21.0%	30.1%	25.3%
Both	13.4%	17.5%	15.3%
Mean number of CWDs in HH, other than the sampled child, is 1.5, the maximum is 7			
Mean number of adult PWDs in the HH, other than the sampled child, is 1.3, the maximum is 4			

The high number of households with several CWDs draws attention to the genetic and environmental risks facing Palestinian children—and the poor health care available to mothers and newborns.

Consanguineous marriages are very common in Palestine and have been linked to the county's high rate of siblings with disability (Sirdah, 2014). Furthermore, especially in Gaza, pollution is rampant. This too has been linked the growing rate of birth defects (Abed et al., 2014). Many of the disabilities facing newborns are preventable if appropriate measures are taken. Health awareness about disability, genetic counselling, preconception care, appropriate antenatal care, healthy nutrition, appropriate neonatal support, postnatal care support and follow-up are examples of measures that have been proven to contribute to disability reduction. All are sadly lacking in Palestine.

Our qualitative work, which did not set out to over-sample families with more than one CWD—but rather discovered on arrival that the sampled child had one or more siblings who were also disabled—found that some families with several CWDs had children with the same type of disability and other families were juggling children with very different needs. One family in Jenin, for example, had two children with visual impairments, one with cystic fibrosis and one with microcephaly. A family in the Jordan Valley was raising three sons, two with visual impairments and two with varying types of autism. A family in Yatta had four children with hearing impairments and a fifth with a visual impairment, while a fourth in Ramallah had three sons with muscular dystrophy. A family in Hebron had four daughters with microcephaly and a family in a village outside Ramallah had four children with a similar intellectual disability. Our research found that, while a few families did not understand why so many of their children were disabled, in many other cases they did. Some were aware of the possibility of having children with disabilities from consanguineous marriages but they refused to believe the level of risk because they had at least one child born without a disability (among four or five children with a disability). The mother of a 10-year-old Gazan girl with muscular dystrophy explained the following:

> *We weren't shocked by Nada's physical disability because this wasn't the first time. I and my husband are relatives. Three of our children died as a result of disability; two of them died when they were babies and a third when she was 11 years old as a Down syndrome case. Then I have Nada's sister who is partially blind since birth and suffering from problems in her retina and then Nada who is suffering from muscle atrophy… [Pointing to her husband] This is the man who insisted on marrying his daughter to her cousin where she now has a disabled girl because of consanguinity. I will never ever forgive him for what he did. I completely rejected this marriage because I suffered a lot with my three disabled children because of marrying my cousin and I didn't want the same destiny for my daughter… [Husband speaking] It is their destiny (Naseeb). I love my brother and couldn't reject a request for him so I gave my daughter to him for his son.*

No families with several CWDs appeared to be receiving adequate support. Poverty levels are extreme, parental tensions are high and mothers are often desperate. One mother with four CWDs, who is struggling to raise her family in Nusirat Jadeed Refugee Camp in Gaza, explained how overwhelming her life was—especially since her husband married a second wife to provide him with healthy children:

> *I had four disabled children who all suffered from cerebral palsy; two of them died suffering from different diseases and I still have another two disabled. I didn't know that these disabilities were because of relatives marrying (cousins) as none of our relatives had the same disabilities in such a number. When I had the first child, I was almost living in hospitals because he suffered a lot from different diseases (coughing, blue baby when born, infections). I stayed in the hospital for eight months, which was the most difficult for me, until he died. For the second baby, it was even more shocking as I couldn't believe for less than 1% that such a disability will recur. Every time I gave birth to a disabled child I felt so traumatised, sometimes I felt dizzy and fainted on the ground. I stayed in my room by myself for days and days thinking of my destiny. I don't speak with anyone. My husband felt the same but he tried to console me. Later, doctors told us that because of relatives marrying, the disability percentage would appear in our children as 25% disability 75% healthy. Every time I give birth to a child, I say to myself, 'The child will be most likely from the 75%,' but it is Allah's will that the majority of our children came under the 25% and were disabled! Till now and even after giving birth to four CWDs, if I give birth to a newborn baby I will never ever know if he going to be disabled or not. I don't know the symptoms and I can't tell! I have never received any awareness-raising or at least a recommendation from doctors to stop having children because there is a high possibility of disability. Just once a doctor advised me saying, 'As are having all these disabled children, why you don't separate and leave your husband!!'*
>
> My husband never mentioned that he was going to divorce me or marry another woman till I delivered the third child. One of his friends convinced him, saying that 'You are becoming older and older. See how you don't have any healthy boys who can carry your name and family name! Why you don't marry another woman to bring healthy boys, so he decided to marry after that.' I felt so much oppression and injustice in my life compared with other girls my age who are not even married. When my husband married another wife, I was only 25 years old. I don't and I will not ever feel that it is his right to marry rather he should stay beside me supporting me with these huge burdens. My husband doesn't help me at all in taking care of my CWDs, I do all the required care starting from feeding, showering and providing physiotherapy myself. He doesn't like to do that, so I ask my eldest daughter to help me.
>
> I will never forget how my co-wife fully rejected helping me to carry my second child as I can't carry both. She said, 'Carry them by yourself or bring another one to help you. It isn't my business.' She was very arrogant, and showed her disgust. My husband moved me with my children to live with my co-wife in her rented flat for one month (Ramadan) to reduce the financial cost as he can't bear the expenses of two houses. I suffered a lot at that time; she was treating us very badly and she never helped me even if she saw my children crying or even dying.

Table 22: Distribution of reported difficulties the CWD or his/her family experience in accessing supports because of the disability

Variable	Locality	Very difficult	Average difficult	Not difficult	% of mean	P value
	SoP	22.0%	8.5%	12.2%		
Difficulties securing willing caregivers	Gaza	18.2%	7.3%	50.8%	60.5%	.000
	West Bank	24.6%	10.3%	12.3%		
	SoP	21.2%	8.7%	32.7%		
Forgone educational opportunities for HH members	Gaza	5.8%	2.9%	78.7%	43.6%	.000
	West Bank	10.0%	15.8%	43.3%		
	SoP	7.8%	8.9%	62.0%		
Forgone recreational opportunities for HH	Gaza	10.9%	10.2%	77.4%	48%	.000
	West Bank	11.5%	21.1%	38.1%		
	SoP	11.2%	15.3%	58.9%		
Forgone work opportunity for HH members	Gaza	4.2%	1.8%	77.6%	42.7%	.000
	West Bank	10.8%	13.0%	44.9%		
	SoP	7.3%	7.1%	62.2%		
Forgone opportunities to socialise with others for HH members	Gaza	12.7%	12.4%	74.0%	50%	.000
	West Bank	14.3%	22.3%	38.3%		
	SoP	13.4%	17.1%	57.2%		

Lack of respite care also featured in our quantitative sample, with over a third of mothers shouldering the entire care burden. As Table 22 shows, this not only prevents them—and other family members—from pursuing education or employment but also restricts their opportunities for socialisation and recreation. One result of this isolation and stress is that mothers of Palestinian CWDs have very high rates of mental illness. Phua et al. (2015), for example, found that 65% exhibited depressive symptoms.

Our qualitative work found that, in many cases, part of the burden mothers must bear is GBV on the part of husbands and sometimes older sons (see also Box 9). Many mothers explained that, because their husbands and/or in-laws blamed them for their child's disability, they were often targeted for psychological, verbal or physical abuse. As the mother of an 11-year-old with multiple disabilities in Khan Younis noted,

> *'There is no single day that passes without trouble and problems between me and my husband, maybe he is sad or angry because of our situation or because of our low financial level, maybe because of seeing his child disabled, it's not easy to see his child like this, it's not easy for him nor me.'*

In the same vein, a mother with two disabled children in the Jordan Valley explained that marital violence was an entrenched pattern—and while she understood her husband's frustration she was indignant that she was suffering from his anger. She said,

> *My husband hits me and my children for no reason. Whenever he wants. Violence is here. I have been asking for help at MOSD but no one helps… I feel insulted in front of my children. Women should never be beaten by their husbands. It is insulting. Whenever he gets angry—from work, from people—if anyone upsets him he uses his family as a way to express his anger… I understand why. I understand the situation is very bad but this is not a way to express your feelings towards us. The father used to beat the children—the deaf child too—maybe the fear they have of their father is why they are now so afraid of beatings from their teacher.*

A number of women also explained that they had been abandoned or divorced for giving birth to a child with disabilities. One mother with two disabled children from Beit Lahia told us,

> *I was 13 years when he married me. I was in school till Grade 3, and I was learning sewing in that period of time. My cousin proposed to me, and my dad told him I was still young, but he refused to accept this as a reason. Then they decided for me, and I was not mature then,*

Box 9: GBV as a negative coping mechanism in families caring for CWDs

> *Before I am so nervous about my situation—I have 11 children and four children with hearing impairments and one who is blind—I had decided to commit suicide. My husband has a neurological disease, he beats me, he shouts all the time and he beats the children and this impacts them a lot. I hated life I want to burn myself. But then I thought about to whom I would leave my children, who would care for them, and so I handed myself to God and I trust in him to take care of me. Nowadays I work [as a school janitor] as a way to escape from the life, all the time I am doing this for my children… Sometimes I thought to go to media [to appeal for help] but then it would be aid and I did not like to announce about my case publicly… My nightmare is my daughters I am so worried about them as we heard a lot of stories about girls—stories of sexual harassment by men against girls here. My situation is so difficult—if my husband left the house my sons will rebel against theirs sisters and exploit them, the father ironically now is like a protection for them.*
>
> *The boys do not respect their sisters, they beat their sisters. If one of their sisters wants to go to bathroom she must take permission from them if I am out of my home, not one of the brothers gives them food, even if they are hungry.*
>
> *I took a loan from the bank to marry my older son, he loved a girl and I was forced to take this loan so that I have debt payments until 2020. I did that because I fear that he will escape or do horrible things. Our life is so difficult; I discovered after his marriage that I added new problems to my house. Our meal is oil and thyme, we have no electricity for three days because we have no money to pay the NIS 100 for electricity. Life is full of stress, there is no love in this home, this older son controls all things. If he needs cigarettes and I have no money to give him he starts beating me (mother of five children with disabilities, Yatta).*

> *so I just did what they wanted for me. That is how we got married… But then our children came along and he simply abandoned us… He contacted me six years ago. He sold our house in Al-Jalaa' and escaped with the money. Later I found out he was married in Sudan through his brothers who usually communicate with him. He told my sons that they have four Sudanese brothers.*

Another Gazan mother, living in Der Al Balah Refugee Camp with her five-year-old daughter, who has a physical disability, noted,

> *After our divorce, I knew that he was in secret contact with one of his relative's doctors who assured him that Deema was disabled. Then, after eight months, I noticed that my husband fully changed negatively towards my baby… My husband hated my baby girl so much once the disability symptoms started to appear. He asked me to stop taking her to receive her vaccinations. He was somehow disgusted and stopped carrying her… Since I received my divorce papers from the court up until now (it has been four years), he has never asked about his disabled daughter or picked the phone to ask about her; he fully abandoned her… I resorted to the court to demand my right to alimony; he didn't appear before the court. The judge had to send the police who brought him to respond to the court order, so he came, where the judge spat in his face saying, 'Aren't you ashamed of yourself, don't you have any feelings, what guilt does such a girl commit to make her father abandon her and deprive her from right of alimony?'*

Mothers of CWDs also explained that they were blamed by their parents-in-law for producing CWDs. One young mother of a 10-year-old blind boy in Jenin, for instance, explained that her in-laws ostracised her completely from family occasions and that even her attempt to invite them to an awareness-raising event at her son's school for the visually impaired fell flat.

> *Although my older son (the one who can't see) is very smart and is always on the school's honour roll, my parents in law only have sympathy for his father… They do not treat him the same as his brother who can see… They are deeply dead inside. They don't have feelings—sadly this type of social stigma is very strong around here.*

Another mother from Gaza, who has a child with intellectual disabilities, explained that,

> *My mother-in-law's pressures heavily increased on my husband once she started to notice the disability symptoms in my child. She advised him several times to divorce me and she wanted to marry him to another*

> *woman. Thus my husband succumbed to her demands and divorced me… I heard my mother in law saying to my husband, 'Now, you are with one CWD, but later you will you will be with two, three, four'. She was convincing him that he has nothing to do with his child's disability and it is only my problem and that I am the main source of disability and he was convinced.*

6.3.2 Awareness about adequate care, support services and rights

As noted in previous sections, while in the past support for the disabled was seen as a religious obligation owed by the more fortunate, recent decades have seen a shift towards recognition of PWDs' rights to services. One result of this has been the proliferation of CBR programmes, which aim to facilitate the inclusion of PWDs into all facets of community life. However, as Table 23 shows, while CBR programming is widespread, nearly half of families with CWDs in our sample were not aware it was available (37.3% in Gaza and 61.5% in the West Bank). Furthermore, nearly 90% did not know about the PDL. Unsurprisingly, given that even families with CWDs had low awareness of disability rights, study respondents reported that service providers and the broader community also had little understanding of the rights of CWDs.

Our qualitative work also found that parents had limited knowledge about CWDs' rights and what services were available to help them access these. In cases of children with intellectual or complex disabilities, this problem was often exacerbated by the fact that they had not been provided with an understandable diagnosis of their children's condition. We interviewed a number of parents who not only did not know what was 'wrong' with their child but also were tragically focused on a 'cure' rather than care and rehabilitation. This was especially the case with parents of children with complex mobility and neurological conditions. For example, one mother of a six-year-old boy with mobility and neurological disabilities, who lives in Yatta, reported,

> *We know that he had a lack of oxygen at birth—we went to the doctors many times when he was young—to find out when he would get better. We visited one doctor who gave him a massage which he said was to put oxygen into his body but it involved the doctor sitting on him and it looked so painful we had to stop this.*

A father of two children with brittle bone disease in the Jordan Valley voiced similar frustration. He had been to many doctors when the children were infants, but beyond a one-page certificate from MOH documenting their percentage disability the family had little information on how to care for them. Now nine and 12, the children were not even enrolled in school, because their parents did not understand what they might be capable of.

Table 23: Awareness of disbaility-related programmes and rights

Variable	Gaza	West Bank	SoP	P value
Lack of awareness of availability of CBR programmes for CWDs	37.3%	61.5%	48.7%	.000
Not familiar at all with rights of CWDs	51.4%	51.5%	51.5%	.237
Not aware at all of PDL	91.6%	84.5%	88.2%	.001
Not consulted at all about disability programmes	88.7%	98.0%	93.1%	.000
Not aware of existence of any disability-related bodies/forums including internet forums	88.2%	92.3%	90.1%	.051
Not a member of disability-related body/forum including internet forums—of those who are aware	64.2%	69.7%	66.3%	.597
Low rate service providers' understanding and respecting rights of CWDs	36.8%	44.0%	40.2%	.102
Low rate community understanding and respecting rights of CWDs	57.4%	47.5%	52.8%	.003

> *'I would try [to send them to school]—if he had support from someone. If there is someone available to support—to help them continue their study that would be great.'*

Parents find it especially difficult to support their CWDs' transition through adolescence and into adulthood. One mother, whose 17-year-old son is severely spastic, reported,

> *'I wish someone would teach him an appropriate job… I wish he could have a small shop to sell things. I would like him to work in a shop or on a computer—use his brain. We moved out of my brother-in-law's house so we could give him a small room—even he just sat there selling things with no profits I would be happy to see that… I have not asked anyone but I hope someone will help him.'*

In short, besides basic social assistance, which many respondents did view as their children's right, parents tended not to view tailored education and medical care similarly; rather, they hoped for charitable support but were often poorly informed as to which organisations might be able to provide this and, with relatively few exceptions, were not proactively seeking out assistance.

For the minority of parents who had been fortunate enough to receive support as caregivers of CWDs the contrast was stark. Not only their awareness about their children's rights and programmatic options but also their psychological wellbeing was significantly better, as these testimonies highlight:

> *The National Society for Rehabilitation in cooperation with Palestine Future for Childhood Foundation gave us training and awareness sessions, and then they selected five caregivers with CWDs to conduct a workshop for other mothers on how to deal with CWDs. I was selected among them, where I gave five training sessions (each session 20 women) where I trained myself on the training material under their guidance and support… It was a tremendous experience for me as we are all mothers or caregivers of CWDs; so it was better for us to listen and learn from each other as we all share the same sufferings and burdens (mother of a five-year-old girl with a physical disability, Gaza).*

> *My two children with disabilities, we send them to the Hope Centre. I have been part of a support group all these years—mothers come together and have snacks and leave behind their chores in this group. Sadly, because of building works and the lack of a room, we don't meet any more. I miss the group; I feel that it made me become younger. I was 36 years old, I felt 19 or 20 when I was in this group—it reduced my stress. If we don't have this support we can go crazy with stress… Everything that was in our minds we talk about! Still we talk by phone—when we meet in the school we say where is the fun that we used to have… Before the group I was very angry and very sad about my situation with my children but when I joined the group suddenly I started to turn on another life. I saw those with worse conditions in the group—I realised God sent these children to us because we are strong—these children will take us to heaven (Bedouin mother of two disabled children near Bethlehem).*

CWDs who were asked about their rights had some awareness, but generally lacked confidence that they had the same rights as other children. This was based on their experiences with education and health care, with CWDs having less access to rights than children without disabilities. As an 18-year-old Gazan girl with a visual impairment noted,

> *'Knowing the rights of CWDs doesn't makes any sense. These rights are not real and achievable in our society; that's why I don't care about them. Not knowing them is even better.'*

Another Gazan girl, aged 17 years old, with a hearing impairment, was also confident that CWDs enjoyed fewer rights than their peers without disabilities:

> *'The people without disabilities have rights more than the people with disabilities, but I don't like the people without disabilities. I don't know why. They are annoying.'*

A 19-year-old girl, also from Gaza, also with a hearing impairment, noted,

> *'I know that I have rights to study and work, and to have a translator in public places and on TV—I know this in theory but I don't know about the details of the law or how it is enforced.'*

6.3.3 Social attitudes and discrimination

The stigma surrounding disability in Palestine is both pervasive and strong. While our survey respondents indicated that mothers were almost universally supportive of their CWDs, fathers and siblings are less so (see Table 24). Extended family members are the least supportive.

Respondents noted that it was not uncommon for CWDs to receive less than their 'fair share' of family resources because CWDs are seen, even in some relatively well-off households, as poor investments. Indeed, a few CWDs indicated that the social isolation of richer CWDs could be even worse than that of poorer CWDs, as when families are over-concerned with status and prestige they may effectively hide their CWD from public view.

Table 24: Proportion of people who are supportive of CWDs with regard to his/her disability

People with whom CWD interacts	Gaza	West Bank	SoP
Mother	96.4%	98.8%	97.5%
Father	90.7%	86.3%	88.6%
Sisters	88.0%	87.3%	87.6%
Brothers	85.6%	85.5%	85.5%
Other family members like aunts	82.7%	71.7%	77.5%

Table 25: Proportion of people who are supportive of CWDs with regard to his/her disability

People with whom CWD interacts	Gaza	West Bank	SoP
Peers at schools/pre-school	42.7%	46.5%	44.5%
Neighbours	47.1%	45.5%	46.4%
Teachers	45.4%	50.5%	47.8%
Taxi drivers	26.9%	30.8%	28.7%
Health care providers (such as doctors and nurses)	47.6%	62.0%	54.4%
Salesman at shops	29.6%	26.5%	28.1%
People at mosques/church	23.1%	16.8%	20.1%
People at recreational places like restaurants—staff/customers	24.7%	22.3%	23.5%
People on the street	23.5%	20.8%	22.2%

Outside of the household, CWDs encounter very little support. As Table 25 shows, less than half of school peers, neighbours and teachers are considered by CWDs to be supportive, and less than a quarter of people on the street or at mosques/churches. Especially concerning is that even health care providers are very often unsupportive of CWDs. For example, 62% of respondents in Gaza reported unsupportive doctors and nurses.

The lack of support offered to CWDs can sharply limit the spaces and opportunities open to them. For example, as Table 26 shows, over 20% of respondents in our survey reported great difficulty in attending school because of

Table 26: Distribution of responses by difficulties faced because of people's perceptions and attitudes about disability

Item		No difficulty	Some difficulty	A lot of difficulty	N/A
Attending schools	Gaza	45.5%	7.3%	23.1%	24.2%
	West Bank	52.8%	11.5%	17.0%	18.8%
	SoP	48.9%	9.3%	20.2%	21.6%
Attending universities	Gaza	2.0%	0.4%	0.0%	97.6%
	West Bank	22.8%	2.0%	3.3%	71.9%
	SoP	11.8%	1.2%	1.5%	85.5%
Communicating with people	Gaza	41.0%	27.7%	30.8%	0.4%
	West Bank	47.3%	25.8%	18.5%	8.5%
	SoP	43.9%	26.8%	25.0%	4.2%
Fulfilling emotional needs	Gaza	40.0%	29.8%	30.0%	0.2%
	West Bank	46.0%	27.8%	18.5%	7.8%
	SoP	42.8%	28.8%	24.6%	3.8%
Socialising with others	Gaza	56.8%	23.3%	20.0%	0.0%
	West Bank	41.5%	28.8%	15.3%	14.5%
	SoP	49.6%	25.9%	17.7%	6.8%
Seeking health/rehabilitation services	Gaza	33.5%	28.2%	35.7%	2.7%
	West Bank	30.0%	23.5%	23.5%	23.0%
	SoP	31.8%	26.0%	30.0%	12.2%

Distribution of responses by difficulties faced because of people's perceptions and attitudes about disability (continued)

Item		No difficulty	Some difficulty	A lot of difficulty	N/A
Seeking social services	Gaza	33.7%	29.5%	31.5%	5.3%
	West Bank	30.8%	20.3%	19.5%	29.5%
	SoP	32.3%	25.1%	25.9%	16.7%
Seeking a job	Gaza	7.3%	2.0%	5.1%	85.6%
	West Bank	28.0%	13.8%	10.0%	48.3%
	SoP	17.0%	7.5%	7.4%	68.0%
Participating in public meetings	Gaza	35.3%	22.6%	27.1%	15.1%
	West Bank	30.6%	18.8%	12.8%	37.8%
	SoP	33.1%	20.8%	20.4%	25.8%
Understanding others	Gaza	53.2%	20.0%	26.8%	0.0%
	West Bank	43.0%	28.0%	21.0%	8.0%
	SoP	48.4%	23.7%	24.1%	3.8%
Being understood by others	Gaza	47.0%	22.0%	31.0%	0.0%
	West Bank	42.0%	27.5%	23.3%	7.3%
	SoP	44.7%	24.6%	27.4%	3.4%
Feeling he/she is integrated in the community	Gaza	38.8%	30.8%	30.4%	0.0%
	West Bank	39.3%	30.5%	21.8%	8.5%
	SoP	39.0%	30.7%	26.3%	4.0%

other people's attitudes and beliefs about disability. A full 30% reported great difficulty in seeking health care.

Table 27 highlights the pervasive nature and impacts of stigma in a different way. About one in four Palestinian CWDs, for example, reported that they felt the always community discriminated against CWDs. About 30% reported that they avoided doing things that they could do simply because of other people's attitudes towards them. One in five felt service providers discriminated against CWDs based on disability type—with physical and hearing-related disabilities relatively more privileged than mental and multiple disabilities. While less common, some respondents also felt poor CWDs, girls with disabilities and adolescents with disabilities were also subject to more discrimination from service providers. Some service providers give preference to CWDs injured by conflict, with those born with congenital or hereditary disabilities particularly stigmatised because of implications for the family reputation.

CWDs are frequently subject to name-calling—usually from other children in the community or in their extended family. As Figure 7 shows, about two thirds of CWDs are taunted by their neighbourhood peers and about a quarter by their cousins.

Social discrimination towards CWDs and their caregivers was a cross-cutting theme in our qualitative interviews as well—in both rural and urban areas, in Gaza and the West Bank and regardless of disability type. As one Gazan mother of two sons with visual impairments noted,

> *Society's view is very bad and harsh on them. People never understand their case and they are not kind to them. They don't understand that they have vision disability and can't see like other children. They face many difficulties in their daily life with such people. For example, Abdallah always returns to me cry with bitterness and ask Allah to take him. If he stumbles into someone unintentionally, the other person looks to him shouting angrily, 'Can't you see?? Open your eyes!!' He always says to me, 'Why did Allah create us like that and deprive us from our eye sight. I can't see like the most of children.'*

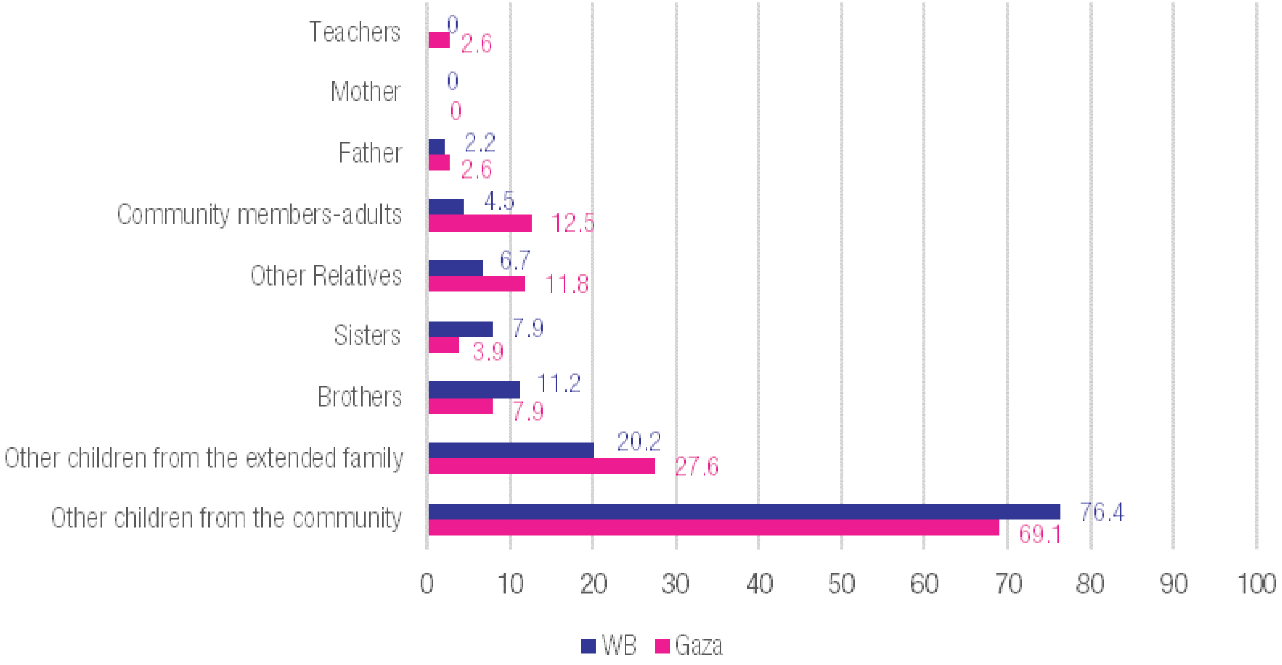
A Gazan mother with three children with dwarfism lamented how cruel the community can be:

> *'I felt so sad when his classmates insulted him in front of me on the day I attended his school ceremony where he was rewarded for high marks—seeing this really hurt me… When my children look at me, their eyes speak. I feel bad when someone nicknames them dwarfs.'*

Table 27: Distribution of responses about discrimination-related variables

Variable		Gaza	West Bank	SoP	P. value
Feeling the community in general discriminates against CWDs	Never	28.7%	23.8%	26.4%	0.00
	Sometimes	26.0%	26.3%	26.1%	
	Frequently	28.2%	18.0%	23.4%	
	Always	17.1%	32.0%	24.1%	
Avoiding doing things CWDs can do because of people attitudes towards disability	Never	72.9%	70.3%	71.6%	.064
	Sometimes	12.7%	13.8%	13.2%	
	Frequently	9.1%	6.5%	7.9%	
	Always	5.3%	9.5%	7.3%	
People in the community call the CWDs names in reference to his/her disability that CWDs don't like		33.0%	22.8%	28.2%	0.001
Service providers and policy-makers discriminate among CWDs in reference to type of disability		24%	16.5%	20.8%	0.002
Service providers and policy-makers discriminate among CWDs in reference to reasons behind disability		18.2%	1.5%	10.3%	0.001
Service providers and policy-makers discriminate among CWDs in reference to the age of CWDs		12.4%	5.3%	9.0%	0.001
Service providers and policy-makers discriminate among CWDs in reference to the gender of CWDs		6.9%	3.0%	5.1%	0.007
Service providers and policy-makers discriminate among CWDs in reference to socioeconomic status		19.1%	10.0%	14.8%	0.001

Figure 7: Distribution of responses by people who usually call the CWD with names in reference to his/her disability



While some parents continue to brave the insults of strangers towards their children, a significant number lamented that they had had to limit the social participation of their children because of discriminatory attitudes in the community. A Bedouin mother of an adolescent boy in a wheelchair in Ramallah villages, for example, reported,

> *'They ask questions and I feel sad—and they are sometimes very rude—he has nappies or he pees himself and then they make fun of him. One day I left a wedding party because of the questions. I started crying and only one other woman supported me and took us back to the compound.'*

Similarly, a father in Ramallah with three disabled sons explained that, even though he was proud of his sons and saw them as a gift from Allah, he was uncomfortable taking them into the mosque on a Friday. Instead he drives them near the mosque and leaves them in the car to watch, even though the youngest boy often begs to be taken inside. '*I do not want to hear the insults, I do not want to see the pitying looks.*'

Children also reported having to weather repeated insults from both relatives and strangers. A 14-year-old girl with multiple disabilities from Gaza City recalled that,

> *There was a girl in Grade 1 in the mosque who was always making fun of me with sarcasm saying, 'Ya Haram, we can walk, but you can't.' Sometimes, I get very angry and beat her… Once when I was going to a wedding with my family, there was a girl who was making fun of me and said laughing, 'Why do you walk like this? Are you crippled?' I answered her, 'This is the way Allah created me.'*

A 10-year-old girl from Gaza with muscular dystrophy told us,

> *'I will never return to the government school. School children were beating me and throwing me from my wheelchair while others were looking and making fun of me saying, 'Crippled, can't walk.'*

Similarly, an 18-year-old Gazan girl with mild Down syndrome said she was often verbally abused by her parents because of her disability:

> *Here in the centre I feel free to sit in the schoolyard and smell the clear air, but at home I feel suffocated because my parents refuse to let me go outdoors with them. One time my mother prevented me going with her to the wedding party… She insulted me and shouted at me, 'Stay here at home like a watchdog… you are a dog.' Also, my father insulted me with bad terms without any reason… They only insult me… They don't insult my siblings.*

Table 28: Distribution of responses by social participation in the past month

Social activity	Gaza	West Bank	SoP
Go with friends and family to places such as restaurants	38.1%	39.6%	38.8%
Visit friends and relatives in their homes	76.8%	71.7%	74.4%
Participate in social events (weddings and funerals)	54.6%	43.2%	49.2%
Send emails to friends and family or use the phone or mobile	27.8%	24.2%	26.1%
Play with other peer	67.3%	54.8%	61.3%
Visit clubs and organisations	14.3%	12.5%	13.5%
Use the internet to access information	15.9%	26.2%	20.8%
Use internet social media	14.6%	21.1%	17.7%
Invite friends and relatives in their home	37.4%	41.7%	39.5%
Participation in any kind of sports/play	54.1%	32%	34.8%
Being a member in one of the sport teams or sports institution	3.5%	1.2%	2.4%
Proportions of CWDs who reported NOT facing difficulties in participation			
Going to market	31.9%	31.3%	31.6%
Travelling for holiday or leave	26.2%	21.4%	23.9%
Visiting friends and family	48.6%	41.4%	45.2%
Going out to public places such as restaurants	38.6%	29.2%	34.1%
Performing in religious occasions	45.5%	36.6%	41.3%
Participating in local activities such as volunteering or community work	24.1%	26.2%	25.1%

6.3.4 Social participation

As Table 28 shows, our survey found Palestinian CWDs faced a variety of barriers to their participation in social life. Over the previous month, only a third had *not* experienced difficulty going to the market or out to public places such as restaurants. Indeed, more than half had faced difficulties in attending religious services or visiting friends and family. While nearly three quarters of CWDs had visited friends and relatives within their own home, and nearly half had attended social events such as weddings, CWDs were less likely to have visited clubs (13.5%) or been members of sports teams (2.4%).

The reasons CWDs gave for their lack of social participation varied considerably. As Figure 8 shows, the most common were a need for a personal assistant, cost and social stigma.

Our qualitative work also found that opportunities for children to participate in activities outside the home—especially for those out of school—were limited, because of both inadequate infrastructure and discriminatory social norms and attitudes. As a 15-year-old Gazan girl with a mobility disability explained,

> *The happiest day for me is when my school friends come to visit me. I feel very happy because I don't go to school and I miss them from time to time I feel very bored at home now; I just sit sadly waiting for the electricity to come. I feel very happy when we have electricity as it is only solace to watch TV and chat through Facebook.*

An 11-year-old Gazan boy with a visual impairment agreed,

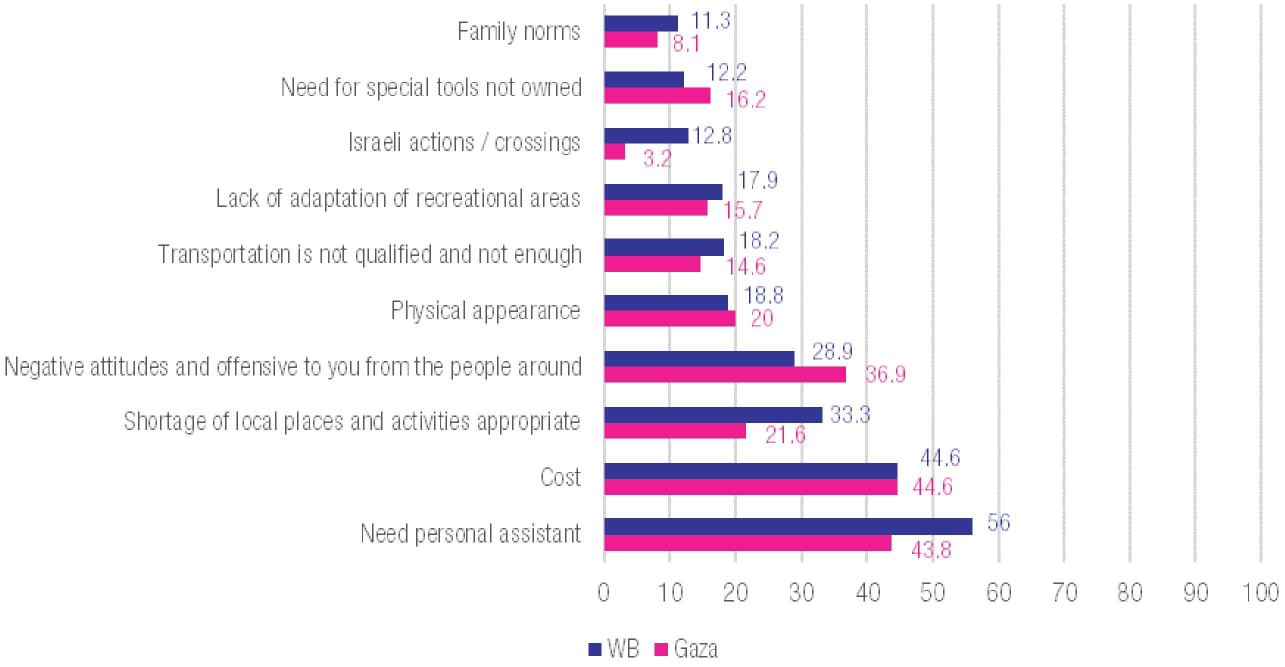
> *'None of my cousins comes to me and I can't go to them because I can't see and can't go alone. I sit only at the door and I don't go away. I just play close to my house door. If I go away, I will be lost.'*

Mothers agreed CWDs lacked social opportunities. The mother of a teenage Gazan boy with a physical disability told us,

> *'There is lack of opportunities for entertainment specially for children with disabilities, this is unfair. Who cares about those children!'*

A mother from Khan Younis, whose son has severe multiple disabilities, added,

Figure 8: Reported reasons hindering CWDs' participation in social activities



> *'I hope to get other services for entertainment of CWDs like my child as they spend most of their time between four walls or lying on their back.'*

For the few CWDs who are fortunate enough to be part of a supportive programme, the transformational effect of being able to take part in recreational activities is marked. As one boy with multiple disabilities explained,

> *It's a competition held for disabled persons in the Gaza Strip. There are 12 clubs for disabled persons. We participated in the game playing with three teams. The last one was with Al-Helal. We reached the finals. It was so crowded and people were encouraging us. For the first time in my life, I felt I lived in a great different world. Big difference!*

A graduate of the Alfaluna School for the Hearing Impaired, who is now 24, similarly looked back on the empowering experience the school had afforded her:

> *I have many talents, especially acting and singing, and I was a leader of the band here in this centre, they arranged many parties and many people from Gaza or outside Gaza were invited to watch our show, always they appeared surprised at our abilities and talents. The invited people didn't believe children with cerebral palsy could stand up on the stage and act, but they always were surprised about what we did.*

In some cases, particularly for boys, parents have been instrumental in making sure their CWDs have access to community life. A 14-year-old boy with a visual impairment in a highly socially conservative part of the Jordan Valley, for example, spoke confidently of joining his sighted peers in a football game—guided by a voice-activated ball. Largely thanks to his parents' encouragement, he is every bit as capable as his friends. His mother explained,

> *I've taught him to depend on himself and not to rely on people in general. He loves to challenge other children—I'm like you—don't think you are better than me… He is good at getting other children to think differently… and now he joins in regular football games and even leads other activities… He now coordinates an online forum across the region… He doesn't think in terms of barriers.*

Similarly, the family of an 18-year-old boy from the Jordan Valley, rendered mobility-impaired by cerebral palsy, explained that he was regularly out socialising with neighbours until the late evening.

> *He is very active—talks to different kinds of people. He is very loved by people around here… He is strong enough to push the chair by himself so he can go to weddings etc. by himself. He can get in and out of the chair by himself. At first we were carrying him everywhere but then he figured it out. He can even get down the stairs out of the house by himself… He usually goes outside to play—when the sun goes down—until the evening… This gave him the freedom to act like any other person. Too much time inside is not good for his health. He has the right to go out and play… I do get scared from time to time and yes he has been teased but his brothers protect him and I talk to the neighbours when I discover a problem.*

For adolescent girls, however, the situation is significantly more complicated and restrictive. As a 19-year-old Gazan girl with a hearing impairment summed up, '***Girls with disabilities have more difficulties than boys, because boys can go outside by themselves and have more freedom.***' A caregiver of a 14-year-old girl with a hearing impairment from Gaza added,

> *Saja is infuriated by the way boys in the street deal with her as a girl with a disability (calling her 'blind girl'). They annoy her very much .One day she took a stick to her school and she said to her teacher, 'My mother gave this stick to hit the boys who annoy me.' I was fully shocked with what she did. I never send a stick with her, but she is afraid of them hurting her, so she wants to defend herself.*

Girls' freedom is also compromised by parents' concerns about sexual harassment and risks to family honour. For example, in the case of one family in Hebron, which has two adolescents—a boy and a girl—with muscular dystrophy, the son is allowed to attend school and the daughter is not. Expectations regarding gendered social norms are deeply entrenched and often take precedence over other care concerns, as highlighted in the story told by a mother of two CWDs in Box 10.

Box 10: Double vulnerabilities of gender and disability-related discrimination

A Gazan mother of two sons with disabilities told us this story, which highlights the extra vulnerability of girls with disabilities:

> *I went to visit my son once, and there I found a girl in her early 20s. She wore jeans and was smoking a cigarette and drinking coffee while sitting on the corner of the street. I stopped the car and told her to come with me. She asked me if I was taking her to the 'madhouse'. I said no, but in fact I was returning her the mental health institution from which she escaped. I told the taxi driver to take me inside the hospital… Can you believe that the hospital manager beat her with a whip? I yelled at the hospital manager and asked if she even had a conscience. She replied, 'I want her to learn some manners and not flee the hospital anymore.' When the manager went away, psychiatrists there said they wished there were more people like me who did what I did. I knew that from the look of her clothes [not conforming to local modest dress standards for young women]. When I saw the manager whipping the girl after she returned to the hospital I told her, 'Even though I respect your rank and that of the doctors, I do not mind going to Anasar Prison. I should sue you for that behaviour. Then the doctors praised me and said I am a great woman and respect-worthy.'*

6.3.5 Quality of life/psychosocial well-being

Well-being is a multidimensional, complex concept that reflects people's evaluation of their physical and emotional lives. Our quantitative research used the KIDSCREEN well-being scale to evaluate the well-being of Palestinian CWDs. This instrument consists of 27 questions about five facets of life: physical health and activity; psychological well-being; friends; family and free time; and school and learning. As Table 29

Table 29: CWDs' overall well-being as evaluated by the KIDSCREEN tool

Item	Area	Excellent	Very good	Good	Fair	Poor
General rating of CWDs' health	Gaza	12.0%	19.5%	39.9%	18.6%	10.0%
	West Bank	13.3%	22.3%	37.6%	18.7%	8.2%
	SoP	12.6%	20.8%	38.8%	18.6%	9.1%
Feeling life was enjoyable	Gaza	20.0%	19.5%	32.9%	23.4%	4.3%
	West Bank	17.3%	24.0%	33.1%	19.1%	6.5%
	SoP	18.7%	21.6%	33.0%	21.4%	5.3%

show, there is reason to be concerned about the wellbeing of Palestinian CWDs. Only a third rate their overall physical health as excellent or very good. Even more concerning, fewer than 40% consider their lives very enjoyable.

Table 30 presents an in-depth exploration of CWDs' responses to the KIDSCREEN tool. It shows, for example, that about 40% of CWDs are very often or always full of energy and able to be physically active. It also shows that only about 15% of CWDs are happy with the way they are

Table 30: Distribution of CWDs' responses on the KIDSCREEN well-being scale

		Not at all/ never	Slightly/ seldom	Moderately/ quite often	Very/ very often	Extremely/ always
Physical activities and health						
Feeling fit and well	Gaza	3.9%	16.8%	39.2%	31.3%	8.8%
	West Bank	4.1%	17.1%	42.2%	27.4%	9.2%
	SoP	4.0%	16.9%	40.6%	29.4%	9.0%
Being physically active	Gaza	7.5%	19.7%	32.9%	30.4%	9.5%
	West Bank	9.6%	22.0%	28.0%	29.0%	11.4%
	SoP	8.5%	20.8%	30.6%	29.7%	10.4%
Ability to exercise well	Gaza	27.9%	19.2%	23.1%	22.6%	7.3%
	West Bank	27.6%	22.2%	22.0%	20.7%	7.5%
	SoP	27.8%	20.6%	22.5%	21.7%	7.4%
Feeling full of energy	Gaza	10.9%	17.2%	34.2%	25.6%	12.0%
	West Bank	9.8%	14.9%	36.6%	23.7%	14.9%
	SoP	10.4%	16.2%	35.3%	24.7%	13.4%
General mood and feelings about yourself						
In a good mood	Gaza	14.5%	15.5%	43.6%	22.7%	3.6%
	West Bank	12.6%	21.3%	43.4%	17.0%	5.7%
	SoP	13.6%	18.2%	43.5%	20.0%	4.6%
Child had fun	Gaza	10.2%	15.4%	40.6%	27.9%	5.9%
	West Bank	11.5%	15.1%	43.1%	24.4%	5.9%
	SoP	10.8%	15.3%	41.8%	26.2%	5.9%
Child felt sad	Gaza	18.9%	20.2%	38.2%	20.5%	2.3%
	West Bank	11.3%	18.7%	34.9%	23.6%	11.5%
	SoP	15.3%	19.5%	36.6%	21.9%	6.6%
Child felt so bad he/she didn't want to do anything	Gaza	19.7%	21.3%	38.1%	17.9%	2.9%
	West Bank	15.9%	20.0%	31.5%	22.1%	10.5%
	SoP	17.9%	20.7%	35.0%	19.9%	6.5%
Child felt lonely	Gaza	37.7%	21.4%	23.4%	13.9%	3.6%
	West Bank	23.5%	22.2%	27.6%	15.2%	11.6%
	SoP	31.0%	21.7%	25.4%	14.5%	7.4%
Child is been happy with the way he/ she is	Gaza	39.0%	21.5%	26.3%	11.3%	1.8%
	West Bank	36.8%	18.4%	26.3%	13.6%	4.9%
	SoP	38.0%	20.1%	26.3%	12.4%	3.2%

Distribution of CWDs' responses on the KIDSCREEN well-being scale (continued)

		Not at all/ never	Slightly/ seldom	Moderately/ quite often	Very/ very often	Extremely/ always
Family and free time						
Having enough time for him/herself	Gaza	10.7%	8.9%	37.0%	35.9%	7.5%
	West Bank	12.0%	12.5%	30.4%	24.8%	20.2%
	SoP	11.3%	10.6%	33.9%	30.7%	13.5%
Able to do the things he/she wants to do in his/her free time	Gaza	13.6%	13.8%	41.5%	26.5%	4.5%
	West Bank	19.0%	18.0%	31.1%	19.0%	12.9%
	SoP	16.1%	15.8%	36.6%	23.0%	8.4%
Child felt his/her parent(s) had enough time for him/her	Gaza	6.3%	5.9%	25.6%	41.0%	21.1%
	West Bank	3.1%	3.8%	17.6%	26.1%	49.4%
	SoP	4.8%	4.9%	21.9%	34.0%	34.4%
Child felt his/her parent(s) treated him/her fairly	Gaza	5.9%	2.9%	11.6%	48.8%	30.8%
	West Bank	2.0%	2.8%	8.2%	24.6%	62.4%
	SoP	4.1%	2.9%	10.0%	37.4%	45.7%
Child able to talk to his/her parent(s) when he/she wanted to	Gaza	13.7%	7.8%	18.5%	35.2%	24.9%
	West Bank	10.5%	5.9%	15.1%	21.2%	47.3%
	SoP	12.2%	6.9%	16.9%	28.6%	35.5%
Child had enough money to do the same things as his/her friends	Gaza	18.2%	29.5%	27.7%	16.8%	7.7%
	West Bank	32.5%	13.8%	26.6%	12.5%	14.6%
	SoP	24.9%	22.1%	27.2%	14.8%	11.0%
Child felt he/she had enough money for his/her expenses	Gaza	18.6%	26.8%	28.8%	17.9%	7.9%
	West Bank	29.7%	13.6%	30.0%	14.4%	12.3%
	SoP	23.8%	20.6%	29.4%	16.2%	10.0%
Friends						
Child spent time with his/her friends	Gaza	25.4%	11.1%	27.9%	24.9%	10.7%
	West Bank	29.2%	14.1%	25.4%	22.3%	9.0%
	SoP	27.2%	12.5%	26.7%	23.7%	9.9%
Child had fun with his/her friends	Gaza	26.1%	10.7%	27.4%	25.9%	10.0%
	West Bank	28.0%	16.2%	25.7%	20.6%	9.5%
	SoP	27.0%	13.3%	26.6%	23.4%	9.8%
Child and his/her friends helped each other	Gaza	37.9%	12.5%	27.2%	16.6%	5.9%
	West Bank	38.1%	12.3%	24.8%	18.2%	6.6%
	SoP	38.0%	12.4%	26.1%	17.3%	6.3%
Child able to rely on his/her friends	Gaza	47.2%	15.6%	22.9%	9.8%	4.5%
	West Bank	50.5%	13.1%	19.0%	11.3%	6.2%
	SoP	48.7%	14.4%	21.1%	10.5%	5.3%

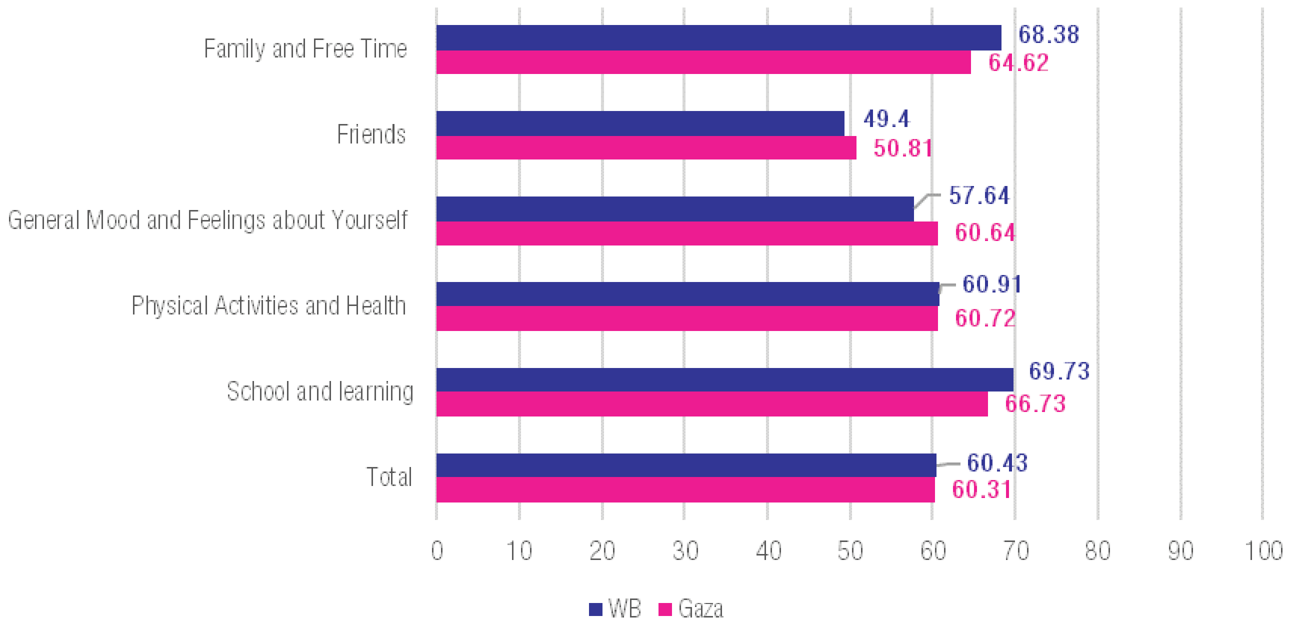
		Not at all/ never	Slightly/ seldom	Moderately/ quite often	Very/ very often	Extremely/ always
School and learning						
Child happy at pre-school/school	Gaza	8.9%	15.0%	22.5%	40.7%	12.9%
	West Bank	7.6%	8.9%	27.1%	33.1%	23.3%
	SoP	8.3%	12.2%	24.6%	37.2%	17.6%
Child got on well at pre-school/school	Gaza	9.7%	15.8%	24.0%	40.5%	10.0%
	West Bank	6.4%	12.8%	30.6%	30.6%	19.6%
	SoP	8.2%	14.4%	27.0%	36.0%	14.4%
Child able to pay attention	Gaza	12.5%	12.5%	31.4%	32.5%	11.1%
	West Bank	10.6%	20.8%	33.1%	18.2%	17.4%
	SoP	11.6%	16.3%	32.2%	26.0%	14.0%
Child got along well with his/her teachers	Gaza	5.0%	9.6%	26.1%	40.4%	18.9%
	West Bank	3.8%	5.5%	23.7%	36.4%	30.5%
	SoP	4.5%	7.8%	25.0%	38.6%	24.2%

and about 60% of children had felt so bad in the previous month that they did not want to do anything.

In terms of relationships with family and friends, while CWDs reported often not having enough money to do what they wanted to do, they were overall quite satisfied with the attention they received from their parents. Friends, on the other hand, were often a different matter. Nearly half of CWDs reported that they could never rely on their friends; only about 5% said they could always rely on them. Finally, despite the concerns about school presented earlier, according to the KIDSCREEN tool most CWDs are overall happy at school (about 75%) and feel they get on well with their teachers (about 90%).

Figure 9 shows our calculations for children's overall well-being. As noted above, the tool includes 27 items—all of which are scored on a five-point Likert scale. After combining them, the average well-being score for the CWDs in our sample was only 60%—far less than other studies have found using the same scale, albeit in very different cultural contexts (Ravens-Sieberer et al., 2014). As expected, given the results in Table 30 above, well-being composite scores are relatively higher for the family and free time and school and learning domains, and relatively lower for friends and general mood.

Figure 9: Composite KIDSCREEN domain scores



In terms of differences in well-being and quality of life, some important differences emerged between groups of CWDs. According to results from the Quality of Life Survey, CWDs with multiple or cognitive disability had the lowest quality of life scores. Older adolescents also reported lower satisfaction—possibly because of increased psychosocial and financial demands. There were also differences by governorate—with CWDs in Salfit and Rafah reporting the highest scores and those in Hebron and North Gaza the lowest. Interestingly, CWDs in regular and special education reported higher scores than those who were out of school and enrolled in vocational training (see Annex 6).

Our qualitative work found the psychosocial wellbeing of CWDs was closely linked to a combination of supportive parents and supportive educational facilities. Children who had been through appropriately tailored schools often spoke confidently about their capabilities and the inner strength they had developed to respond to the discriminatory attitudes they encountered in their communities. The Alfaluna School for the Hearing Impaired was often singled out. As one 24-year-old woman with cerebral palsy said,

> *Actually I don't care about people's vision and opinions about me, I don't try to know people in depth who discriminate against people with disabilities… Many times while I was in the street I heard some bad words, irony and insults from people, and they were looking at me in a strange way. This pitying look—we don't need it. I always asked myself what the difference is between me and between those people who look at me with pity. However, I did not care. I tried not to give any value to their negative attitude.*

The CWDs in the focus group we held at Hebron School for the Blind were also very confident about pursuing tertiary education and achieving an 'ordinary' life in the future.

However, for CWDs outside of the school system or in schools where they were poorly integrated or even subject to abuse, psychological stress was a significant concern, as CWDs and mothers noted. A 15-year-old boy with a hearing impairment in Gaza said,

> *'As a deaf person I feel oppressed by society so this affects me a lot and causes me sleeplessness and insomnia. The difficulty contacting people made me enclosed on my own.'*

> *I fully reject the idea of integrating her in normal schools (Ramla School) since I am afraid children will tease her and she will be depressed. Children of that age have a different mind-set and maybe they will not accept her case… She feels very shy of the taxi driver and of her young cousin who takes her to and from the care, so she now fully rejects going to school [for children with special needs]. I wish if she has any psychological support, I wish so… They may be able to convince her to return to her school (mother of 15-year-old girl with physical disability east of Gaza City).*

> *An 18-year-old girl with a physical impairment in Gaza said, 'I have no photos of me. Whenever I take a photo for myself, I find it ugly then I tear it up immediately.'*

> *Only recently has he accepted to go in his wheelchair. He used to resist as he didn't want to admit the weakness in his legs. He sees his older brother [who is bedridden] and is very depressed about his future. He is very talented at art and at singing but his future will be very tough. We feel so sad about this and this is why we try to spoil our sons… as their lives will be short and painful (mother of three sons with muscular dystrophy, Ramallah).*

Unfortunately, psychological support services are limited in general in Palestine and we came across only a few cases of CWDs receiving such support. For example, while approximately 30% of children reported requiring psychological support, only 8% in Gaza and 4% in the West Bank reported having received it in the past year. Generally, children relied on their mothers—or siblings—for support. In the case of families with several CWDs, children often reported that their best friend was their disabled sibling. A 15-year-old hearing impaired boy from Gaza explained,

> *'Ahmed is my friend and my classmate, he has the same hearing disability as mine he understands me easily and we talk to each other for hours easily, and he likes me and always there to listen to me.'*

Compounding the social discrimination and isolation many CWDs feel are the effects of the ongoing conflict with Israel—especially in Gaza. In some cases this is related to the fact that the conflict has destroyed any semblance of accessible infrastructure and in other cases it is because of the trauma of seeing siblings and friends injured and even killed by violence. For example, as a 17-year-old adolescent boy with a physical disability explained,

> *'We are very poor, we don't have anyone who could give us the basic needs. Our home is fully demolished because of the war, until now no one started the reconstruction process or did a minimum maintenance for us.'*

Similarly, a 17-year-old girl with Down syndrome explained that,

> *'I was shocked when I came back after the war and found my society was partially damaged. I was afraid.*

> *My friend passed away in that war. I went with my mother to visit my friend's family after her death.'*

The mother of a 15-year-old girl with a hearing impairment added,

> *She is very affected by war scenes. Since her brother was injured, she saw his injury and the blood in front of her eyes, she was traumatised and became very frightened. The bombing was so strong in all our area and targeted our house. Despite her deafness, Saja could hear the sound, which was incredibly high, then she fainted on the ground.*

7. Analysis of barriers to service delivery

Disability-related legislation and policy have evolving continuously. As Section 4 noted, the legal and policy framework currently in place in Palestine is largely responsive to international frameworks for PWDs and, in principle, to the needs of those with disabilities. There are, however, significant barriers to the adequate and effective implementation of services—including weak coordination among services—which results in CWDs being unable to have their rights met. Some of the main barriers identified during the course of the research through discussions with key stakeholders and decision-makers working for children with disabilities are explored below.

7.1 Dearth of information on CWD

One of the central concerns in being able to provide CWDs (and PWDs more broadly) with the services to which they are entitled is the fact that many of them are not known to service providers. At the moment, there is no central database to document CWDs (as encountered by our team when developing the sample for this study) or even separate clinical reports on the number or type of disabilities seen at centres run by MOH. While MOH recognises that this critical information needs to be incorporated into the reporting system, staff lack the skills or knowledge to do this. As an example, there is currently no special section in the ministry's annual report with statistics on the attention provided to CWDs in MOH hospitals and clinics. As such, planning for health services that these children need at the different levels of attention is impossible. What is more, according to interviews at MOH, there is no system for referral for CWD within the ministry, or one that coordinates with other health service providers.

Similarly, in the education sector, there is no specialised admission system to assess children to identify their areas of disabilities and level of functions in different aspects of their lives, and to compile data on their social, economic and environmental conditions or their need for further support. Therefore, there is no such data on CWDs entering attending government schools, making it hard to plan, monitor and follow up on cases.

MOSD, despite being the main coordinating agency for PWDs/CWDs, lacks a comprehensive database for PWDs—although Gaza is closer to achieving this than the West Bank due to its 2012 house-to-house disability survey. This gap is the result of the inadequate diagnostic and reporting system in place—particularly by the health sector—but also of the limited expertise of social workers in terms of identifying disabilities and reporting them into the system so they can be monitored and supported. Registration of CWDs is based largely on parents registering their families with MOSD or other services, although in Gaza it is also bolstered by the efforts of the Palestinian Medical Relief Society and the National Society for Rehabilitation, which register PWDs in the eastern and northern areas of Gaza and the Gaza Strip respectively.

As Section 6 discussed, families of CWDs complain about not getting adequate support from MOSD or not being accepted to benefit from the PNCTP. In addition to the incomplete database, and based on discussions with staff at MOSD, another reason for their exclusion from this benefit is that the current PNCTP uses a formula that does not give special weight to CWDs in the appraisal process. The director in charge of disability at MOSD has been working within the ministry to promote changes to this formula so that more weight is given to disability, accounting for the additional challenges and costs facing families in this situation, but such efforts have so far been unsuccessful.

7.2 Lack of institutional coordination and fragmentation of services

The lack of coordination in service delivery is particularly visible in the weak referral mechanisms in place between the different ministries in charge of CWDs, as well as in limited awareness of available (government and NGO) service providers by some of the organisations. It is also visible in the knowledge gaps on what the different organisations working with CWDs are doing at the different levels. Having such coordination in place is particularly important given the context of limited resources, where the government relies on NGO and private service providers, and also to maximise the attention provided to users by ensuring they have access to the relevant caregivers.

This situation can be improved by developing agreements among the different service providers of PWDs, requiring organisations to provide up-to-date and regular information about the services they give, their capacity, etc.—via a web portal, for example, or municipal authorities—so that this information can then be channelled to those in need via social workers or service providers they do have access to. This would enable organisations to utilise their resources more efficiently. However, this type of ground-level knowledge management system is not currently in the pipeline.

Partnerships between ministries at a higher level is also essential to ensure better access to services for CWDs who face marginalisation from a number of services at the same time, but these are currently missing. As Section 5 noted, the Coordinating Council on Disability is not performing its role, and there is a vacuum in this function. MOSD, which should—in principle—act as the coordinating agency between governmental and non-governmental service providers for CWDs does not at the moment effectively coordinate with other agencies. For example, given that MOSD social workers are generally in contact with families with PWDs, they would be well positioned to provide PWDs and their caregivers with information about the services they could access, as well as referring them to the relevant service providers (CBR, health clinics or schools). However, at the moment there is no comprehensive picture of organisations in the system that can be accessible within MOSD for all PWDs and that social workers could know about and share. Social workers currently provide information based on their knowledge and experience but this varies according to the individual.

While MOSD's is responsible for leading the Coordination Council on Disability, a body that should put in place top-line policy and programming and foster coordination among ministries, as discussed this body is not yet fully functional. The members meet occasionally—annually or biannually—so not much gets done. This is largely the result of limited commitment by staff in ministries and institutions and in some NGOs working with PWDs to the objectives of coordination and sharing of information. This is exacerbated by competition—including for funding and support—among MOSD and NGOs in the sector. In many cases, MOSD is sought to endorse NGO projects but it becomes a beneficiary rather than a player or a leader in the field. For example, the Union of PWDs does not try to coordinate or communicate with MOSD, and as such is unable to promote more coordination among the different service providers.

The reactivation of the Council requires political will, commitment and good policies that best serve the different gaps in coordination and communication among the different players. So far, there has not been sufficient agreement to take this Council forward to meet the demands of PWDs.

At the individual ministry level, there needs to be greater clarity in each relevant ministry's organisational structure (health, education, labour, transportation, etc.) as to the location of its disability unit to promote accountability, adequate delivery of services and better coordination.

7.3 Inadequate staff capacity

The dearth of services for CWDs is closely linked to inadequate or unprepared staffing in the different sectors, as noted by many of the interviews with CWDs reported in Section 5.

Discussions with top-line decision-makers uncovered that staff working with CWDs, including medical professionals, teachers and social workers, did not have the technical or professional qualifications or knowledge to work with PWDs/CWDs and therefore were unable to provide quality services. In many occasions, there was even discrimination and abuse by public servants towards PWDs.

In the case of the health sector, for example, interviews at MOH in Ramallah revealed that governmental health care services did not have sufficiently trained personnel. MOH physicians are not skilled or trained to detect many disabilities, except for basic mobility-related disabilities such as hip dislocation, as there are no policies, guidelines or instruments that could serve as resources to help them provide better services to PWDs, particularly young children. While MOH's medical committees should use the International Classification of Functions (ICF) to guide and standardise their work and this should serve as a reference at the national level, this is not consistently the case. Capacity of health service providers such as doctors, nurses, speech therapists, special educators, etc. should be improved in to work towards the early detection of developmental delays and disabilities and interventions, through trans-disciplinary training and development of standardised guides and instruments for early detection and interventions. This will help in avoiding inappropriate diagnosis and reporting and making sure teams of professionals are around the family and the child. Given the lack of capacity of service providers and standardised guides and instruments, many children are misdiagnosed with an overestimated level of disability to allow them to benefit from health insurance, cash transfer or customs exemption. However, this can also jeopardise the opportunities of these children—particularly those with mental or intellectual disabilities—to benefit from future scholarships to pursue education as they can be excluded from educational services inappropriately.

In the case of MOEHE, preparations for inclusive education were gradual, starting in 1997/98 with training for a few education counsellors. By 2005/07, MOEHE had in each school assigned a teacher as a focal point to follow up on inclusive education. An interviewee from MOEHE explained that in 2015 the ministry had adopted the Inclusive Education Policy, with some successes in integrating children with visual and physical disabilities in education supported with some services and aids as these children required more minimal specialised services to accommodate them in the school system. However, despite improvements in the awareness of families, teachers, school personnel and those at ministerial level, inadequate social support for CWDs deters them—especially those with mental illness—from accessing education.

MOEHE recognises that its human resources are still inadequately trained and there are insufficient dedicated staff available to enable full implementation of the policy. As such, more training is needed to prepare school teachers, counsellors, district education supervisors and qualified experts in different areas of inclusive and special education.

While every school has been appointed a teacher responsible for monitoring or addressing inclusive education in the West Bank's 1,800 schools, these special teachers are not compensated or provided with incentives to cover all the cases or the issues facing CWDs in these schools. Many of these teachers are exhausted because they also have to do their full teaching load. In fact, MOEHE explained that trained special education counsellors were responsible for 100–170 schools so were overburdened. This may be one reason why, as reported in our quantitative and qualitative research, schools in practice are unable to identify a focal point for CWDs, with many respondents saying they did not have a specialised teacher in the school to support inclusive education. Our data shows that, as a result of this important gap, many CWDs are effectively excluded and drop out. This suggests some level of disconnection at MOEHE between how the Inclusive Education Policy is being planned and what happens in practice.

MOSD is similarly aware of the limited training of its social workers to deal with CWDs. In fact, it has been considering funding options in order to be able to provide specialised training to social workers on how to deal with PWDs, including on the role of social workers in connecting PWDs. This is critical given that—as our primary research found—most of the social workers who interact with CWDs have limited to no knowledge of how to support them or channel them to adequate services.

The MOL also lacks sufficient staff capacity to meet the occupational training needs of older CWDs. While its centres offer training in a wide variety of fields, including carpentry, painting, and tourism, the ministry admits that they have a shortage of trainers who are equipped to help CWDs benefit from their services. While programmes can be relatively easily adapted for those with physical disabilities, there is little capacity to adapt programming to meet the needs of those with intellectual disabilities or speech and hearing issues. Trainers facile with sign language are particularly difficult to locate.

7.4 Poor diagnostic capacity

The Palestinian health system faces significant challenges affecting both the efficiency and the effectiveness of its operations (MOH, 2014)—challenges which all too often result in some children becoming needlessly disabled and prevent others from receiving the timely services that would mitigate the severity of their disability. While overall health services have good numerical coverage in terms of hospitals and health centres, and medical staff population density rates are high for the key health professions (PCBS, 2015a), specialisation of medical professionals in disabilities is limited, and protocols to diagnose and treat disabilities—particularly to undertake early diagnostic in the youngest children—are weak.

Critically for CWDs, prevention and early intervention programming is largely absent. As noted above, many disabilities are not diagnosed until children enter primary school, meaning they are denied services during the crucial years from birth to three. According to WHO (2013), for instance, 50% of deafness and hearing impairment is avoidable through prevention, early detection and diagnosis and early intervention. In Palestine, however, although medical professionals have a high level of commitment, most lack knowledge and expertise to diagnose and treat developmental delays and disability in early childhood.

As noted in Section 6, many respondents in both the quantitative and qualitative interviews stated that children had been diagnosed quite late in their lives, and were frequently misdiagnosed. This is important, because a child who has an inadequate diagnosis is less likely to receive the medical, educational and social services he or she requires

According to interviews with MOH, the ministry has no specific policy for early detection of CWD; such diagnosis is part of its overall maternal child services but without any specific guidance on how to diagnose babies *in utero* or newborns with a range of disabilities. From three to six years of age, children receive partial follow-up care through casual visits by health care providers for those in nurseries. While children receive a medical check-up, they do not have adequate follow-up mechanisms if they identify a delay or disability. At age six, children in Grade 1 are examined and can be screened and diagnosed for visible disabilities such as vision, hearing or learning difficulties; mental health screening is part of the package added to school health services. Palestine is actually considered a pioneer in the region for these integrated health screenings, done in collaboration between MOH and MOEHE. However, there are no specialised diagnostic centres to detect different degrees of mental illness and non-specialised referral centres that can help deal with more complex cases, which therefore reduces the capacity for rehabilitation and stimulation or education.

Diagnosis of the type and level of disability is useful for MOH to determine eligibility for health insurance or exemption from customs (to import disability aids), or education fees. As Section 4 noted, health insurance applies only to those considered at a level of disability of more than 60%. However, the approach to determining this level of disability is outdated and does not follow international standards—plus it is applied with significant variation across Palestine. As a result, there are huge discrepancies in how disabilities are diagnosed and who receives health insurance and other benefits. It is therefore necessary for MOH and other health providers to start using the ICF to guide and standardise the work of these medical committees to become a more objective reference at the national level.

At the moment, MOH is thinking about formulating guidelines and instruments to assess children's development and appropriately target interventions, but lacks the human and financial resources to do so. Implementation of these guidelines would also require a detailed reporting system that includes numbers, types, abilities, learning abilities, social abilities, cognitive and life skills abilities, to make it possible to provide services that are more responsive to needs as well as to have more robust knowledge about the situation of PWDs in Palestine.

Inadequate diagnosis is also a problem in schools. According to interviews with MOEHE, while school teachers should be able to identify and refer CWDs, this does not typically happen in practice. Schools lack the expertise to identify disabilities (beyond the more obvious ones), so many children remain undetected, while failing to progress to the next school year or make adequate progress at school. In many cases, only after several years of these children performing badly do teachers start considering the need to refer these cases to more specialised schools or recommending they stay home (when they cannot think of relevant alternatives). This is especially the case for children with mental difficulties. In addition, schools lack adequate diagnostic equipment, aids, wheelchairs, hearing aids and other items needed to support students with special needs, especially in terms of cognitive and mental disabilities. This situation identified by MOEHE was corroborated through our primary research.

7.5 Insufficient adaptation in response to disabilities: inadequate inclusive services

The inadequacy of inclusive services is linked to many factors, including insufficient implementation of policies and legislation. In the health sector, the basic package of health services provided by MOH and UNRWA, the two main providers, is excessively medically oriented and does not incorporate specifically designated services for PWDs. Rather, PWDs are served without taking their disability-related needs (e.g. disposables such as nappies or therapies such as speech therapy) into account—leaving NGOs to provide disability-specific care. The lack of disability-specific health care also means the families of Palestinian PWDs must rely on their own funds to meet needs—which has exacerbated existent socioeconomic inequalities. Similarly, while the universal health insurance covers children until the age of six, it does not take account of developmental delay or disability. As a result, the standard services provided to children aged six and below does not respond to specific needs resulting from disabilities, except if they are lucky enough to be referred to a specialised centre or if the family is able to pay for a private health provider (which, as Section 5 showed, does not necessarily result in better services for the CWD). This is the result of the health law not having any specific reference to dealing with PWDs.

Despite the 1999 Disability Law and on and the 2015 policy on inclusive education, there are still many barriers preventing schools and the education system in Palestine from really becoming inclusive. In fact, the disability law of 1999 is outdated and virtually inactivate. It needs to be reformed based on the Inclusive Education Policy to promote its implementation. The Tracking Disability and Out-of-School Children Framework, which is part of the Global Out-of-School Children Initiative, considers barriers to school participation for CWDs and is a good starting point for analysing the barriers that remain in Palestine to promoting real inclusive education that goes beyond laws and policies and into practice (UNICEF and UNESCO Institute for Statistics, 2015).[8]

There has recently been attention to adapting infrastructure and providing teaching staff with disability-related training and support, but this is still insufficient. The literature indicates that transportation, financial constraints, attitudes (individuals, peers, parents, teachers), teaching and care provisions, curricula and physical access are interacting factors that create barriers to their education (Zaqout and Abu-Hamad, 2013), especially for poorer families, given that transport costs and adapted educational materials are most often out-of-pocket (PCBS and MOSD, 2011; Zaqout and Abu-Hamad, 2013). Results from the PCBS and MOSD survey (2011) indicate that a variety of adaptations are urgently needed if CWDs are to equitably access education. For example, 24.5% of children with seeing disabilities require adaptations to transportation to their schools in order to continue their education, and 38.5% require adaptations to classrooms. Similarly, 24.2% of children with hearing disabilities require adaptations to classrooms and 50.0% of children with mobility disabilities require transport and toilet adaptations.

The youngest and oldest CWDs are the most likely to encounter poorly adapted facilities. A quarter of pre-schools have un-adapted classrooms and toilets and, outside of a handful of specialist schools, there are very few educational programmes in tertiary schools for CWDs who wish to pursue secondary education, TVET or university education. Additionally, the framework calls for flexible curricula that respond to different learning needs, challenges and strengths, but this has not yet been put in place.

In line with the literature, according to our primary data collection one of the initial and most important barriers—as identified by many respondents—is the lack of transportation arranged for PWDs from their homes to their schools. This denies many CWDs the possibility of attending

---

[8] http://www.uis.unesco.org/Education/Documents/oosci-operational-manual.pdf

school, particularly those from poor households whose parents are unable to pay for private transport services.

Most schools also lack the necessary resources for inclusion of CWDs. For example, although EFA reports having rehabilitated 523 general schools, schools designated 'accessible' often have only an entry ramp, and the Department of Engineering lacks sufficient resources to provide facilities more carefully adapted for all types of disability (ICHR, 2014). Tailored curricula for older CWDs are also often lacking (Alawni et al. 2012). While some may have ramps for accessibility of children in wheelchairs, other facilities, such as toilets and computer labs, are usually out of reach. Further, adaptations for children with other types of disabilities—such as sight and hearing disabilities—are seldom in place, and there is a dearth of the materials and technologies they need to progress in school (such as braille computers).

In most schools, infrastructure has not been adapted for inclusivity. The physical accessibility of schools is still a major limitation and there are no services provided for children with hearing impairments who need sign language interpretation or for children with moderate to severe intellectual disabilities, as these are almost excluded from the formal education system.

Teachers trained to educate CWDs should be the cornerstone of the inclusive education system. However, training on inclusive education is provided by core special education trainers, who are very few so their reach is limited: 24 core trainers cover all directorates in different West Bank districts. Occasionally, MOEHE recruits trainers from local partner organisations such as the Arab Rehabilitation Organisation in Bethlehem (especially in visual difficulties), or Palestinians trainers from Israel; on rare occasions, they bring international experts. Similarly, there are only four special education advisors covering 16 educational directorates in the West Bank; MOEHE estimates there should be one special education advisor per educational directorate.

Further complicating the delivery of inclusive education, there is no national referral system with policies and guidelines to govern school-aged CWDs. Schools accept all students and then perform referrals occasionally, without clear guidelines. They refer children with severe disabilities, and generally also those with Down syndrome or speech difficulties and cases of intellectual disabilities. Referrals can be for a short period of time or longer periods depending on the severity of the case. According to interviews with MOEHE, it is tasked with following up on these cases to refer them to the most appropriate school or centre. However, our interviews with families with CWDs suggest proper follow-up on referrals is seldom done, and, given that many of the specialised centres are distant and they can be expensive, only a few CWDs effectively attend. The high number of out-of-school CWDs as shown in Section 5 is a clear illustration of how this integration and referral system is not working well.

A specific challenge facing primary schools that teach CWDs—both specialised and inclusive schools—is that many receive children who have not had access to pre-school, access to which is not guaranteed by law in Palestine. The schools also then see their students effectively abandoned after Grade 10, when they must transfer to poorly resourced government schools in order to complete their education.

Also importantly, although the policy recognises the importance of 'citizenship education'—that is, it includes the principle of 'Promoting understanding and attitude change', which entails 'raising awareness of the importance of (and change attitudes towards) child-friendly, inclusive education and of non-discrimination and diversity in education'—most of the emphasis is placed on teachers and on the school system, with less on work with peers to sensitise them to improve their attitudes towards CWDs. Active sensitisation and engagement of children without disabilities is crucial to effectively include CWDs in peer groups, rather than condoning discrimination, which is currently the common practice.

In practice, according to discussions with MOEHE staff as well as evidence from our interviews with CWDs, MOEHE is not able to do much to get a CWD back to school once he or she has dropped out. Officials realise that constraints may lie at the family level (in terms of willingness to send a CWD to school or lack of resources to pay for transport or a special school), but the limited personnel available at the district level to work on such difficult cases proves a challenge.

7.6 Insufficient funding and resources

While it is difficult to extrapolate the amount spent on services for PWDs because sector spending is not disaggregated (PCBS, 2010, p.98), there appear to be no clear financing strategies or budget allocations to ensure the sustainable financing of services for PWDs/CWDs (World Bank, 2016, p.5). Furthermore, despite the fact that the vertical (sectoral) rather than cross-cutting nature of disability-relevant strategies and policies means related activities tend to be isolated from each other (Alawni et al., 2012), sectoral data on disability has never been collected as part of the national strategy (World Bank, 2016). Enforcement mechanisms and tools are also lacking, in part because the roles and responsibilities of line ministries are neither clearly understood nor effectively put into practice by government staff (Pereznieto et al., 2014), and clarity on referral mechanisms between government bodies and non-governmental service providers is poorly articulated (YMCA, 2015). Finally, a lack of coordinated collective action across the full spectrum of stakeholders—the state, donors, NGO service providers and communities—fosters competition and fragmentation of efforts (World Bank, 2016, p.3).

During many of the interviews at national, intermediate and local levels, insufficient resources came up as one of the main challenges for the provision of services to CWDs. MOEHE, for example, highlighted during an interview that it had insufficient financial resources to implement the missing components of the inclusive education plan on the ground. As noted above, the first steps to do this include training of teachers, adaptation of schools and developing a referral and monitoring system. Similarly, in the health sector, establishing and following international guidelines to diagnose and treat PWDs require an important investment of resources in developing the guidelines, training personnel at all levels and setting up more established coordination mechanisms with health providers that can more effectively collaborate with the ministry's efforts at all levels.

In addition to the limited funding available for government agencies, the organisations that provide services to CWDs not provided by the government—including the organisations we visited—identified a common challenge. While acknowledging the broader budgetary limitations in Palestine, the finance gaps surrounding disability services also speak to the reality that providing comprehensive, quality services to Palestinian PWDs is not a national priority. Indeed, informants at most centres and organisations reported that they depended on multiple sources of 'seasonal' funding, which inhibits long-term planning and compromises service quality. Additional resourcing is critical in order to expand the reach of services, given the large scale of the under-served population.

While the Palestinian budget is no doubt restricted in terms of budgetary resources, political decisions by decision-makers and top-level politicians play a key role in deciding how these funds are allocated and used. It is therefore important to consider whether the necessary policy and resource attention is being given to this group in view of others, and whether donor and private sector funds can be channelled more effectively to plug the financial needs in this sector. Our primary research actually indicates that, in terms of support for complementary service providers who are filling the gaps of services not currently provided by ministries, there is a dearth of commitment or support from relevant government ministries, including MOEHE, MOH and MOSD. Further, service providers are unsupported by key ministries, which are failing to provide the coordination necessary to meeting the multiple and intersecting rights of CWDs. Informants in most of the organisations we visited reported that they wanted more ministerial support—including standard setting, guidance and coordination.

7.7 Weak social protection for children with disabilities

While the PNCTP is widely recognised as successful in terms of the regular support it provides to households living below the poverty line (Hackstein et al., 2013; Silva et al., 2013), and has been found to have rates of exclusion and inclusion errors lower than other programmes considered successful (such as Bolsa Família in Brazil and Oportunidades in Mexico) (World Bank, 2012), Pereznieto et al. (2014) found it was not particularly responsive to the needs of families with CWDs. Noting that it found that the majority of PNCTP households contained at least one PWD[9], highlighting the particular vulnerability of those households to extreme poverty, the study reported two major shortcomings—one financial and one social. First, while disability is one among several indicators included in the targeting formula, the PNCTP does not recognise the higher day-to-day costs disability entail—for special diets, nappies, transportation, etc. Given the large number of families with more than one PWD, these costs can be extreme (Hamdan and Al-Akhrass, 2006). Second, it fails to couple cash payments with other supportive programming that might help reduce women's care burdens, which can be overwhelming given that most receive negligible help from their husbands and are caring for multiple small children at once in the context of both destitution and disability-directed stigma. The authors report that, while social workers visit families in order to conduct the regular proxy means tests that are required for benefit continuation, there is no space in the PNCTP for those social workers to spend time addressing psychosocial needs—even when mothers admit to beating their disabled children out of frustration. This is a result of barriers created by siloed funding, whereby the PNCTP programme operates largely independently of other programmes and in a fragmented manner. More recently, however, MOSD has been looking into different support mechanisms for this specific group.

On the positive side, however, families with CWDs that participated in the Pereznieto et al. (2014) study did feel the cash transfer had helped them, mainly through the entitlement to health insurance, as well as the cash itself, which had enabled them to pay for goods and services for the disabled family member, which they had previously found very difficult to afford.

---

[9] In this sample, about 30% of PWDs in beneficiaries households were children

7.8 Weak support for the participation of children with disabilities and lack of referral mechanisms for child abuse

Palestinian CWDs have very few opportunities to participate in the broader experiences critical to childhood. For example, most have little access to the group play that helps children learn and work out who they are, how the world works and where they fit into it. In addition, many face stigma, both within and outside of the family. In some households, disability is regarded as a divine punishment that brings shame on the family (Pereznieto et al., 2014). It is common for parents to keep a CWD hidden at home. This stigma translates into self-exclusion in adulthood (ibid.). Further, CWDs are disproportionately vulnerable to violence, exploitation and abuse from the community and sometimes even within the family.

Another issue of concern is that informants at several centres reported that child abuse (generally by parents or other family members at home) was a common problem for CWDs. However, since there is an inadequate child protection system at both the state and the local levels, there are no established referral mechanisms or support systems available to CWDs experiencing abuse. While some centres (e.g. Star Mountain) have developed internal counselling services to work with families to reduce the protection risks such children face, including the risk of sexual violence and exploitation most common to adolescent girls with disabilities, these efforts appear rare—leaving most children with little recourse.

7.9 Lack of monitoring and evaluation to improve services

Our research found virtually no M&E mechanisms in either government-run facilities or even the most advanced private or NGO service provision centres. Informants primarily attributed this gap to a lack of either funds or capacity to conduct M&E—although some also acknowledged that it had simply not been prioritised. Yet there is a need to establish better M&E practices in order to understand what works and what does not, spending scarce resources as wisely as possible.

Despite the barriers discussed above, some promising actions and initiatives have been taken in recent years that suggest potential positive progress in some areas in the medium term.

One of the most salient examples of these innovative actions is the development of a case management system for PWDs by MOSD, with the support of Save the Children. This work is multi-pronged and includes the development of software that enables the registration of relevant information on PWDs at the ground level to keep in a central system so PWDs can be referred to adequate services and monitored more easily. In order for social workers to be able to capture the information at the household level, Save the Children is planning to support MOSD to buy tablets for social workers and to train them to use them to collect information on MOSD-beneficiary PWDs in some directorates, creating an electronic directory. Such information includes type of disability by age, gender, type of assistance and other indicators. Save the Children is supporting the integration and coding of such indicators into the information system so MOSD can have better understanding of the type of PWDs being served within the system and beyond, improving the capacity for referrals and service provision.

MOSD also plans to create a central department to focus on working with specialised institutions working with PWDs in order to build the capacity of local staff and improve control in the coverage and quality of services. This would make MOSD more self-reliant in trying to bridge the professional and expertise gaps in different areas of social protection, especially with PWDs. Partnership with all professional organisations and stakeholders can reduce the financial burden on MOSD and improve services to needy beneficiaries, especially PWDs.

MOSD has been implementing the pilot Alshiekh Khalifa Centre in Nablus with a focus on building the occupational skills of children and young people with disabilities. This centre was set up in 2010 and has graduated three groups of young people with physical and mild mental disabilities. Skills training is held on sewing, carpentry, aluminium work, blacksmith and hair styling, among others. The centre also connects employers with students and new graduates to ensure they have a place to work and can become self-reliant. It is a good model, and now MOSD is trying to contract local suppliers to provide the centre with needed raw materials for training at a low cost to families. The model seems to be working and MOSD is pleased with its outcomes. There is even follow-up with graduates to ensure they are being supported or they can even access further training.

MOH is planning to develop diagnostic and treatment guidelines for different types of disabilities and difficulties to facilitate the work of health care providers, but these efforts have been delayed as they require additional resources, more training and a policy that enforces the use of such guidelines. Part of this effort would also require the development of a detailed reporting system that includes numbers, types and learning, social cognitive and life skills abilities, for more effective referrals.

MOEHE is currently rolling out training for teachers, supervisors, education counsellors, communities and other partners working with CWDs, although this has not yet had much penetration. The ministry does identify, however, that more specialised training is needed for its trainers so they can better deal with learning difficulties and more severe cases of intellectual disability. Despite these shortcomings, and while there is no systematic monitoring to assess the impact of training on school teachers, feedback received by the ministry during field visits by special education counsellors to different schools suggests some positive impact, as teachers are more tolerant of students with different disabilities.

8. Conclusions and policy and practice implications

Our research finds Palestinian CWDs are highly vulnerable on multiple dimensions. They are very likely to be extremely poor, woefully under-supported to realise their rights to an appropriately tailored education and health care, have very few opportunities to participate in the social activities that are required for healthy development and poorly protected from abuse and exploitation. Both our quantitative and qualitative work, like the body of more narrowly targeted research that preceded it, finds CWDs' health, schooling and well-being outcomes are markedly worse than those of their siblings and peers without disabilities. Our research finds that the families of CWDs—and especially their mothers—were also highly vulnerable. Given the dearth of disability-targeted services and the discriminatory social norms surrounding disability in Palestine, caregivers are not only largely left without respite but also, even when they have children with severe disabilities or several children with disabilities, often marginalised, isolated and abused, even by their own families members. Indeed, even the health care and educational providers meant to provide service sometimes perpetuate such stigma.

The vulnerabilities facing Palestinian CWDs are often overlapping, leaving some children at particular risk. For example, those living in rural areas have far less access to services, owing to transportation deficits. Bedouin children appear particularly vulnerable. Not only are their families the least likely to have easy access to services, also but our research finds their communities have especially limited awareness about disability rights, the care needs of CWDs and where to seek necessary services. Adolescent girls with disability are also at heightened risk of neglect and abuse. The restrictive gender norms of the broader community mean they are often denied their right to an education, and the extreme stigma directed at disability, which plays into notions of family honour and can prevent their siblings without disabilities from finding marriage partners, means they are often hidden even within the family. Risks are also multiplied where families have several CWDs, which we found to be quite common.

Our research finds that the social assistance provided to CWDs is grossly inadequate. The PNCTP, while laudable in reducing the depth of poverty on a national level, is far from adequate for families burdened by the extra costs of caring for CWDs since benefit levels are not sensitive to disability-related need. Similarly, the health insurance with which families are provided, because it is targeted at mainstream populations and takes no account of disability-related health needs, is useful but insufficient. Families of CWDs must purchase nappies and medication out-of-pocket and children all too often must do without the wheelchairs and hearing aids that they need—sometimes because their families literally cannot make ends meet and sometimes because their needs are deprioritised because they are seen as less valuable than their siblings without disabilities

CWDs' access to basic social services is also limited, especially for the youngest children just showing signs of developmental delay, children with severe or intellectual disabilities or older CWDs transitioning out of primary school. Public schools are over-crowded, poorly adapted and largely lacking the specialised teachers and teaching materials that make inclusion possible. Bullying from other students—and even from teachers—appears to be rampant, and transportation to and from school very expensive. While our research finds children in tailored educational settings generally have better psychosocial outcomes than those at mainstream schools, demand for such education—like that for TVET—far outstrips supply. Additionally, the Inclusive Education Policy aims to limit specialised schools to a few cases, and for most CWDs to attend regular schools providing inclusive services, but this is far from becoming a reality. Health care too falls short. Prevention efforts are negligible, which is glaring given the high incidence of disability owing to cousin-marriage and inadequate antenatal care, and early detection and intervention services are rare, particularly given the high number of children with congenital disabilities and the number of newborns who suffer birth injuries. Indeed, the providers most likely to come into contact with young children, including paediatricians, nurses and kindergarten teachers, are typically untrained in developmental assessment and have little access to the standardised guides and instruments that might help them identify and prevent permanent disability. CWDs' psychosocial needs are particularly ignored as there effectively are no experts or mechanisms dedicated to seeing that they are met.

Critically, our research finds Palestinian CWDs effectively exist in a 'no man's land'. While MOSD is ostensibly tasked with overseeing the needs of all citizens with disabilities and leading the Coordinating Council on Disabilities, it has no particular mandate to serve children, despite the cascading implications of neglect during childhood, and is poorly equipped to drive the cross-sector coordination CWDs need to realise their rights and meet their potential. Indeed, because of the extremely fragmented way in which disability services in Palestine are delivered, with the government and UNWRA sharing space with literally hundreds of NGOs, families seeking services are effectively abandoned to their own devices to map the service landscape and arrange interventions for their children, often without resources to pay the fees required for such services or transport to access them. The end result is CWDs disabilities remain largely invisible.

Based on our research, we make the following recommendations to better address the needs of Palestinian CWDs and the families who care for them, clustering them according to quick wins and medium-term goals:

8.1 Quick wins

- Raise policy-makers and communities' awareness of disability by revising the disability law, which is both dated and pejoratively named. The PDL should be revised to better align with international conventions in order to further progress towards the realisation of disability rights. Resources from donors should be channelled towards improving the way information on disability and services for people with disabilities is communicated to service providers and communities.
- Involve PWDs and their families in order to demonstrate recognition of those rights and ensure policies and programmes are better centred around users' needs. Local governments and MOSD coordinating offices at the local level could take a lead role in involving families more actively in programme design, monitoring and evaluation, including through establishing feedback and participatory accountability mechanisms (e.g. citizen score card exercises).
- Operationalise the disability law by developing a national strategy for disability prevention, early detection and management. This should include adopting a working definition of disability that is common across government agencies and with clear indicators on the basis of which to monitor prevalence, risk factors and outcomes. It should also translate the law into a concrete set of services and support for children with different types of disabilities (whether the disability be cognitive, emotional, physical, compound). The MOSD should seek to revitalise the Coordinating Council for Disabilities and through it facilitate coordination between ministries in charge of such actions and service providers to improve capacity, awareness and practice with regard to services for CWDs.
- Invest in strengthened data collection related to CWDs—and minimise both gaps and duplication—by strengthening the registration of CWDs. Children's needs cannot be met unless they are identified and progress cannot be tracked unless it is measured. Accordingly, the government should make immediate efforts to build an accurate database of all children with developmental delays and disabilities, using Gaza's area-wide survey as a model, and drawing on the efforts Save the Children is supporting with MOSD in the West Bank. Data collection efforts should include prevention efforts, prevalence by age and gender, location of different types of disability and access to social protection and age-appropriate services.
- Strengthen the disability mandate within the government by enhancing coordination across and within government bodies. Implementation of the current law is poor in part because MOSD remains under-equipped to drive a cross-ministerial mandate. In order to improve outcomes for CWDs, disability-related concerns should be handled not within a single ministry but at the supra-ministry level so as to facilitate greater coordination, setting and monitoring of minimum quality standards for the breadth of organisations and facilities that serve CWDs—including not only those providing disability-related services but also kindergartens, neonatal and delivery centres, etc. One option would be to strengthen the mandate of and adequately resource the Coordinating Council for Disabilities so it can oversee and hold ministries accountable for their actions and services *vis-à-vis* CWDs.
- Allocate consistent fiscal space for disability-related needs and make longer-term commitments to purchase services from NGOs and the private sector when they are not publicly available. This would not only allow the government to better meet its existent obligations to CWDs but also stabilise the budgets of non-governmental providers, making it possible for them to better match demand. Having more systematic information about budget resources available would also allow the identification of crucial funding gaps, which development partners could then step in to help fill.
- Step up efforts to prevent disability. Given that our research suggests many childhood disabilities are preventable, as they result from consanguineous marriage and/or poor antenatal and neonatal health care, immediate efforts need to be directed at prevention. These should include investments in pre-marriage genetic testing—using religious leaders and institutions to promote increased uptake, as well as pre-conception counselling (e.g. increasing folic acid intake and especially for families who already have a history of disability) and better antenatal care. Efforts also need to be directed towards ensuring hospitals have

the equipment that can prevent permanent disability (e.g. incubators) and trained health care professionals capable of following the latest evidence-based guidelines and protocols on neonatal care.

- Improve early detection and intervention. Given that the first few years of children's lives are the most critical in terms of preventing longer-term disability, the primary care physicians and nurses who come in contact with infants and toddlers should be trained to assess child development using harmonised standards and instruments and to detect early signs of developmental delay and disability. This should include formal screening tests for all children at key developmental junctures in the first three years of life, as well as informal screens at every point of contact. Consistent referral systems should be built to ensure at-risk children are then seen in a timely manner by experts who can more formally assess their needs and intervene where appropriate. Since the most vulnerable children often live in hard-to-reach areas, home visits should be made to infants and toddlers not seen in clinic (perhaps tracking them by whether they have received vaccinations on time) to ensure their development is on track.
- Educate parents on early detection and support for CWDs. Given that our research highlights that family support is critical to the outcomes of CWDs and that international research suggests parents can be crucial allies in the early detection of disability, use well-child visits (whether in clinics or at home) to educate the parents of infants and toddlers about child development and the importance of positive parenting, as well as on how to provide supportive therapies at home. The Princess Basma Centre already provides such training to the parents of patients who spend time at the centre, as does Atfaluna for children with hearing impairments in Gaza. The MOH could support the development of a manual and training of trainers in which hospital staff develop resources for local health providers or social workers to share this knowledge with families of CWDs.
- Implement community- and facility-based early intervention programmes. Given that the first three years are the critical years for CWDs, the MOH working in coordination with the MOSD can play a major role through health and communication for development as well as through early childhood development services, to support families and practitioners in this area. Focusing on school-age children can often be too late and miss a critical opportunity for appropriate early intervention.
- Support pre-primary and primary teachers to recognise signs of developmental delay and disability and build systems that facilitate their coordination with health care providers and social workers who can help children access interventions. This can be supported by the case management system currently being developed by Save the Children with MOSD, but information about existing services provided in different regions of Palestine needs to become available on a website and in printed form so social workers and local service providers—including teachers—have such information at hand and can share it with families. The MOSD, with the support of organizations such as Save the Children and UNICEF, could support the development of such informational resources. A good model could be the UK National Health Service website, which provides clear information on early detection, support needed and services available, and could be adapted to the Palestinian context.
- Invest in community education to reduce stigma. Using both traditional (e.g. mosques) and new (e.g. TV) outreach channels, work to help the broader Palestinian community understand that disability is neither contagious nor a sign of dishonour and that PWDs have needs, rights and dreams equal to their own. Consider supporting communication campaigns to talk about ability. Also importantly, incorporate citizenship education that includes sensitisation on equality across different dimensions—particularly disability—into school curricula so children from a young age not only become more supportive of their peers with disabilities but also contribute to changing perceptions in the community. UNESCO, working with MOEHE, can spearhead this initiative. Further, given Palestine's obligations under the CRPD, it is important to improve advocacy with all relevant ministries on behalf of CWDs with the support of agencies such as UNICEF, Save the Children and Diakonia, which have been active working in this field. Palestine has obligations under the CRPD, and the CRPD state party drafting process is currently underway. It is clearly important to be able to show progress on key areas between state reports.

8.2 Medium-term goals

- Map and align service providers. Given the fractured nature of service provision in Palestine, with the government, UNRWA and NGOs providing similar services in a non-coordinated manner, we suggest a detailed mapping exercise to identify all providers serving—or potentially serving—CWDs or their families. The map will help identify gaps and overlaps and allow for a more rational allocation of resources. It will also serve as the backbone of future plans to establish a continuum of care for CWDs, who are very often lost between providers. This activity could be spearheaded by MOSD based on the mapping of services developed recently by Save the Children and some of the information presented in this report.
- Direct more human resources to disability in order to focus on the fact that CWDS are first and foremost children. While CWDs may have complex disability-

related needs that affect their health and education, viewing them through problem-focused lenses risks reducing them to problems rather than people. Working with the PNCTP's social workers, we suggest Palestine build up a cadre of dedicated social workers/disability officers able to coordinate the needs and care of CWDs across sectors and address their psychosocial requirements, which are often more pressing to them than their physical needs. Current social work caseloads are more than 10 times higher than they are in the UK (several hundred versus 15) and disability receives no particular focus. Furthermore, not only is there little coordination between schools, health care providers and social workers but also, given the fragmented, NGO-driven nature of the rehabilitation sector, the staff with whom CWDs interact on a regular basis are often trained only on very specific disabilities and not on the broader needs of children. This effort requires more resources, and would benefit from the support of donor grants to train and resource social workers, though their recruitment and salaries should be included in the government's budget to guarantee sustainability over time.

- Improve and tailor social protection for CWDs. Disability can be expensive. Furthermore, because of the stigma surrounding disability in Palestine, even when families are provided resources, CWDs can be left out. We suggest CWDs be provided with categorical, rather than means-tested, support in order to ensure that their disability-specific needs are met—possibly using the PNCTP as a delivery mechanism. This would particularly help the many families that have multiple children with disability or whose children have multiple disabilities. Cash should be provided to mothers until children turn 18—at which point it should be provided directly to the young adult with disability (where developmentally appropriate). We also suggest an in-kind support package for CWDs that covers medication, transport, adapted educational materials, care and—for older CWDs—economic empowerment programming. Critical is that support is provided in a continuous, predictable manner rather than relying on short-term funding streams, that CWDs with congenital disabilities are not ignored in favour of their peers disabled by accident or conflict and that even children with 'hidden' disabilities, such as autism or cognitive impairments, are provided with benefits. In addition to categorical targeting based on disabilities, if families are also within poverty estimates of the PNCTP as per the public targeting, they should also receive the additional benefit to ensure they can meet their needs.
- Rethink the inclusive education approach. Given that schools in Palestine are already over-crowded—and largely unable to meet the needs of children without disability—expecting them to serve the needs of CWDs is currently unrealistic, but rather something to work towards in the medium and long term. The lack of resources available for specialised teachers, materials and infrastructure effectively condemns CWDs to poor learning outcomes—especially in primary and secondary schools. Dedicated schools may provide a good alternative in the short to medium term, especially for children with the most complex needs, and must include free transportation as part of their package.
- Accelerate efforts to make inclusive education a positive experience. This must include not only efforts to make school buildings, classrooms, play spaces and WASH facilities fully accessible to CWDs but also expanding educational opportunities for teachers—training special education teachers and offering in-service disability training to current classroom teachers. MOEHE should include this as part of its plans to roll out the Inclusive Education Policy, and seek technical support from agencies such as UNESCO. Disability should also be integrated into school health programmes, while counsellors should be made available to help address CWDs' psychosocial needs and awareness-raising programmes. In addition, citizenship education for all students should be directed at reducing the stigma and hostility all too often meted out to CWDs within the school environment.
- Step up efforts to provide tailored education for the youngest and oldest CWDs. Our research highlights that pre-school CWDs and post-primary CWDs are the most likely to be deprived of their rights to an education. Given that pre-primary education in Palestine is almost exclusively provided by the private and NGO sectors, the government needs to ensure private spaces, curricula and teaching methods are adapted for CWDs—and schools enrol CWDs and help them achieve good outcomes. Attention also needs to be directed to helping older CWDs transition from specialised schools to public schools and to providing TVET that will help position CWDs for an independent, more financially secure adulthood.
- Expand health insurance to meet the real needs of CWDs. The current package takes only an antiquated view of disability-related costs, leaves families of CWDs vulnerable to 'quacks' who prey on their desperation and is poorly equipped to provide the referrals and coordination that many CWDs need. The health legislation needs to be strengthened with respect to PWDs, including specific guidance for CWDs, in order to provide a strong mandate for service providers and to underpin a broader health insurance. We suggest health insurance meet all of CWDs medically related needs—including the provision and maintenance of all assistive technologies required for their optimal development as well as transport to and from medical appointments. This effort needs to be spearheaded by MOH in coordination with NGOs currently providing health services to CWDs/PWDs. Critically, the costs

of disability-related health care must be shifted into annual budgets in order to eliminate the current system's unsustainable short-term approach. While there are budgetary constraints, the political will to prioritise this issue, plus improvements in the overall efficiency of the health sector budget, could help create fiscal space for such insurance.

- Increase the capacity of disability-related organisations to diagnose and treat CWDs by providing training and exposure to state-of-the-art practices and consistent financial support—perhaps through government subsidies, strengthening financial and management systems and conducting regular M&E. The first step is for MOSD to update and publish relevant guidelines, which it has identified as one of its priorities. Particular efforts should be made to learn from, and expand, the good practice models that offer families of CWDs a more holistic, 'one-stop' care experience (e.g. Princess Basma, Atfaluna and Al Amal).
- Adapt physical and information infrastructure for better accessibility. Beginning with providers with a disability mandate (e.g. MOSD, MOH, MOEHE, etc.), and moving on to the broader community, ensure spaces and information are accessible to PWDs. This will include a wide range of concrete adaptations, including ramps, pamphlets in Braille, sign language interpreters at hospitals, etc.
- Provide support for the families of CWDs. Given the stigma surrounding disability, families with CWDs—and especially mothers of CWDs—are often isolated and overwhelmed. Addressing this is critical seeing that our research finds positive parenting is key to good outcomes for CWDs. According, we suggest Palestine—through local governments and CBR—invest in disability-specific support groups for mothers—possibly led by mothers with older CWDs who have a wealth of experience to share; engage with mothers and fathers—who are often the least supportive; and reach out to Bedouin communities, where stigma is especially high. We also recommend the state provide easily accessible web-based information and diagnostic tools, drawing on good practice from other countries (e.g. the UK) and disability rights NGOs and offer families comprehensive information on child development and care that has been tailored to account for disability—perhaps using social media such as What's App to send regular tips. This should include a comprehensive list of providers and services available, drawing on the mapping exercise above. We also recommend respite care be provided for mothers/families caring for children with severe/multiple disabilities and or multiple children with disabilities, which could entail expanding existing residential services and subsidising community-based respite care options.
- Strengthen the social work network to provide better outreach to CWDs and their families, not only to facilitate access to social services but also to serve as a grievance/complaint mechanism when services are failing, to inform about cases of abuse and negligence and so families feel service providers can be held accountable.
- Address the gender dimensions of disability and disability-related care. Girls with disability, sisters of CWDs and mothers of CWDs often face gender-specific vulnerabilities. To address the fact that adolescent girls with disabilities are especially unlikely to attend school or be allowed to socialise, given the risk of sexual assault and its associated threat to family honour—and particularly since those same girls—and their mothers—are at high risk of intra-familial violence—we suggest more community awareness through communication for development interventions and home visiting by nurses, social workers and disability officers, who should be trained to identify those at risk and refer them to adequate services. Emergency shelters should take account of the needs of those dealing with disability. Currently, referral mechanisms in cases of child abuse are lacking, so these need to be developed—with the support of UNICEF—and such services need to take specific account of the needs of CWDs.
- **Strengthen the role of international NGOs as champions for CWDs.** INGOs who have been actively engaging on the issue of disabilities - such as Save the Children and Diakonia - could play a key role in the donor/multilateral community in championing the needs and rights of CWDs. They could help coordinate the development of a fit-for-purpose database and management information system, assist with social protection system reforms and facilitate sharing of good practice learning across government agencies and NGOs. Donors could also reach out to the private sector and encourage greater investment in service provision for CWDs (e.g. building on the School for Blind in Hebron model).

9 References

Abed, Y., Barqouni, N. Al, Naim, A. and Manduca, P. (2014) 'Comparative study of major congenital birth defects in children 0-2 years in the Gaza Strip, Palestine', International Journal of Development 4(11): 2319–23.

Abu Hamad, B., Jones, N., Pavanello, S. and Shaheen, M. (2013). Beneficiary and community perspectives on the Palestinian National Cash Transfer Programme. Ramallah: ODI.

Abu-Hamad, B., Jones, N. and Pereznieto, P. (2014) 'Tackling children's economic and psychosocial vulnerabilities synergistically: How well is the Palestinian National Cash Transfer Programme serving Gazan children?' Children and Youth Services Review 47(P2): 121–35. http://doi.org/10.1016/j.childyouth.2014.09.009

Abu-Hamad, B., Jones, N., Bayoumi, N. Al and Samuels, F. (2015). Mental health and psychosocial service provision for adolescent girls in post conflict settings: The case of the Gaza Strip. London: ODI and DFID.

Alawni, K., Laisi, K. and Rissanen, J. (2012) Situation analysis of people with disabilities in Palestine, with a special focus on the deaf and hard of hearing. Helsinki: Finnish Evangelical Lutheran Mission.

Al-Bayoumi, N. (2014) The status of wellbeing in Gaza governorates: Correlates and implications. Jerusalem: Al-Quds University.

Al Far, M., Wahba, M. and Wener, G. (2012) 'Mapping of child protection services in the Gaza Strip'. Lausanne: Terre des Hommes.

Christian Aid (2012) Overcoming disability barriers: Christian Aid's partnership scheme project in the Middle East. Ramallah: Christian Aid.

DFID (UK Department for International Development) (2000) Disability, poverty and development. London: DFID.

Development Studies Centre (2012) 'The National Strategic Plan of the Disability Sector in the Occupied Palestinian Territories: for the Supreme Council of the Affairs of Persons with Disabilities'. Birzeit: Development Studies Centre, Birzeit University.

Diakonia (2015) 'CBR Program statistical information'. Stockholm: Diakonia.

Diakonia/Norwegian Association of the Disabled (NAD) (2011) 'Access to formal education for people with disability'. Ramallah: Riyada Consulting and Training.

Economics and Allied Consulting (2011) Early intervention programs to assist children with hearing loss develop spoken language: A social cost-benefit analysis. Washington, DC: Economics and Allied Consulting.

EU (2015) 'Technical assistance to improve and develop the social protection system in Palestine through partnership planning and institutional capacity building: Analysis report of the findings of a mapping study of social services in Jerusalem, Hebron and Nablus'. Ramallah: EU.

Fricke, J. (2010) 'Activities of daily living', in J.H. Stone and M. Blouin (eds) International encyclopedia of rehabilitation. http://cirrie.buffalo.edu/encyclopedia/en/article/37/

Ginsburg, K.R. (2007) 'The importance of play in promoting healthy child development and maintaining strong parent-child bon : Focus on children in poverty'm Pediatrics 119(1): 182–8. http://doi.org/10.1542/peds.2011-2953

Global Campaign for Education/Handicap International (2015) Equal right, equal opportunity: Inclusive education for children with disabilities.

Grosse S. (2001) 'Cost comparison of screening newborns for hearing impairment and biochemical disorders'. Paper presented at the Newborn Screening and Genetics Conference. Atlanta, CA: CDC.

Hackstein, K., Miller, C. and Mahadi, E. (2013) Impact evaluation of the EU contribution to the Palestinian Cash Transfer Programme (CTP) in the framework of the PEGASE programme of support to "vulnerable Palestinian families". Report commissioned by the Delegation of the European Union, Palestine.

Hamdan, M. and Al-Akhrass, N. (2006) 'A survey of people with special needs at 27 Palestinian villages in Tulkarm and Qalqilia Districts'. Nablus: Union of Health Care Committees (UHCC) (http://www.ochaopt.org/documents/opt_health_uhcc_disabled_needs_nwb_july_2008.pdf).

Handicap International (2015) Barrier needs assessment: Opportunities and potential for children with disabilities to access education in Gaza and Rafah cities. Ramallah: Handicap International.

Hussein, M. (2007) Evaluation of community based rehabilitation programs in refugee camps in Gaza. Jerusalem: Al-Quds University.

ICHR (Independent Commission for Human Rights) (2014) Legal review of the right of persons with disabilities to education, health and social protection. Ramallah: ICHR.

ILO (International Labour Organization), UNESCO (UN Educational, Scientific and Cultural Organization) and WHO (World Health Organization) (2004) CBR: A strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities. Geneva: ILO, UNESCO and WHO. Diakonia (2015) CBR Program Statistical Information.

Keenaghan, C. and Kilroe, J. (2008) 'A study on the quality of life tool KIDSCREEN for children and adolescents in Ireland'. Results of the KIDSCREEN National Survey 2005.

MOEHE (Ministry of Education and Higher Education) (2014) 'Education Development Strategic Plan 2014–19'. Ramallah: MOEHE.

MOEHE (2015) 'Palestinian Inclusive Education Policy'. Ramallah: MOEHE.

MOH (Ministry of Health) (2011) Palestinian national health strategy 2011–13. Ramallah: MOH, PA and Save the Children.

MOH (2014) Health Sector Strategic Plan: Gaza governorates 2014-2018. Ramallah: MOH.

MOSD (Ministry of Social Affairs) (2012a) Children with disabilities have rights: Establishing a children with disabilities case management system. Ramallah: MOSD, PA, Save the Children and UNICEF.

MOSD (2012b) The establishment of a case management system for children with disability. Social Policy Paper. Ramallah: MOSD.

National Scientific Council on the Developing Child-Center on the Developing Child (2007) 'The science of early childhood development: Closing the gap between what we know and what we do'. Boston, MA: National Scientific Council on the Developing Child-Center on the Developing Child. http://doi.org/10.1097/DBP.0b013e3181833804

Nilsson, A. and Quttina, M. (2005) 'Evaluation of the CBR program in Palestine — from the perspective of persons with disabilities themselves'. Ramallah: Diakonia and NAD.

Nordic Consulting Group (2012) Mainstreaming disability in the new development paradigm. Oslo: Nordic Consulting Group.

OCHA (UN Office for the Coordination of Humanitarian Affairs) (2015) 'Gaza one year on: Humanitarian concerns in the aftermath of the 2014 hostilities'. Ramallah: OCHA.

PLO (Palestinian Liberation Organisation)/PA (Palestinian Authority) (1999) Law Number 4 for the Year 1999 Concerning the Rights of the Disabled. Ramallah: PLO/PA.

PCBS (Palestinian Central Bureau of Statistics) (2010) 'Report on the implementation of the Convention on the Rights of the Child in the Occupied Palestinian Territories'. Ramallah: PCBS.

PCBS (2012) Disability survey 2011. Ramallah: PCBS and MOSD.

PCBS (2013a) 'Child statistics'. Series No. 16. Ramallah: PCBS.

PCBS (2013b) Disability survey Gaza 2012. Ramallah: PCBS.

PCBS (2013c) Educational Attendance for the Persons (6 Years and Over) by Age,Sex and Region.

PCBS (2015a) Palestine statistical annual vook 2015. Ramallah: PCBS.

PCBS (2015b) The status of the Palestinian population living in Palestine. Ramallah: PCBS.

PCBS (2015c) The status of the rights of Palestinian children 2014. Ramallah: PCBS.

PCBS and MOH (2016) Palestinian national health accounts book 2014. Ramallah: PCBS and MOH.

PCBS and MOSD (2011) Disability survey in Palestine: Main findings. Ramallah: PCBS and MOSD.

Pereznieto, P., Jones, N., Hamad, B. and Shaheen, N. (2014) 'Effects of the Palestinian National Cash Transfer Programme on children and adolescents: A mixed methods analysis'. Jerusalem and London: UNICEF and ODI.

Phua, L.L., Cheung, S.L., Lim, S., Lim, X.M., Yong, J. and Tan, B. Y. (2015) 'Issues faced by caregivers of persons with dementia in a dementia care support project in a community hospital'. Singapore: Community Care Forum.

Protection Cluster Occupied Palestinian Territory (n.d.) 'Needs analysis framework, 2014–16. Ramallah: Protection Cluster.

Ravens-Sieberer, U., Herdman, M., Devine, J., Otto, C., Bullinger, M., Rose, M. and Klasen, F. (2014) 'The European KIDSCREEN approach to measure quality of life and well-being in children: Development, current application, and future advances', Quality of Life Research 23(3): 791–803.

Sida (Swedish Agency for International Development Cooperation) (2014) Disability rights in Palestine. Stockholm: Sida.

Sirdah, M.M. (2014) 'Consanguinity profile in the Gaza Strip of Palestine: Large-scale community-based study', European Journal of Medical Genetics 57(2): 90–4.

Silva, J., Levin, V. and Morgandi, M. (2013) Inclusion and resilience: the way forward for social safety nets in the Middle East and North Africa. Washington DC: International Bank for Reconstruction and Development/The World Bank.

UNICEF (UN Children's Fund) (2013a) 'Children and young people with disabilities'. Fact Sheet. New York: UNICEF.

UNICEF (2013b) The state of the world's children: Children with disabilities. New York: UNICEF.

UNICEF (2013c) Sustainable development starts and ends with safe, healthy and well-education children. New York: UNICEF.

UNRWA (UN Relief and Works Agency for Palestine Refugees in the Near East) (2011) 'UNRWA response to OHCHR request for information: Addressing violence against women and girls with disabilities'. Gaza City: UNRWA.

UNICEF and UNESCO Institute for Statistics (2015) 'Global initiative on out-of-school children. New York: UNICEF.

Washington Group (n.d.) 'Child functioning'. http://www.washingtongroup-disability.com/washington-group-question-sets/child-disability/

WHO (World Health Organization) (2002) 'Health and sustainable development meeting of senior officials and ministers of health'. Geneva: WHO.

WHO (2010) Monitoring the building blocks of health systems: A handbook of indicators and their measurement strategies. Geneva: WHO.

WHO (2013) 'Millions of people in the world have hearing loss that can be treated or prevented'. Geneva: WHO. http://www.who.int/pbd/deafness/news/Millionslivewithhearingloss.pdf?ua=1

WHO (2013) Right to health: Barriers to health access in the occupied Palestinian territory, 2011 and 2012. Special Report. Geneva: WHO.

WHO (2014) Health conditions in the Occupied Palestinian Territory. Geneva: WHO.

WHO (2015) WHO global disability action plan 2014–21: Better health for all people with disability. Geneva: WHO.

World Bank (2003) Caring for the disabled in the West Bank and Gaza. Washington, DC: World Bank.

World Bank (2012) 'Targeting Assessment of the Cash Transfer Program, West Bank and Gaza'. Report No: ACS890. 25 June. Washington DC: World Bank

World Bank (2016) 'West Bank and Gaza. Disability in the Palestinian Territories: Assessing situation and services for people with disabilities'. Ramallah: World Bank.

World Bank and WHO (2012) World report on disability. Washington, DC: World Bank and WHO.

YMCA (2015) The reality of access to educational, social and health services for children with disabilities in the West Bank. Ramallah: Save the Children.

Zaggout, B. (2012) 'Palestinian Medical Relief Society', available at: http://www.alwatanvoice.com/arabic/news/2012/07/22/299867.html

Zamani, G., Heidari, M., Malamiri, R. A., Ashrafi, M. R., Mohammadi, M., Badv, R.S., … Fathi, M.R. (2016) 'The quality of life in boys with duchenne muscular dystrophy', Neuromuscular Disorders 26(7): 423–27. http://doi.org/10.1016/j.nmd.2016.05.004

Zaqout, B. and Abu-Hamad, B. (2013) *Quality of care provided to PWDs in Gaza: Clients' perspectives*. Saarbrucken: LAP Lambert Academic Publishing.

ANNEXES

Annex 1: UNICEF Terms Of Reference

unite for
children

unicef

Terms of Reference

A situation analysis and needs assessment of children with disabilities

Background and context

According to the World Health Organization (WHO), there are currently approximately 600 million people living with disabilities worldwide and nearly 200 millions of them are children (WHO 2010). It is estimated that 80 percent of children with disabilities live in developing countries (UNICEF and the University of Wisconsin 2008). Often, people with disabilities live on the fringes of society, in isolation and despair. They face high degrees of stigma and discrimination from their own society, communities, and even families. The poor are disproportionally affected by the burden of disability. A World Bank study estimates that people with disabilities make up 15 to 20 per cent of the poor in developing countries (Elwan 1999). Children with disabilities are higher risk of deprivation and exclusion, often lacking access to basic services such as education, health care and water and sanitation. They are also at higher risk of abuse, neglect and exploitation. Young people with disabilities lack skills and resources necessary to construct decent livelihood.

In order to address the challenges faced by people with disabilities, a number of international legislative frameworks and instruments have been put in place. The most comprehensive human rights convention for people with disability is the 2008 Convention on the Rights of Persons with Disabilities, which recognizes the rights of people with disabilities and seeks to integrate them into mainstream society. For children with disabilities, the Convention on the Rights of the Child, which was adopted by the United Nations General Assembly almost 20 year earlier, includes several articles aiming at protecting the rights of children with disabilities. In the State of Palestine, there are similar efforts to improve legislative and policy environment for children with disabilities. For example, the Ministry of Education and Higher Education (MoEHE) adopted an inclusive education policy in its Development Plan 2008-2013 and increased its budgetary allocation for special education (UNICEF 2013).

Notwithstanding such efforts, the majority of children with disabilities continue to face daily obstacles in realizing their rights and participating fully in society. According to the 2011 Disability Survey, 40 per cent of people aged 15 years and older have never enrolled in school and 53 per cent of them are illiterate. In the Gaza Strip, the situation has been compounded by a 50-day escalation of violence that erupted in July-August 2014. Between 8 July and 26 August, more than 3,300 children were reportedly injured. It is estimated that out of those injured 1,000 children will suffer from a disability for life and require rehabilitation and specialized care and support.

Purpose

The purpose of this study is the following:[1]

1) Increase knowledge and awareness about the situation and rights of children with disabilities
2) Analysis of the extent to which their rights as defined in the Convention on the Rights of Persons with Disabilities (CRPD) and other human rights treaties are being met
3) Identify existing bottlenecks and barriers facing children with disabilities in fulfilling their rights
4) Assess gaps in current service provision capacity / identify service providers that can meet their needs
5) Identify existing and future policy and programmatic responses to address those bottlenecks and barriers
6) Identify what children themselves see as the most pressing needs
7) Identify who are the key duty-bearers that are responsible for protecting and upholding their rights.

Specific objectives

This consultancy seeks to answer the following questions:

General

1) To what extent are the rights of children with disabilities and their families articulated in national policies and programmes?[2]

2) How do outcomes and trends differ across sub-groups of children with disabilities (e.g. girls, indigenous, or youth), by geographical areas, during humanitarian action and in development contexts? What are the underlying causes of inequalities among the disability community? Which are the most deprived groups of children and parents with disabilities in terms of access and facing negative attitudes? What forms of deprivation and exclusion do they face? What are the determining factors that give rise to and perpetuate their exclusion? It is important to note that children with disabilities may face some specific barriers depending on the nature of their impairments.

3) What is the situation of children who incurred long-term injuries and other debilitating conditions during the recent conflicts in Gaza?

---

[1] Adopted from UNICEF, *Guidelines for Disability Situation Analyses*, version 5, 26 June, 2013. http://www.unicef.org/disabilities/files/General_Suggestions_for_Disability_SITANS.pdf (accessed 18 May, 205).

[2] The policies and programmes to be reviewed will be discussed and agreed upon at the outset of this study.

unite for
children

unicef

Enabling Environment

4) Has the government signed or ratified the CRPD, analyze if national legislations and policies are compliant with the CRPD, and to what extent is the government taking steps to realize the rights?
5) What existing social, institutional and political factors (e.g. social norms, institutional capacities at all levels of government, accountability and coordination mechanisms, policy and legal frameworks) could potentially support the creation of an enabling environment for the realization of the rights of children with disabilities?
6) What are the immediate, underlying and structural barriers and bottlenecks to the well-being of children with disabilities and to accessing and utilizing basic social services and other critical resources?

Supply

7) What capacities (financial, technical and institutional) exist at national, sub-national and community levels to provide essential services and address inclusion of children with disabilities more broadly? The supply of services includes making general services as inclusive as possible in addition to creating specific disability programmes where needed.
8) To what extent do social protection measures exist and are inclusive of and reach children with disabilities and their families?
9) To what extent is the physical, communication and information environment accessible for people with disabilities?

Demand

10) To what extent are families of children with disabilities aware of financial programmes and social protection measures from the government, and to what extent do they access them?
11) To what extent are children with disabilities and their caregivers excluded from participation in society based on social and cultural practices, and beliefs?
12) How are the voices of children with disabilities and their families or their representative organizations incorporated into the design and planning of national/local strategies and programmes?

Quality

13) How satisfied are children and their families with the current policies, services and programmes?
14) To what extent to children with disabilities have the same level of participation and the opportunity and access to services as their peers without disabilities?

Study methodology / specific tasks

The process to develop the Situation Analysis will make use of multiple methodologies and techniques. Both primary and secondary data will be collected, and quantitative as well as qualitative information will be used. Analysis of available quantitative data and undertaking detailed analysis of the existing secondary data to establish trends and relationship is needed. The process of conducting this study extends beyond specific methodology. A study that does not include in-depth dialogue between key stakeholders will be much less rich and valid than one that does therefore it is necessary to detail this out in the proposal.

1) Desk review and conceptual and analytical secondary research on selected topics published in existing studies, research and survey reports
2) Analytical primary research using quantitative and qualitative research techniques. For qualitative techniques, semi-structured interviews, focus group discussions and other techniques, as life stories of children and adolescents will be used.
3) An in-depth analysis of the needs of children with various forms of disability (physical, mental, psychological and other) in relation to the types of care and support services needed.
4) Comparative analysis of available legislation, social policy, budget allocation and expenditure documents in conformity with provisions of the CRPD and relevant articles in the CRC.
4. An assessment of gaps in current service provision capacity / identification of service providers that can meet children's needs
5) Key informants consultations with those who shape and implement public policies
6) Socio-demographic trend analysis, at the most possible disaggregated level on the basis of micro data sets. In addition to future forecasting.
7) Participatory workshops to undertake the causal analysis, role pattern analysis and capacity gap analysis including validation of the study findings.

The study will embrace a comprehensive assessment of the rights of children with disabilities, using a human rights-based approach that consists of:

1) the identification of unfulfilled rights;
2) the identification of duty bearers and rights holders; and
3) The determination of key gaps (knowledge, commitment, authority, resources) in the capacities of duty bearers and right holders as defined in international instruments, most especially the Convention on the Rights of Persons with Disabilities (CRPD), the Convention on the Rights of the Child (CRC), and the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW).

The provisions and principles of the CRPD and CRC will stand at the centre of the Situation Analysis. For synergies between CPRD, CRC and CEDAW, see Landsdown, *Using the human rights framework to promote the rights of children with disabilities: working paper*, 2012. http://www.unicef.org/disabilities/files/Using_Human_Rights_Working_Paper-2012.pdf

The Situation Analysis will adopt an integrated, cross-sectoral approach that takes a holistic view of the child. A life-cycle approach will be used to undertake the analysis of the key issues affecting children aged 0 to 17 years. A causal and trends analysis using -year age intervals (0-59 months, 5-10 years, 10-14 years, 14-17 years) will be helpful in determining the developmental needs and the ensuing programmatic interventions that need to be undertaken, keeping in mind inter-linkages and variations among sex, various socio-economic groups and geographic locations.

Gaps in unfulfilled children rights, relevant legislative and policy frameworks together with institutional and service delivery mechanisms and data will be identified. Key recommendations emerging from the analysis will be linked with responsible duty bearers and will include suggested timeframes for implementation.

Ethical considerations

The study will follow UNICEF guidelines on the ethical participation of children. In addition, any participants will be fully informed about the nature and purpose of the assignment and their requested involvement. Only participants who have given their written or verbal consent (documented) will be included in the consultations. A research ethics approval will be sought from relevant authorities.

Proposed timelines

This consultancy will start in October 2015 / as soon as possible and will last 5 months. The timeline is shown below.

No.	**Activity**	**timeline**
1	Conduct desk review	Week 1
2	Conduct initial meetings ; obtain relevant information; review additional relevant documents	Week 2
3	Draft study / research protocol	Week 3-4
4	Present draft study / research protocol	Week 5
5	Obtain ethics approval	Week 6
6	Conduct workshops and field work	Week 7-11
7	Conduct data analysis and prepare a draft report	Week 12-16
8	Submit to UNICEF for draft review and reflect comments	Week 17

9	Conduct a validation workshop for partners	Week 18-19
10	Finalize the report	Week 20-21
11	Present to UNICEF and partners	Week 22

Expected deliverables

The expected outputs for the study are the following:

- Study protocol, including survey plan, data collection instruments, field work plan, data analysis, report preparation and dissemination plan
- Ethical protocol
- Survey instruments (both quantitative and qualitative)
- A study report
- Collected data files (both quantitative and qualitative)
- Transcripts of focus group discussions and key informant interviews
- A documented desk review of existing literature on children with disabilities in Palestine
- Data analysis programming codes
- A bibliography
- Dissemination materials
    - A 3-4 page brief including key findings, conclusions and recommendations
    - Presentation materials (e.g., PowerPoint slides)

Supervision and reporting

The consultant will report to the Chief of Social Policy M&E, working closely with all programme sections in the UNICEF State of Palestine office. UNICEF’s Regional Office for Middle Eastern and Northern Africa and the Disability Section in UNICEF HQ will provide quality assurance support.

Qualification of service provider / expected background and experience

The consultancy requires the following qualifications and experiences:

- Post graduate degree in social sciences, policy analysis, statistics, survey design or other related fields
- At least 10 years in applied research and policy analysis, including publications in peer reviewed journals
- Familiarity with social protection including social transfers
- Previous experience in impact evaluation and policy analysis. Previous experience in qualitative research an advantage
- Knowledge and experience in development issues in Palestine
- Excellent writing, communication, presentation and public speaking skills.
- Fluency in English and Arabic
- Ability to work in teams and in a multi-cultural environment

Annex 1: Key Elements of Disability SitAns

- Human Rights Based Approach:

In line with UNICEF guidelines to apply a rights-based approach to Programming (EXDIR 1998-04) disability SitAns must consider the country's efforts towards implementing the rights of all children as outlined in the CRPD, CRC, and CEDAW.

- Equity:

For children with disabilities, equity means having an opportunity to survive, develop and reach their full potential without discrimination, bias or favouritism of this population or a sub-group or it. This is critical for children with disabilities who often do not receive the same level of services (e.g. education) as their peers without disabilities, due to difficulties with access, discrimination, and availability of appropriate services. It is also critical to considering different subgroups of children with disabilities, with their specific needs and situation.

- Social Model of Disability:

In line with the CRC, disability SitAns should focus on identifying barriers created by society or the physical environment that limit a child with disabilities from enjoying their human rights. This includes for example identifying negative attitudes; environmental and communication barriers; gaps in policies or their implementation. The framework of the social model and CRPD should form the reference points.

- Inclusive Development Approach:

In accordance with the right to participation outlined in Articles 4 and 21 of the CRPD, and in accordance with the slogan of the disability community "Nothing about us, without us", people with disabilities and their families must be engaged and consulted throughout the SitAn process. This will promote ownership within the disability community and ensure their voices are heard in setting priorities, planning, implementation and monitoring.

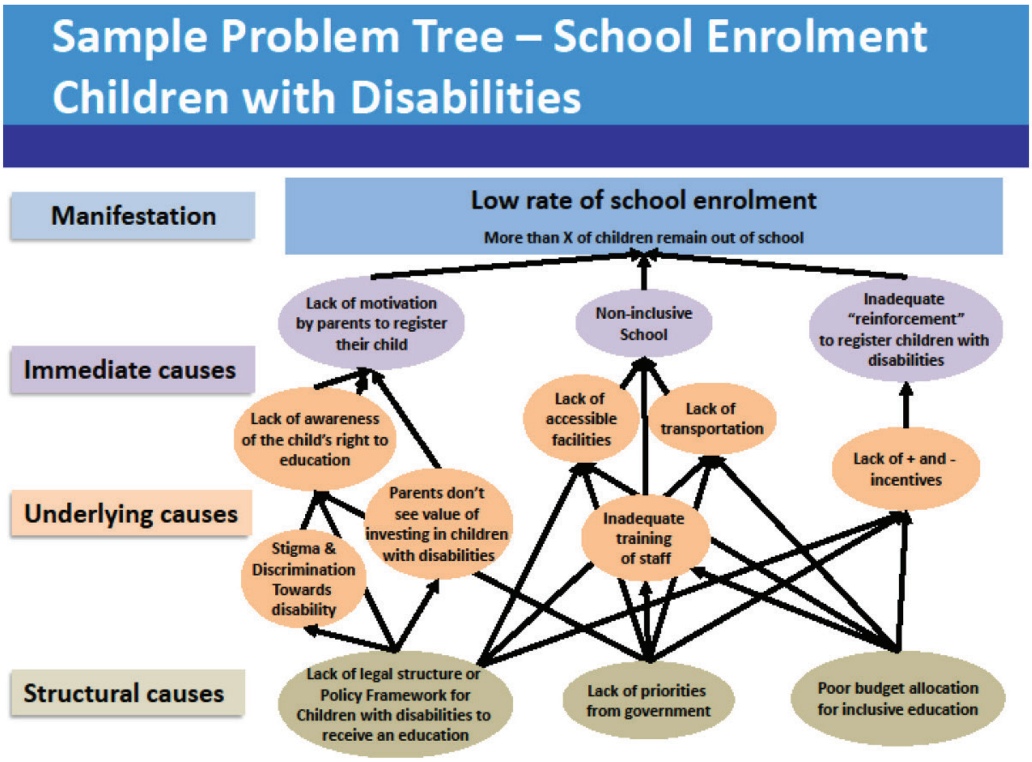
- Lifecycle approach:

Disability varies across the lifespan and depending on a variety of factors. Therefore, SitAns should consider the variations and implications in each of the phases of life and particularly during transitions from one phase to another (e.g. transition from out-of-school to work): childhood, adolescence, adulthood and old age.

Annex 2: Checklist for a disability SitAn

1) Definitions of children and people with disabilities are clearly outlined (should be in line with the social or human rights model and article the difference between an impairment and disability)
2) Overview of the situation and number of children with disabilities and their families in the country, placing emphasis on accessibility to the physical, communication and information environment, and social and cultural norms
3) Introduce and refer to the Convention on the Rights of Persons with Disabilities and disability-specific legislation
4) Clear link made between the CRC, CEDAW and CRPD(See UNICEF document: 'Analysis of Synergies between the CRC, CRPD and CEDAW: Using the human rights framework to promote the rights of children with disabilities')
5) Review key legislation and policies on health (including immunizations, HIV/AIDS, sexual and reproductive health), education, child protection, WASH, nutrition, social protection, employment and human rights and discrimination for inclusion
6) Language about children with disabilities and their families is empowering and does not further stigmatize (avoid words like 'dealing with', 'confined to', and 'suffering' for example)
7) While acknowledging existing special or segregated approaches, inclusive approaches should promoted throughout the document
8) Entire lifespan of a child is covered
9) Perspectives from children, their families and particularly girls, women and minorities (e.g. indigenous) clearly articulated in the report, highlighting the key role of parents
10) Information covers all disability areas (physical, visual, sensory, intellectual, psycho-social)

Annex 3: Sample problem tree



Sample Problem Tree – School Enrolment Children with Disabilities

Manifestation

Low rate of school enrolment

More than X of children remain out of school

Immediate causes

Lack of motivation by parents to register their child

Non-inclusive School

Inadequate "reinforcement" to register children with disabilities

Underlying causes

Lack of awareness of the child's right to education

Parents don't see value of investing in children with disabilities

Stigma & Discrimination Towards disability

Lack of accessible facilities

Lack of transportation

Inadequate training of staff

Lack of + and - incentives

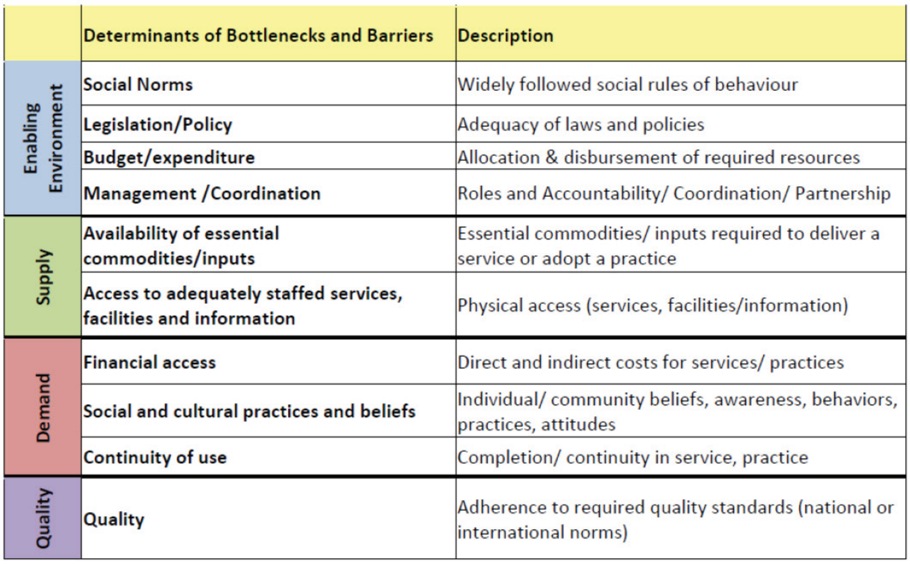
Structural causes

Lack of legal structure or Policy Framework for Children with disabilities to receive an education

Lack of priorities from government

Poor budget allocation for inclusive education

Annex 4: Critical Determinants for assessing Bottlenecks and Barriers to Equitable outcomes for Children



	Determinants of Bottlenecks and Barriers	Description
Enabling Environment	Social Norms	Widely followed social rules of behaviour
	Legislation/Policy	Adequacy of laws and policies
	Budget/expenditure	Allocation & disbursement of required resources
	Management /Coordination	Roles and Accountability/ Coordination/ Partnership
Supply	Availability of essential commodities/inputs	Essential commodities/ inputs required to deliver a service or adopt a practice
	Access to adequately staffed services, facilities and information	Physical access (services, facilities/information)
Demand	Financial access	Direct and indirect costs for services/ practices
	Social and cultural practices and beliefs	Individual/ community beliefs, awareness, behaviors, practices, attitudes
	Continuity of use	Completion/ continuity in service, practice
Quality	Quality	Adherence to required quality standards (national or international norms)

Annex 5: Measuring child disability

Practically all countries have attempted to collect some information on the number of persons with a disability and these efforts have been going on for a long time. However, data collection on disability has been done in very different ways and with wide variations in the definitions and questions used. This lack of consistent definitions and indicators of disability, combined with disparities in the methodologies used to gather the data and in quality of study designs, have been major challenges in producing reliable and comparable disability statistics. Measuring child disability, in particular, presents a unique set of challenges and the poor quality of data on child disability stems, in some cases, from a limited understanding of what disability is in children and, in other cases, from stigma or insufficient investment in improving measurement.[3]

Defining disability

Historically, disability was conceptualized and measured from a medical perspective. That is, disability was thought of as the experience of a certain physical or mental impairment. This approach to defining disability has largely been replaced by a bio-social approach that focuses on the relationship between the individual and their environment in terms of limitations or barriers in performing daily activities and restrictions or supports to social participation. While there is general agreement that definitions of disability should incorporate both medical and social determinants, the measurement of disability is still predominantly medical, with a focus on specific physical or mental impairments. Estimates of disability prevalence vary depending on what definition of disability is used. When the new bio-social approach has been used, it has generally yielded reported disability prevalence rates that are much higher than the ones that can be obtained from methods that rely on narrow medical definitions of disability.

Measuring disability in children

In both developed and developing countries, data on the incidence of child disabilities are rarely available.[4] Because children develop and learn to perform basic tasks at different speeds, it can be difficult to distinguish significant limitations from variations in normal development.[5] The varying nature and severity of disabilities, together with the need to apply age-specific definitions and measures, further complicate data collection efforts.[6]

---

[3] UNICEF, *State of the World's Children: Children with disabilities*, UNICEF, New York, 2013, p. 63.

[4] UNICEF and the University of Wisconsin, *Monitoring Child Disability in Developing Countries: Results from the Multiple Indicator Cluster Surveys*, UNICEF, New York, 2008, p. 8.

[5] UNICEF, *State of the World's Children: Children with disabilities*, UNICEF, New York, 2013, p. 63.

[6] Ibid.

In the absence of incidence rates, prevalence estimates are typically used to describe the proportion of children in a population found to have a disability.[7] Prevalence estimates of child disability need to be interpreted with caution however, as they are a function of both incidence and survival, particularly in countries where infant and child mortality rates are high.[8] A low reported prevalence of disability may be the consequence of low survival rates for young children with disabilities or it may reflect high levels of institutionalization of children with disabilities since these children will not be captured by certain types of data collection methods (e.g., household-based surveys). On the other hand, a decrease in mortality rates could contribute to a spike in reported prevalence of children with disabilities. In this case, the actual numbers of children with disabilities are not necessarily increasing but rather more children are surviving long enough to be counted in disability estimates.

Culture also plays an important role since the interpretation of what may be considered 'normal' functioning varies across contexts and influences measurement outcomes. The attainment of certain milestones may not only vary among children, but differ also by culture. It is therefore important to assess children against reference values appropriate to local circumstances and understanding.[9]

Collecting data on child disability

In many developing countries, children with disabilities might not be adequately identified due to a lack of infrastructure such as educational and medical settings or national registries that are commonly used among more developed nations to identify children with disabilities. Where schooling or other formal services for children with disabilities are lacking, other methods of data collection, such as censuses, general and targeted household surveys, and interviews with key informants, have been used to estimate disability prevalence.[10]

General data collection instruments such as censuses are widely recognized as underestimating the prevalence of disability. They typically employ a generic or filter question, such as whether anyone in the household 'is disabled', or use the same questions for all household members regardless of their age.[11] The broad nature of these types of questions means that the interpretation of what constitutes a disability is left entirely to respondents. Not surprisingly,

---

[7] UNICEF and the University of Wisconsin, *Monitoring Child Disability in Developing Countries: Results from the Multiple Indicator Cluster Surveys*, UNICEF, New York, 2008, p. 8.

[8] Durkin, M. S., 'The Epidemiology of Developmental Disabilities in Low-Income Countries', *Mental Retardation and Developmental Disabilities Research Review*, vol. 8, no. 3, 2002, p. 211; UNICEF and the University of Wisconsin, *Monitoring Child Disability in Developing Countries*, p. 8.

[9] UNICEF, *State of the World's Children: Children with disabilities*, UNICEF, New York, 2013, p. 64.

[10] Ibid.

[11] UNICEF, *State of the World's Children: Children with disabilities*, UNICEF, New York, 2013, p. 66.

reported disability prevalence rates from surveys or censuses that have included such general questions about disability are often unusually low (e.g., less than one per cent). Research suggests that general data collection instruments are inadequate at identifying children with disabilities, and that children might be missed on surveys that do not specifically ask about them.[12] Indeed, these types of questions often under-enumerate children; girls and children of low socioeconomic status with disabilities are especially likely to be overlooked.

When compared to other methods that ask about disability in general, targeted household surveys that specifically address the issue of child disability or that incorporate measures designed specifically to evaluate disability in children have produced more accurate results.[13] Such surveys tend to report higher prevalence rates because they usually include more numerous and detailed questions.[14]

Prevalence rates of disability are extremely sensitive to, and affected by, the types and ways in which questions are asked. Questions posed to adults are often inappropriate or not applicable for children (for example, questions about memory loss etc.), yet many surveys apply a single set of questions to both adults and children to determine disability status.[15] Making explicit reference to the elderly/invalid population is clearly not relevant for assessing functioning difficulties among children and introduces a bias in the respondent's mind in terms of what should be considered as disability.[16] Ideally, questionnaires should include separate sets of questions for adults and children when collecting information about disabilities.

Well-designed surveys that include separate questions for children can still misreport disability if a single set of questions is applied to children across the age spectrum.[17] The choice of questions must be tailored to a child's age in order to reflect his or her developmental stages and evolving capacities.[18] Some areas, such as self-care (e.g., washing and dressing oneself), will not be appropriate for infants or very young children.[19] It is generally agreed among academics that

---

[12] Durkin, M. S., 'Population-based studies of childhood disability in developing countries: Rationale and study design', *International Journal of Mental Health*, vol. 20, no. 2, 1991, pp. 47-60.

[13] Ibid; UNICEF and the University of Wisconsin, *Monitoring Child Disability in Developing Countries: Results from the Multiple Indicator Cluster Surveys*, UNICEF, New York, 2008, p. 9.

[14] UNICEF, *State of the World's Children: Children with disabilities*, UNICEF, New York, 2013, p. 66.

[15] UNICEF, *State of the World's Children: Children with disabilities*, UNICEF, New York, 2013, p. 66-67.

[16] UNICEF and the University of Wisconsin, *Monitoring Child Disability in Developing Countries: Results from the Multiple Indicator Cluster Surveys*, UNICEF, New York, 2008, p. 9; Durkin, M. S., 'Population-based studies of childhood disability in developing countries: Rationale and study design', International Journal of Mental Health, vol. 20, no. 2, 1991, pp. 47-60.

[17] UNICEF, *State of the World's Children: Children with disabilities*, UNICEF, New York, 2013, p. 66.

[18] World Health Organization and the United Nations Economic and Social Commission for Asia and the Pacific, *Training Manual on Disability Statistics,* Bangkok, 2008, pp. 107–108.

[19] UNICEF, *State of the World's Children: Children with disabilities*, UNICEF, New York, 2013, p. 66.

capturing disability among children below two years of age may not be feasible through population surveys given the complexity of developmental processes that take place at such a young age.[20]

Household-based surveys (whether general or targeted) and censuses are based solely on parental responses, with caregivers normally expected to assess and report on the disability status of children.[21] Parents/caregivers then are assumed to be in a position to adequately judge whether their child has a disability or not; however, many children will not have been previously screened for disability and parents may not be able to detect, by themselves, manifestations of certain conditions. Certain temporary conditions, such as an ear infection for example, could be misreported as a form of disability if it is causing acute difficulties. On the other hand, parents may overlook certain signs, or hesitate to report them, because of a lack of acceptance or stigma surrounding disability in their culture.[22] Therefore, parental knowledge of norms and standards and expectations of children's performance will impact estimates of disability prevalence. While parents and other caregivers often do well at identifying difficulties their children may have in performing specific tasks, their responses alone are not sufficient to diagnose disabilities or establish a prevalence of disability.[23]

Along the same lines, language which is stigmatizing or judgmental is commonly found in questions used to determine disability status. Depending on the country context, the language used can be especially important as respondents may be hesitant to report their own or a family member's disability if there is a lack of acceptance or stigma around disability in the country.

---

[20] UNICEF and the University of Wisconsin, *Monitoring Child Disability in Developing Countries*, pp. 8–9; Nair, M. K., et al., 'Developmental Screening Chart', *Indian Pediatrics*, vol. 28, no. 8, 1991, pp. 869–872.
[21] UNICEF, *State of the World's Children: Children with disabilities*, UNICEF, New York, 2013, p. 67.
[22] Ibid.
[23] Ibid.

Annex 6: Information sources

UNICEF Disability Materials

- Disability Website www.unicef.org/disabilities
- UNICEF Disability Orientation www.unicef.org/disabilities
- Analysis of Synergies between the CRC, CRPD and CEDAW: Using the human rights framework to promote the rights of children with disabilities – 2012
- What are the Benefits of Ratifying the CRPD - 2013
- UNICEF Programme Guidance (April 2007) on Children with Disabilities: Ending Discrimination and Promoting Participation, Development and Inclusionhttp://www.intranet.unicef.org/pd/childprotection.nsf/bebddba2e89ddfb685256fa500598afe/aaebde0d60ecf3d6852570de0059f9e4?OpenDocument
- It’s About Ability - An explanation of the Convention on the Rights of Persons with Disabilities http://www.crin.org/docs/VP_Ability.pdf . Learning Guide for Children on the CRPD http://www.unicef.org/malaysia/Its_About_Ability_Learning_Guide_EN.pdf
- UNICEF CHILDINFO: Statistics on Children with Disabilities http://www.childinfo.org/disability_resources.html
- Innocenti Research Center: Innocenti Digest on the Rights of Children with Disabilities (Volume 13) by UNICEF (http://www.unicef-irc.org/publications/pdf/digest13-disability.pdf)
- Video materials developed by UNICEF on disability UNICEF disability vimeo page.

External Resources: International

- Convention on the rights of Persons with Disabilities (CRPD)
- A short animation United Nations Convention on the Rights of Persons with Disabilities http://www.youtube.com/watch?v=uUwHlbQFszU
- Including the rights of persons with disabilities in UN programming at country level– UNDG Programme Guidance Note – 2011
- UN Secretary General Report on the Status of the Convention on the Rights of the Child – 2011
- UN Omnibus resolution on the Rights of the Child on CWD – 2011
- World Report on Disability – WHO/World Bank – 2011 (You can focus on the summary and specific chapters related to children and the SITAN)
- OHCHR training on CRPD (http://www.ohchr.org/EN/Issues/Disability/Pages/TrainingmaterialCRPDConvention_OptionalProtocol.aspx)
- UN Enable website www.un.org/disabilities, for example materials from UN Enable website on mainstreaming disability the Development Agenda (http://www.un.org/disabilities/default.asp?id=1569)
- Health Policy and Planning Advance Access published July 4, 2011, Models and measurement in disability: an international review, Michael Palmer and David Harley

- International Disability Alliance (IDA), The Right to Education: Enabling Society to Include and Benefit from the Capacities of Persons with Disabilities
- WHO report on Developmental Difficulties in Early Childhood: Prevention, Early Identification, Assessment and Intervention in low- and middle-income countries: A Review, 2011.
- Checklist for Inclusion (Excerpt from 'Building an Inclusive Development Community Manual') (http://www.miusa.org/publications/freeresources/Checklist_for_Inclusion.pdf)

External Resources: Regional

- Asia
    - Incheon Strategy to "Make the Right Real" for Persons with Disabilities in Asia and the Pacific, 2012 (http://www.unescap.org/publications/detail.asp?id=1523)
- Europe:
    - Innocenti Insight: Children and Disability in Transition in CEE/CIS and Baltic States by UNICEF, 2005 (http://www.unicef.org/ceecis/Disability-eng.pdf)
    - EDUCATION AND DISABILITY/SPECIAL NEEDS policies and practices in education, training and employment for students with disabilities and special educational needs in the EU, 2012 (http://www.nesse.fr/nesse/activities/reports/activities/reports/disability-special-needs-1)
    - INCLUSIVE EDUCATION FOR YOUNG DISABLED PEOPLE IN EUROPE: TRENDS, ISSUES AND CHALLENGES A synthesis of evidence from ANED country reports and additional sources, Serge Ebersold, (National Higher Institute for training and research on special needs education, INSHEA) with Marie José Schmitt and Mark Priestley, April 2011 (http://www.disability-europe.net/content/aned/media/ANED 2010 Task 5 Education final report - FINAL (2)_0.pdf)

External Resources: National

- Human Development Reports, UN Development Assistance Framework (UNDAF),Poverty Reduction Strategy Paper (PRSPs), Sector-wide Approaches (SWAPs)
- Reports to Convention Committees; General and Concluding comments from Treaty Bodies
- National legislation, plans and programmes, statistics
- Indicators measured by MICS or MICS reports (if country carried out the data collection)
- Reports from local Disabled People's Organizations and NGOs
- Coverage of disability in the media

Sample disability SitAns from UNICEF COs

- Sudan: http://www.unicef.org/sudan/children_7485.htmlor http://www.unicef.org/sudan/children_7487.html
- Bangladesh: Good example of a report outline based on the CRPD (forthcoming)

Annex 2: Detailed methodology

Sampling for quantitative data collection

The sample in each area was developed slightly differently as a result of the different data sources available to identify households with children with disabilities. This is explained in greater detail below. The sample includes 400 households in each of the West Bank and Gaza (800 households in total). The sample size in each area was determined in ODI's original proposal on the basis of the minimum statistically significant sample size in each area to ensure robust data. The budget was prepared on that basis. Then, with that overall number of households per area, the distribution of the sample to capture the necessary strata (disability, locality, sex) was calculated in each area using Epi Info TM[1] software which enables the calculation of a robust sample distribution. The sampling parameters included 95% confidence level and a 5% confidence interval. The suggested sample by the epi-info was approximately 370 households which we increased to 400 participants. Further, to ensure we reached 400 participants we oversampled by 20% more households to compensate for non-respondents. Annex 3 presents the output of the calculated sample for each area.

In order to develop the sample in each area, the research team first approached the Ministry of Social Development (MOSD) in order to introduce the study and to obtain necessary information on CWDs to develop the sample. MOSD collaborated and provided the datasets that are available in the ministry's database. However, while MOSD has the most comprehensive dataset, in neither area was this dataset complete, so the research team complemented it with databases from other organizations working with disabilities. The situation in Gaza was different than that in the West Bank because there are fewer organizations that keep central registration of CWDs in Gaza, but at the same time, a comprehensive census of persons with disabilities was conducted in Gaza in 2012 so there was more data to enable a comprehensive sample of CWD. The sample approach in each area was as follows:

Gaza

- The research team approached MOSD and received a list of all CWDs which were collated based on a comprehensive house-to-house screening that was conducted in Gaza in 2012. The list provided by MOSD contains around 9000 CWDs. Children born or who acquired disabilities after 2012 were not included.
- To include CWDs who were not in the 2012 survey, the research team visited the two organizations that register PWDs: Palestinian Medical Relief Society which works in Northern Gaza and Khan Younis and the National Society for Rehabilitation which covers the rest of the Gaza strip. Both operate according to the CBR approach. Data about the children who recently acquired disability as a result of 2014 conflict were also obtained from Al Salama Association.
- The research team compiled all the lists into one single master list and removed duplicates. The final figure of children with disability in Gaza according to the lists was 14, 244.
- Using the SPSS software, the research team selected 420 cases to be included in the study. This is higher than the planned 400 cases in order to compensate for non-respondents. The selected sample includes children with different types of disabilities, children of different ages and education levels, MOSD's beneficiaries, non-beneficiaries, beneficiaries from NGOs and children not benefiting from the support of any organization. In addition, the research team oversampled a group of children who recently acquired disability as a result of the 2014 conflict with Israel (around 31) to capture this relevant information which has so far not featured in any systematic analysis.
- There is a slightly higher share of boys (54.8%) than girls (45.2%) in the sample, representing the slightly higher share of boys with disabilities than girls with disabilities in the sample.

West Bank

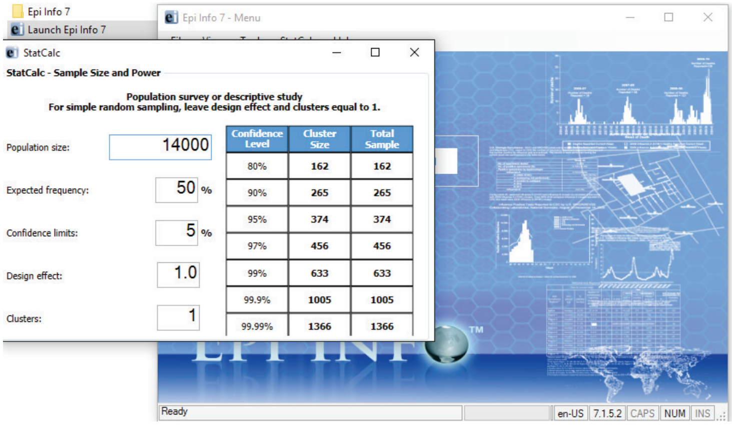
Since MOSD in the West Bank does not have a comprehensive list of beneficiaries like in the case of Gaza, we included beneficiaries from different organizations to be able to develop a more comprehensive master database. However, the database does not represent a "census" of households with disabilities as in Gaza. The following multi-stage cluster sampling approach, which is different to what was done in Gaza, was the sample methodology used in the West Bank:

- The West Bank was divided into three parts, North, South, and Middle to capture possible differences in socioeconomic status, service provision, access to services, security environment, distance and other vulnerabilities. From each area we selected around 160 cases in order to compensate for non-respondent and the non-reachable households. The governorates included in the sample are Hebron, Ramallah and Jenin.
- In each of the three selected governorates, we included children with disabilities living in different contexts: rural areas located in areas known as Area B and C, urban and refugee camps.
- Generally, nearly half of children with disabilities are served by MOSD through the cash transfer program. So, from each area, we took 50% from MOSD's list of households with children with disabilities. The other half of the sample was taken from datasets from other NGOs working with children with disabilities in the three governorates (Palestinian Medical Relief Society and the Palestinian General Union of the Disabled) but who are not in MOSD's lists. Children with different types of disabilities were included in the sample.
- The lists provided by these disability related organizations were used to select the beneficiaries with consideration of gender, type of disability, and so on. The sample of the West Bank is also representative to the universal population.

Annex 3: Output from Epi Info of the calculated sample for each area

The table in Figure 3.1 suggests 374 cases with a confidence level of 95% and confidence level/limit of 5%

Figure 3.1



StatCalc - Sample Size and Power

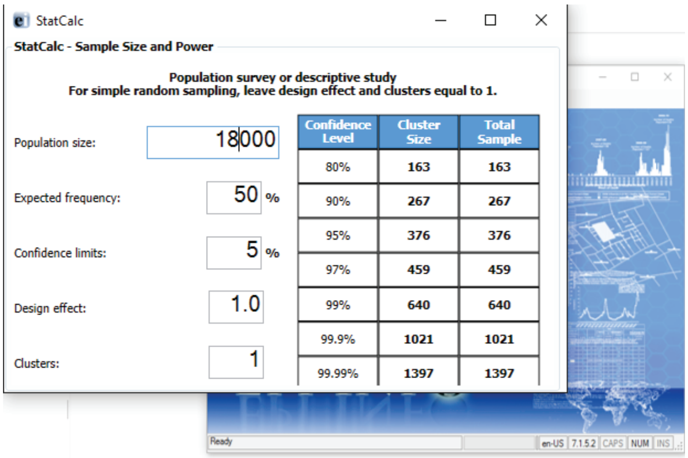
Population survey or descriptive study
For simple random sampling, leave design effect and clusters equal to 1.

Population size: 14000
Expected frequency: 50 %
Confidence limits: 5 %
Design effect: 1.0
Clusters: 1

Confidence Level	Cluster Size	Total Sample
80%	162	162
90%	265	265
95%	374	374
97%	456	456
99%	633	633
99.9%	1005	1005
99.99%	1366	1366

For the West Bank see below. The table in Figure 3.2 suggests 376 cases with confidence level of 95% and confidence level/limit of 5%

Figure 3.2



StatCalc - Sample Size and Power

Population survey or descriptive study
For simple random sampling, leave design effect and clusters equal to 1.

Population size: 18000
Expected frequency: 50 %
Confidence limits: 5 %
Design effect: 1.0
Clusters: 1

Confidence Level	Cluster Size	Total Sample
80%	163	163
90%	267	267
95%	376	376
97%	459	459
99%	640	640
99.9%	1021	1021
99.99%	1397	1397

Annex 4: Characteristics of the research team

In Gaza, 10 data collectors, two field supervisors, and one central auditor were recruited to collect the data. In the West Bank, there were eight data collectors and the same team of supervisors. All the data collectors met the following criteria:

- University degree or high diploma in a related specialty (public health or social work)
- Experience in conducting similar studies
- Communications skills and ethical standards
- Willingness and ability to travel under the current circumstances; preferably living close to the communities included in the survey.
- Willingness to conduct home visits to interview the CWDs and their families.
- All data collectors will be women as it is easier for them to access peoples' homes to conduct the surveys.

Data collectors were trained over the course of three days from February 10, 2016. The training included introducing the participants to the assessment objectives and how it might inform decision making and policy setting and interviewing skills. Trainees were also be introduced to the sampling frame, method of approaching households, and the lead researchers went over the survey with enumerators in detail to ensure their full understanding of the questions.

The team's disability expert led a remote session (via skype) to both the Gaza and West Bank enumerator teams including an overview of disability in Palestine (particularly focusing on children), and introduction to the rights based approach for children with disabilities, types of disability, needs of children with disabilities; and ethical aspects of conducting research on children.

A sign language interpreter was hired in each area, with the support of the Palestinian Disability Union to facilitate interviews with children who have hearing or speech disabilities. In the case of children with sight related disabilities or learning disabilities, enumerators were trained to ask the questionnaire more slowly, but in these cases it was envisaged that caregivers will participate in responding, as indicated in the section above.

During the last day of training the questionnaire was pilot tested by conducting a small number of actual surveys in households. This ensured that the enumerators practiced the questionnaire and their approach to engaging children with disabilities and their family members. A full pilot testing of the questionnaire was done a few days after the training. Importantly, a comprehensive field work manual was developed for enumerators and used during the training, to promote consistency and quality in data collection.

Pilot testing

A two-stage pilot testing was done between February 15 and 18 in both territories. This was done with the aim of having a nearly final version of the questionnaire ready to start the quantitative data collection as soon as the protocol was approved by MOSD. The pilot testing was done to ensure reliability and the highest possible validity of the results.

Annex 5: List of key informants interviewed

West Bank

	Organization	Name of KI
1.	General Union of Disability Persons	Rafeeq Abo Safeen
2.	General Union of Disability Persons	Ramzi Al-Amli
3.	Red Crescent Society	Suheer Badarni
4.	El-Ehssan Charitable Society	Saher Qossmi
5.	UNRWA	Mohammed Araji
6.	The Independent Commission for Human Rights	Islam Tamimi
7.	Save The Children	Lubna Iskander
8.	Blind Charitable society	Rateb Bakri
9.	Star Mountain Rehabilitation center	Ghada Naser
10.	Abo Raya /Rehabiltaion center	Arfat Eideh
11.	Bethlehem Arab Society for Rehabilitation	Rima Canawati
12.	Diakonia	Ghada Harami
13.	The Princess Basma Centre for Children with Disabilities	Nisreen Manarious
14.	Local Government	Rasha Solyman
15.	High Council of Youth and Sports	Nissar Bassalt
16.	Ministry of Labour	Rami Mehdawi
17.	The Princess Basma Centre for Children with Disabilities	Waddah Malhees
18.	Ministry of Social Development	Zaid Amor
19.	Ministry of Education and Higher Education	Shifa Sheikhah
20.	Ministry of Social Development	Ayamn Sawallaha
21.	Annahda Women Association	George Rantisi
22.	Ministry of Health	Waleed Alkateeb
23.	Yatta Community Center	Omar Khaleel Mohmmad
24.	Medical Relief	Azam Abo Rass
25.	Ministry of Social Development	Amin Inabi
26.	Ministry of Social Development	Daoud Al-Deek

Gaza

Organization		Name of Key Informant	Level
1.	Atfaluna Society for Deaf Children	Naeem Khabaja	Central
2.	Amal Society for Rehabilitation	Suha Abu Ghaza	Local
3.	Jabalia Society for Rehabilitation	Akram Eid	Local
4.	Noor Institute- UNRWA for vision impairment	Mohamamd Farahat	Central
5.	Right to Live (for children with Down syndrome and autism)	Nabeel Janeed	Central
6.	Future Palestine	Ahmad Khasief	Central
7.	Dear Balah Rehabilitation Society	Khali Shoeeb	Local
8.	Eyes Association for Combating Blindness	Mohammad Khashief	Some activities are central –ECD is local in Gaza City
9.	Physically Disabled Association-	Sameer Abu Jaiab	Central
10.	National Society for Rehabilitation	Hussam Shaik Yousief	Central
11.	Medical Relief Society	Mustafa Abed	Central
12.	Wafa Rehabilitation Hospital	Ali Abu Ryala	Central
13.	Red Crescent Society	Jenne Kadler-Hussien Nassar- Dalal Taji	Local
14.	Ministry of Education and Higher Education	Khalid Fada	Central
15.	Independent Committee for Human Rights	Khaleel Shaheen	Central
16.	UNRWA	Hussam Abu Hussien	Central
17.	MOSD	Etimad Tarshawi	Central
18.	MOSD	Ghassan Felfel	Central
19.	MOSD	Khader Mansour	Local
20.	MOSD	Osama Sharief	Local
21.	MOSD	Shoqq Hanona	Local
22.	Handicap International	Samah Abu Lemda	Central
23.	Girls School for Visually Impaired Children (secondary school)-MOEHE	Suhair Murtaga	Central
24.	MOEHE Deaf Secondary School –	Jehad Hassan	Central
25.	Woman Affairs Centre	Amal Siam	Central
26.	Islamic Court – Shara'a perspectives	Emad Hemo	Central
27.	World Health Organization	Walaa Ammar	
28.	PWDs Community Coalition	Rawida Hamedi	Local
29.	MOH-Rehabilitation Department	Ayman Halabi	Central
30.	Child health committee-neonatology services	Dr Alam Abu Hamada	Central
31.	Red Crescent Society	Dalal Al Taji	Central

Annex 6: Research Instruments

Annex 6.1 Quantitative Survey

Code Number (for computer use): ___________
Participation Consent

Hello I am ………................. working with the Overseas Development Institute (ODI), a UK based organization, on a study titled *"Situation analysis and needs assessment of children with disabilities in Palestine"*. The study is being funded by UNICEF and implemented by ODI through local and international researchers. I am collecting data for this study which focuses on analysing the status, needs, services available to and quality of life of children with disabilities in Palestine. The study also considers relevant legislative and policy frameworks and gaps in the fulfilment of children's rights. Key recommendations emerging from the analysis will inform the process of setting corrective strategies and interventions by policy makers, responsible duty bearers and other international development agencies.

You (your child with a disability) have been randomly selected from the lists of CWDs available at MOSD and NGOs to participate in this study as you met the inclusion criteria. The purpose of this visit is to gather information about your (your child's) case that will help us as researchers to better understand the real situation as lived and experienced by children with disabilities and their families. We are not entitled to provide any services.

Although participation in this study is voluntary and you can choose not to answer some or all of the questions, we would very much appreciate your participation as your responses are important to us. Participation in this study involves filling a questionnaire which will require around 30 minutes of your time. Whatever information you provide will be kept strictly confidential and will be seen only by the research team; your name will not be shared with the authorities or any other organization. Again, this is voluntary and you may choose either to answer the questionnaire or not to participate — completely or partially.

There will be no cost implication to you as a result of your participation; the information obtained about you and your family in this study will not affect services/support you receive and your data will be handled as confidential.

Do you have any questions?

Others (specify)	Ask for postponing	Refused	Agreed

Interview date: ___/____/________
Interviewer name: ________________

The questionnaire is to be answered by children aged 12 to 18 when they are able to respond, and they can do so with the help of their parent/care-giver. For children younger than 11 or who are unable to respond, then it should be answered by the primary care-giver and/or parent.

1.	**Completed by**	1-Respondent (CWD)	2-CWD's Representative	3- Both		
2.	**If answered by or assisted by a representative please, state the relationship with the CWD:**					
	1. Mother	2. Father				
	3. Brother or sister	4. Other relatives-specify ------------				
	5. Friends	6. Other-(please specify) --------------------				
3.	**Name of the CWD? :**______________________________________					
4.	**Place of living**	West Bank	Jerusalem	Gaza		
5.	**Governorate**	--				
6.	**Locality**	City	Town	Village	Camp	Area C
7.	**Address in details :**	-- ---				
8.	**Telephone land-line --------------------------**	**Mobile --**				
9.	**Record sex of CWD as observed?**	1. Female	2. Male			
10.	**Chronological age of the CWD in years?**	………………				
11.	**Current marital status?** *ask only if CWDs age above 15 years*					
	1. Never married	2. Currently married				
	3. Separated	4. Divorced				
	5. Widowed	6. Not applicable-for children under 15 years old				
12.	**Refugee status**	1. Non refugee	2. Refugee			
13.	**Who do the CWD currently live with?**					
	1. Alone	2. Nuclear family				
	3. Extended family	4. Institution/residential place				
	5. Other (please specify) ______________________					
14.	**Having other HH members with disabilities**	1. Yes	2. No Go To Q 16			
15.	**If yes in the previous question,**	Number of CWD------	Number of adults with disability --------			
16.	**Mother's educational level attained**	1. Illiterate	2. Elementary			
		3. Preparatory	4. Secondary			
		5. Diploma	6. Bachelor			
		7. Post graduate/Higher education				
17.	**Mother's Employment status**	1. Housewife (not employed)	2. Working full time			
		3. Working part time	4. Working intermittent			
		5. Retired	6. Others …………			
18.	**Father's educational level attained**	1. Illiterate	2. Elementary			
		3. Preparatory	4. Secondary			
		5. Diploma	6. Bachelor			
		7. Post graduate/Higher education				
19.	**Employment- father (current)**	1. Not working	2. Working full time			
		3. Working part time	4. Working intermittent			
		5. Retired	6. Others			
20.	**Average HH monthly income from all sources**	1. ………… NIS	2. DK			
		3. Refused to answer				
21.	**What is the main source of income for the CWDs or his/her HH?**					
	1- Employment of the CWD	2- Employment of parents				
	3- Revenues from family assets	4- Assistance from MOSA				
	5- Assistance from UNRWA	6- Charitable local NGOs-indicate name				
	7- INGOs-indicate name ------------	8- Spouse's Employment				
	9- Extended family	10- Other families –not relatives				
	11- Pension from a family member	12- Employment from siblings				
	13- Other (please specify) _____________					
22.	**Is the house you live in:**	1. Owned	2. Rented			
		3. Extended Family	4-Others __________			
23.	**Room numbers in the house (except kitchen and bath room)**	______________ Rooms				
24.	**Total Household size**	____________ persons				
25.		1- MOH	2- MOSA			

	Is the CWD registered as a person with disability at any of the listed organizations (tick all that apply)	3- NGOs (indicate name)	4- INGOs (indicate name)	
		5- Not registered at any organization	6- Other ___________	
26.	**Having health insurance**	1 Yes, for CWD only 2 Yes, for all the family members 3 No Go To Q 28		
27.	**Who provides the health insurance**	1- MOSA because of having CWD 2- MOSA because of poverty 3- Voluntary enrolment-paid by family 4- Paid by other charity organizations 5- Paid by relatives 6- Employment benefit–one of the parents/family members is a government employee 7- Others ______________________		
28.	**Does the CWD/or his family receive Cash assistance**	1- Yes because of the child disability 2- Yes, because the family is poor 3- No Go To Q 30		
29.	**If yes, who provides the assistance (tick all that apply)**	1- MOSA 2- UNRWA 3- NGOs indicate name 4- IGOs, indicate name 5- Zakat Committee 6- Injured and wounded Association 7- Sponsorship/support by families-local 8- Sponsorship/support by families-international 9- Others specify		
30.	**Does the CWD/or his family receive in-kind assistance**	1- Yes 2- No Go To Q 33		
31.	**If yes, type of in-kind assistance received (tick all that apply)**	1- Food 2- Disability assistive devices 3- Clothes 4- Disposables (such as diapers) 5- Games/play tools 6- Books and stationaries 7- Others ____________________________		
32.	**If yes, who provides the assistance (tick all that apply)**	1- MOSA 2- UNRWA 3- NGOs indicate name ------------------------ 4- INGOs indicate name ---------------------- 5- Zakat Committee 6- Sponsorship/support by families-local 7- Sponsorship/support by families-international 8- Others specify ____________________		
33.	**Does the CWD receive the following services from MOSA? (Tick all that apply)**	**1. Yes, received**	**2. Needed but Not received**	**3. Not applicable – not needed**
	1- Health Insurance			
	2- Cash assistance			
	3- In-kind assistance			
	4- Financial support to purchase technical aids and assistive devices			
	5- Sponsorship/adoption of the CWD			
	6- Economic empowerment program for HH			
	7- Economic empowerment for CWD			

	8- Duty-free cars for the family of the CWD (for personal use and turn of the CWD)				
	9- Emergency assistance program (Utilities, adaptation of households, financial aid, medical transfers)				
	10- Pay a fee to enrol in special centres (purchase of service				
	11- Services, training and rehabilitation centres affiliated to the ministry that serves all of the categories				
	12- Counselling and guidance				
	13- Information about community resources available for CWD				
	14- Information about the package of services for CWDs				
	15- Information about the bill of rights guaranteed by law to CWDs				
	16- Psychosocial services				
34.	**Because of the disability, did CWD or his/her family experience any of the listed below (tick all that apply)**	Very difficult	Average difficult	Not difficult	Not applicable
	1. Financial difficulties because of the expenses related to disability				
	2. Difficulties in securing needed disability related assistive devices				
	3. Difficulties in securing needed medications				
	4. Difficulties in securing transportation				
	5. Difficulties in securing rehabilitation services				
	6. Difficulties in securing maintenance services for disability related devices				
	7. Difficulties securing willing caregivers				
	8. Difficulties mixing with other people				
	9. Difficulty in finding a job for CWD				
	10. Mistreatment of CWD at work because of the disability (underpaid, overworked)				
	11. Difficulty in enrolling in education				
	12. Difficulty in staying in school				
	13. Difficulty in securing recreational activities				
	14. Forgone educational opportunities for HH members (including care givers)				
	15. Forgone recreational opportunities for HH member (including care givers)				
	16. Forgone work opportunity for HH member				
	17. Forgone opportunities to socialize with others for HH member (including care givers)				
	Awareness about services and rights				
35.	Are you aware about the availability of CBR programs for CWDs?	yes, How you knew about it -----------------			No
36.	Did the CWD receive any services from a CBP program?	Yes, indicate name of the NGO -------------		No	Don't know
37.	If yes, indicate type of services received?	----------------------------, -------------------------------------- ----------------------------,-------------------------------------			
38.	If yes, how satisfied you are about services received	To high extent		Moderate	Not satisfied
39.	How much you are familiar with the rights of the CWDs?	To high extent		Somewhat	Not at all

40.	If yes, (first two answers), indicate by whom?	--			
41.	Are you aware about the Palestinian disability law?	To high extent	Somewhat	Not at all	
42.	Have you been consulted about disability programs?	To high extent	Somewhat	Not at all	
43.	If yes (first two answers), by whom?	--			
44.	Are you aware about the existence of any disability related bodies/forums?	Yes,	No		
45.	Are you a member of disability related body/forum?	Yes, indicate name	No		
46.	If yes, indicate nature of services or support you received from that body	--			
47.	**What is the current enrolment status of the CWD in education (standard, special, vocational)**				
	1. Currently enrolled in regular education Indicate grade -------	2. Currently enrolled in special education vocational training indicate grade -------	3. Currently enrolled in vocational training indicate Craft -------grade --		
	4.Less than 3 years	5. Not enrolled			
48.	**What is the highest level of education attained by CWD?**				
	Grade	**Standard education**	**Special education**		
	Kindergarten				
	Primary				
	Secondary				
	Vocational training				
	Others specify -------------------------------				
49.	**How many years in total did the CWDs spend studying?**				
	1. Never been in education	2. Number of year __________			
50.	**At what age did the CWD start preschool?**	1- ....Years	2- Didn't attend		
51.	**At what age did the CWD start primary school?**	1- .... Years	2- Didn't attend		
52.	**At what age did the CWD finish school?**	1- .... Years	2- Still studying	3- Didn't attend	
53.	**Does the disability affect or limit access of CWD to education?**	1. Yes	2. No		
54.	**Does the school/ educational institution need to be adapted in order to meet the CWD needs (tick all that apply)**	Availability 1- Yes 2- No	If yes, 1- Adapted 2- Somewhat 3- Not adapted	Needed to school continuation 1- High 2- Somewhat 3- Low	
	1. Transportation Adaptation				
	2. Class rooms adaptation				
	3. Toilets adaptation				
	4. Educational tools Adaptation				
	5. School entrance and exits				
	6. Roads leading to school				
	7. School playfield				
	8. Resource centres such as computer lab				
	9. Others specify				
55.	**Which of the following does the CWD need (apply to your case) in order to follow his/her education and exams- tick all that apply)**	**1. Does not need**	**2. Yes, needs and its available**	**3. Needs and unavailable**	**4. Not applicable**
	1. Personal Assistant				
	2. Personal computer				
	3. Sign language interpreter				
	4. Adaptation of curricula				
	5. Reading material such as a line amplifier zoom lens				

	6. Talking books				
	7. Braille				
	8. Logging tools or devices to take notes				
	9. Others specify				
56.	**Has CWD stopped learning against his/her will because of disability?**	1- Yes 2- No			

57.	**If yes, what are the reasons behind stopping education unlike his/her will/desire? tick all that apply)**	**1- Yes**	**2- No**
	1. Lack of emotional family support		
	2. Lack of financial family support		
	3. Transport is inadequate and insufficient		
	4. Buildings and equipment is not appropriate and not adapted to the needs		
	5. The school does not provide personal assistance and educational support you need		
	6. Feel isolated socially		
	7. Find difficulty in learning		
	8. Deterioration of health status		
	9. Negative attitudes associated with disability demonstrated by school management		
	10. Negative attitudes associated with disability demonstrated by teachers		
	11. Negative attitudes associated with disability demonstrated by peer and classmate		
	12. Negative attitudes associated with disability demonstrated by the community		
	13. Conflict with Israel –checkpoints		
	14. Living in Area C		
	15. Feeling not worth investing in CWDs by the CWDs themselves-no future job opportunities		
	16. Feeling not worth investing in CWDs by the families of CWDs- no future job opportunities		
	17. Others specify ----------------------		

58.	**What is the nature of disability? (tick all that apply)**			
	Visual/seeing		Hearing/speech	
	Physical/mobility		Learning/cognitive	
	Behavioural		Other (please specify) _____________	

59.	**At what age did CWD acquire disability?**						
	Age category	**Visual**	**Hearing/ speech**	**Physical/ Mobility**	**Learning/ cognitive**	**Behavioural**	**Other**
	Since birth GO TO Q 64						
	0 – 4 years						
	5 – 12 years						
	13– 18 years						
60.	**How did CWD acquire disability?**						
	Reason for disability	**Visual**	**Hearing/ speech**	**Physical/ Mobility**	**Learning/ Cognitive**	**Behavioural**	**Other**
	Congenital/hereditary						
	Disease/illness acquired						
	Accident						
	Violence						
	Conflict with Israel						
	Not known						
	Other (please specify) ----------						
61.	**What type of therapy/medical care have been provided to CWD this year? By which provider? tick all that apply**						

Service	1- Provider 2- MOH 3- UNRWA 4- Local NGO (specify name) 5- INGO (specify name) 6- Private 7- MOSA 8- Others specify	1 Financing 2 Self-out of pocket 3 Government insurance 4 Family/relatives 5 Local NGO (specify name) 6 INGO (specify name) 7 UNRWA-free of charge 8 Donations from individual people 9 MOSA 10 Others (please specify)
None **<u>GO TO Q 64</u>**		
Speech/language therapy		
Occupational therapy		
Physiotherapy		
Provision of disposables such as dressings, diapers		
Medications		
Specialized medical care		
Medical Follow up		
Audiology services		
Orthopaedic/prosthetic therapy		
Psychosocial/mental health		
Assistive devices		
Others specify ----------------------------		

62. **Regularity of medical/rehabilitation services provision for CWD?**

Frequency	**Visual**	**Hearing/ Speech**	**Physical/ Mobility**	**Learning/ cognitive**	**Behavioural**	**Other**
Regularly						
Limited period						
When required						
Other (please specify) --------------						

63. **Perception about the medical/ rehabilitation care provided to this year**

	Very Poor	**Poor**	**Neither good nor bad**	**Good**	**V. Good**	**Not available**	**Not applicable**
How would you rate the quality of health care provided							
How would you rate the measures taken at the premises to promote access for CWDs							
How would you rate the organization of care provided							
How would you rate the staff interactions with CWDs							
How would you rate the outcome of the medical care							
How would you rate understanding needs and rights of CWDs							
How would you rate respecting the rights of CWDs							
How would you rate the availability of comprehensive health services for CWD							

	How would you rate the continuity of care for CWD medical and rehabilitation services							
	How would you rate the availability of medications for CWD							
	How would you rate the availability of counselling services for CWD							
	How would you rate the information you received explaining the case and status of the CWD							
	How would you rate the information you received about the management plan for the CWD							
	How would you rate the degree of involvement in the management plan for the CWD							
	How would you rate the provision of information related to care for CWD							
	How would you rate the availability of medical disposables for CWD (dressing, Oxygen, tubes, catheter)							
	How would you rate the availability of assistive devices for CWD							

64.	**What assistive devices does CWD use to help him/her get on with day to day life? tick all that apply**		
	Items	1- Yes 2- No	**Who provided the device** 1 Self-out of pocket 2 MOH 3 NGOs (specify) 4 INGOs (specify) 5 Family/relatives 6 UNRWA-free of charge 7 Donations from individual people 8 MOSA 9 Others (please specify)
	None		
	Walking aid		
	Power wheelchair		
	Classical wheelchair		
	Commode chair		
	Hearing aid		
	Braille systems		
	Orthopaedic devices		
	Artificial limb		
	ADL related devices		
	Communication related devices		
	Assistive technology		
	Others specify -------------------------------------		
65.	**What therapy or medical care CWD would like to receive, but unable to receive it? tick all that apply)**		
	Service	**1- Yes** **2- No**	**Reasons for not receiving the services** 1- Lack or unavailability of services 2- Lack of affordability 3- Poor quality of services 4- Physical accessibility barriers 5- Not knowing where to go 6- Lack of adequate number of organizations 7- Too long waiting lists

			8- Not having caregiver to help in approaching organization 9- Social barriers prevent seeking services 10-Not medically insured 11- Israeli measures (wall, checkpoints) 12-Others specify
	None		
	Speech/language therapy		
	Occupational therapy		
	Physiotherapy		
	Provision of disposables such as dressings, diapers		
	Medications		
	Specialized medical care		
	Medical Follow up		
	Audiology services		
	Orthopaedic/prosthetic therapy		
	Psychosocial/mental health		
	Others specify -------------------------------		
66.	**Are there any assistive devices CWDs would like to use to help him/her with day to day activities but which she/he currently does not have? tick all that apply**		
	Items	1- Yes 2- No	**Reasons for not receiving the services** 1- Too much expensive 2- Poor quality of available items 3- Not knowing where to go to get the item 4- Too much waiting lists at organizations 5- Not having items on sustainable basis 6- HH or roads conditions doesn't allow its use 7- Not having Wasta 8- Not medically insured 9- Social barriers prevent seeking services 10-Others specify
	None		
	Walking aid		
	Power wheelchair		
	Classical wheelchair		
	Commode chair		
	Hearing aid		
	Braille systems		
	Orthopaedic devices		
	Artificial limb		
	ADL related devices		
	Communication related devices		
	Assistive technology		
	Others specify		
67.	**Due to the disability, does the CWD have difficulties in the following daily activities tick all that apply)**	1. No difficulty 2. Some Difficulty 3. A lot of Difficulty 4. Can't al all 5. Not applicable	
	Dressing by him/herself		
	Feeding by him/herself		
	Getting in and out of bed		
	Going and using the toilet		
	Bathing/ washing		

	Moving about in the home		
	Moving about outdoors		
	Getting in and out of a motor vehicle (car, van or bus)		
68.	**Who is the main person responsible for helping the CWD (caregiver) in activities of daily living on a day-to-day basis? and what is the continuity of this help/care-select only one**		
		1- Yes 2- No	1- Some days 2- Daily 3- Weekly 4- Else 5- Don't get help 6- not applicable
	1- Self **GO To Q 72**		
	2- Mother		
	3- Father		
	4- Sister/s 5- indicate age ----------------------		
	6- Brother/s indicate age --------------------		
	7- Spouse		
	8- Son or daughter		
	9- Other family member -------------------		
	10- Friend		
	11- Professional caregiver-health care providers		
	12- Other, specify _______________		
69.	**Working status of the main person caring for CWD?**		
	1. Working full time (paid work)	2. Working part time	
	3. Was working but had to give up to provide care to CWD	4. Interested in working but prevented by providing care to CWDs	
	5. Never worked		
70.	**Education enrolment of the main person caring for CWD?**		
	1. In education	2. Was in education, but had to give up to provide care to CWD	
	3. Interested in education but prevented by providing care to CWD	4. Never attended education	
	5. Not interested in education for reasons not related to the care of CWD	6. Completed education to level ---------	
	7. Others specify -- -		
71.	**Who is the main person responsible for providing supplementary support to the main (primary) CWD (caregiver) in activities of daily living on a day-to-day basis? and what is the continuity of this help/care-select only one**		
		1 Yes 2 No	1 Some days 2 Daily 3 Weekly 4 Else 5 Don't get help 6 not applicable
	1 Mother		
	2 Father		
	3 Sister/s 4 indicate age ----------------------		
	5 Brother/s indicate age --------------------		
	6 Spouse		
	7 Son or daughter		

	8 Other family member -------------------				
	9 Friend				
	10 Professional caregiver-health care providers				
	11 Other, specify _________________				
72.	**On average, how many days per week are the CWD requires care giving activities from caregiver?**	1-None	2-__________ days per week		
73.	**On average, how many hours per day are the CWD requires care giving activities from caregiver?**	1-None	2-__________ days per week		
74.	**Does CWD get any of these services from specialized centres for people with disability- tick all that apply)**	1 Yes 2 No	**Does any of these services needed to CWD but he/she can't obtain- tick all that apply)**	1 Yes 2 No	
	Daily care for 5 days a week		Daily care for 5 days a week		
	Daily care for less than 5 days a week		Daily care for less than 5 days a week		
	Residence in specialized care centre for 5 days a week		Residence in specialized care centre for 5 days a week		
	Specialized care centre for 7 days a week		Specialized care centre for 7 days a week		
75	**If the answer is yes in the previous question, indicate source of funding**	1 Self /family	2 Health insurance	3- Family	4- UNRWA
		5- NGO indicate name		6- Others specify	
76	**In general, would you say that the Quality of life of CWD in your case is**	1. V good	2. Good	3. Bad	4. V bad
77	**In general, would you say that the quality of life of CWD in your case is**	1-Improving	2-The same	3-Deteriorating	
78	**How do you evaluate the growth and development of CWD?**	1. Good	2. Fair	3. Bad	4. DK
79	**What do you think about CWD's size (weight)?**	1. Too little	2. Normal	3. Too big	
80	**How you evaluate the CWD's eating/food intake?**	1. Good	2. Fair	3. Bad	4. DK
81	**In comparison to other children similar in age (without disability), how you evaluate the food intake of CWD**	1. Similar		2. CWD receives less than others	
		3. CWD receives more than others		4. DK	
82	**How you evaluate the nutritional status of CWD?**	1. Good	2. Fair	3. Bad	4. DK
83	**How many meals does CWD eat per day? (not including snacks)**	1. Once-twice		2. Three times	
		3. On request		4. More than 3 times	
		5. Others ______________			
84	**Did the CWD receive all the required vaccines according to the immunization schedule**	1. Yes, all	2. Yes, some	3. Not at all	
85	**In case of not receiving all the required vaccines, indicate the reason**	____			
86	**Thinking about the CWD physical health; how many days during the past 30 days, was his/her physical health not good**	-----------days			
87	**Thinking about the CWD psychosocial/mental health; which includes stress, depression, and problems with emotions, for how many days during the past 30 days, was his/her psychosocial health not good**	-----------days			
88	**During the past 30 days, for about how many days did the poor physical or mental health keeps the CWD from doing his/her usual activities, such as self-care, schooling, or recreation?**	-----------days			

	People's attitudes				
89	**Are there things CWDs can do but avoids doing it because of people's attitude toward him/her or because their reaction toward the disability**	1. No never	2. Sometimes	3. Frequently	4. Always
90	**Give example**				

91	**Are the following people's attitudes to the CWD with regard to his/her disability supportive or disabling?**	1- Supportive 2- Disabling 3- Neither supportive nor disabling 4- Not applicable
	Mother	
	Father	
	Sisters	
	Brothers	
	Other family member like aunts	
	Peers at schools/preschool	
	Neighbours	
	Teachers	
	Taxi Drivers	
	Health providers	
	Doctors	
	Nurses	
	Salesman at shops	
	People at Mosques/church	
	People at recreational places like restaurant –staff/customers	
92	**Because of perceptions and attitudes of people dose CWD have difficulty in the following (tick all that apply)**	1. No difficulty 2. Some Difficulty 3. A lot of Difficulty 4. Not applicable
	Attending schools	
	Attending universities	
	Communicating with people	
	Socializing with others	
	Fulfilling emotional needs	
	Seeking health/rehabilitation services	
	Seeking social services	
	Seeking a job	
	Participating in public meetings	
	Understanding others	
	Being understood by others	
	Feeling that he/she is integrated in the community	
	Others specify	

93	**Do people in the community call the (CWD) names in reference to his/her disability that CWDs don't like?**			
	1. Yes	2. No Go To Q 96		
94	**If yes, give example**			
95	**Who usually call the CWD with names in reference to his/her disability**			
	1. Father	2. Mother	3. Sisters	4. Brothers
	5. Teachers	6. Other relatives specify	7. Other children from the extended family	8. Other children from the community
	9. Community members-adults		10. Others specify ---------------------------------------	
96	**Do services providers and or policy makers discriminate among CWDs in reference to**	1- Yes 2- No	Indicate most privileged	Indicate Least privileged
	1- Type of disability			
	2- Reasons behind disability			

	3- Age of CWD			
	4- Gender of CWD			
	5- Socioeconomic status			

97	**Does CWD have difficulties in being a passenger in a private car as a result of their disability**	1. NA (don't have)	2. Yes to high extent	3. Some what	4. Not at all
98	**Does CWD have difficulties in using public transportations on the following cases:**				
	Transport services for PWD				
	Taxi				
	Public bus				
	Public van				

99	**If yes, reasons for facing difficulties in using Public transportations- tick all that apply**	1. Yes	2. No
	Services not available		
	Services not available when needed		
	Services not adjusted to their needs		
	Don't know how to use transportation		
	Difficulty transferring from one transport to another		
	Difficulty of getting out and in other transportation		
	Overcrowding		
	Attitudes of people		
	Attitudes of drivers		
	Not having someone accompanying CWD		
	Affordability and costs		
	Others specify -------------------------------		

100	**Does the CWD use any of the following additions in the entrance and exist your home or inside your home**	**Availability**	**If yes, who conducted the adaption**	**Which of the following additions CWD needs but can't obtain**
		1- Yes 2- No 3- NA	1-Self/family 2- MOSA 3- NGOs specify 4- INGOs specify 5- Individual donor 6- UNRWA 7- Others specify	1- Yes 2- No 3- NA
	Slide stairs at home			
	Adapted bathrooms			
	Adapted kitchen			
	Electric elevators			
	System of visual alerts			
	Adapted house entrance			
	Adapted roads leading to the house			
	Adapted corridors			
	Social Participation			
101	**During last four weeks, has CWD participated in any of the following activities?**	1. Yes	2. No	3. NA

	Go with friends and family to places such as the social and other restaurant				
	Visit friends and relatives in their homes.				
	Participate in social events (weddings and grief).				
	Send emails to friends and family or use the phone				
	Play with other peer				
	Visit clubs and organizations				
	Use the Internet to access information				
102	**With whom CWDs main social activities are carried out**				
	Family members	1. Yes	2. No		
	Peer at school				
	Friends with disability				
	Persons providing services related to disability				
	Others specify ----------------------------				
103	**Does the disability the CWD has, make it difficult for them to participate in the following social activities? To what extent?**	1. No difficulty	2. Somewhat	3. A lot	4. Can't do at all
	Go to market				
	Travel for vacation or leave				
	Visit friends and family				
	The friends and family visiting you				
	Going out to public places such as restaurant				
	Performance of religious occasions				
	Participate in the elections				
	Participation in local activities such as volunteering or community work				
104	**What are the reasons that limits the CWDs participation in social activities?**	**1. Yes**	**2. No**		
	Physical appearance				
	Need for special tools not owned				
	Need personal assistant				
	Transportation is not qualified and not enough				
	Lack of harmonization of recreational areas				
	Shortage of local places and activities appropriate				
	Negative attitudes and offensive to you from the people around				
	Israeli actions / crossings				
	Trends in family				
	Cost				
	Others specify --				
105	**During last four weeks, did CWDs participate in any kind of sports/play?**	1.Yes 2.No			
106	**During last four weeks, how many times did CWDs participate in sports, play?**	No --------------------			
107	**What is the average time spent in play and sports activities weekly usually?**	1. Less than 30 minutes each time 2. 30-60 minutes 3. More than 60 minutes			
108	**Is the CWD currently a member in one of the sports teams or sports institutions?**	1.Yes 2.No			
109	**If no, indicate the reason**	1. Disability doesn't allow him/her to			
		2. No access to sports for CWD			
		3. No transport			
		4. Cost implication			
		5. Difficulty mixing with others			
		6. No knowledge about sport activities he/she could undertake			
		7. Others specify			

Psychosocial

Children aged 12 to 18 years and who are able to respond/ communicate will be asked the below version of the SDQ. For those aged below 12 or unable to communicate, please use the caregiver version in the next page

Quality of life questionnaire

Children aged 12 to 18 years and who are able to respond/ communicate will be asked the below version of the QoL. For those aged below 12 or unable to communicate, use the caregiver version in the next page

QoL Version for children aged 12 to 18 (completed by child)

Physical Activities and Health						
1.	In general, how would you say your health is?	Excellent	Very Good	Good	Fair	Poor
	Thinking about the last week...					
2.	Have you felt fit and well?	Not at all	Slightly	Moderately	Very	Extremely
3.	Have you been physically active	Not at all	Slightly	Moderately	Very	Extremely
4.	Have you been able to exercise well?	Not at all	Slightly	Moderately	Very	Extremely
5.	Have you felt full of energy?	Never	Seldom	Quite Often	Very Often	Always
General Mood and Feelings about Yourself						
1.	Has your life been enjoyable?	Not at all	Slightly	Moderately	Very	Extremely
2.	Have you been in a good mood?	Never	Seldom	Quite Often	Very Often	Always
3.	Have you had fun?	Never	Seldom	Quite Often	Very Often	Always
4.	Have you felt sad?	Never	Seldom	Quite Often	Very Often	Always
5.	Have you felt so bad that you didn’t want to do anything?	Never	Seldom	Quite Often	Very Often	Always
6.	Have you felt lonely?	Never	Seldom	Quite Often	Very Often	Always
7.	Have you been happy with the way you are?	Never	Seldom	Quite Often	Very Often	Always
Family and Free Time						
1.	Have you had enough time for yourself?	Never	Seldom	Quite Often	Very Often	Always
2.	Have you been able to do the things that you want to do in your free time?	Never	Seldom	Quite Often	Very Often	Always
3.	Have your parent(s) had enough time for you?	Never	Seldom	Quite Often	Very Often	Always
4.	Have your parent(s) treated you fairly?	Never	Seldom	Quite Often	Very Often	Always
5.	Have you been able talk to your parent(s) when you wanted to?	Never	Seldom	Quite Often	Very Often	Always
6.	Have you had enough money to do the same things as your friends?	Never	Seldom	Quite Often	Very Often	Always
7.	Have you had enough money for your expenses?	Never	Seldom	Quite Often	Very Often	Always
Friends						
1.	Have you spent time with your friends?	Never	Seldom	Quite Often	Very Often	Always
2.	Have you had fun with your friends?	Never	Seldom	Quite Often	Very Often	Always
3.	Have you and your friends helped each other?	Never	Seldom	Quite Often	Very Often	Always
4.	Have you been able to rely on your friends?	Never	Seldom	Quite Often	Very Often	Always
School and Learning						
1.	Have you been happy at school?	Not at all	Slightly	Moderately	Very	Extremely
2.	Have you got on well at school?	Not at all	Slightly	Moderately	Very	Extremely
3.	Have you been able to pay attention?	Never	Seldom	Quite Often	Very Often	Always
4.	Have you got along well with your teachers?	Never	Seldom	Quite Often	Very Often	Always

QoL Version for children aged 12 to 18 (completed by child)

Physical Activities and Health						
1.	In general, how would your child rate her/his health?	Excellent	Very Good	Good	Fair	Poor
	Thinking about the last week...					
2.	Has your child felt fit and well?	Not at all	Slightly	Moderately	Very	Extremely
3.	Has your child been physically active (e. g. running, climbing, biking)?	Not at all	Slightly	Moderately	Very	Extremely
4.	Has your child been able to run well?	Not at all	Slightly	Moderately	Very	Extremely
5.	Has your child felt full of energy?	Never	Seldom	Quite Often	Very Often	Always
General Mood and Feelings about Yourself						
1.	Has your child felt that life was enjoyable?	Not at all	Slightly	Moderately	Very	Extremely
2.	Has your child been in a good mood?	Never	Seldom	Quite Often	Very Often	Always
3.	Has your child had fun?	Never	Seldom	Quite Often	Very Often	Always
4.	Has your child felt sad?	Never	Seldom	Quite Often	Very Often	Always
5.	Has your child felt so bad that he/she didn’t want to do anything?	Never	Seldom	Quite Often	Very Often	Always
6.	Has your child felt lonely?	Never	Seldom	Quite Often	Very Often	Always
7.	Has your child been happy with the way he/she is?	Never	Seldom	Quite Often	Very Often	Always
Family and Free Time						
1.	Has your child had enough time for him/herself?	Never	Seldom	Quite Often	Very Often	Always
2.	Has your child been able to do the things that he/she wants to do in his/her free time?	Never	Seldom	Quite Often	Very Often	Always
3.	Has your child felt that his/her parent(s) had enough time for him/her?	Never	Seldom	Quite Often	Very Often	Always
4.	Has your child felt that his/her parent(s) treated him/her fairly?	Never	Seldom	Quite Often	Very Often	Always
5.	Has your child been able to talk to his/her parent(s) when he/she wanted to?	Never	Seldom	Quite Often	Very Often	Always
6.	Has your child had enough money to do the same things as his/her friends?	Never	Seldom	Quite Often	Very Often	Always
7.	Has your child felt that he/she had enough money for his/her expenses?	Never	Seldom	Quite Often	Very Often	Always
Friends						
1.	Has your child spent time with his/her friends?	Never	Seldom	Quite Often	Very Often	Always
2.	Has your child had fun with his/her friends?	Never	Seldom	Quite Often	Very Often	Always
3.	Have your child and his/her friends helped each other?	Never	Seldom	Quite Often	Very Often	Always
4.	Has your child been able to rely on his/her friends?	Never	Seldom	Quite Often	Very Often	Always
School-preschool and Learning						
1.	Has your child been happy at preschool/school?	Not at all	Slightly	Moderately	Very	Extremely

(continued)

Physical Activities and Health						
2.	Has your child got on well at preschool/school?	Not at all	Slightly	Moderately	Very	Extremely
3.	Has your child been able to pay attention?	Never	Seldom	Quite Often	Very Often	Always
4.	Has your child got along well with his/her teachers?	Never	Seldom	Quite Often	Very Often	Always

Annex 6.2 FGD with children with disabilities

Instructions for focus group discussion

This is a guide for a focus group discussion with children with disabilities. There will be various focus groups with children who have different disabilities, so the researcher leading the discussion will adapt the questions and the tools used according to the situation. Some of the participatory facilitation tools that might be used includes: problem tree analyses (with flip chart) for children with mobility or hearing disabilities; using post-its for them to write the answers to some of the questions and then paste them on flip charts; story telling (drawn, for children with hearing or speaking disabilities or told for children with visual disabilities); role playing (for specific questions); among others.

While some questions might be asked directly, it is desirable for the interviewer to engage in a discussion with the group which might cover additional issues that stem from the responses to some of these questions.

Estimated duration of discussion with child: Around 1 hour (will depend on how much time is needed for children with different needs – e.g. translation into sign language)

Introduction

We are conducting a study on behalf of UNICEF to better understand what the needs of children with disabilities are. We want to get your views and opinions about things you like and do not like in your life, and what you would need for your life to be better. This is a conversation. There are no right or wrong answers, we want to hear your voices so please feel free to tell us what you are thinking. There will be no direct benefits from participating in the study; but your insights will be useful in informing the report and policy dialogues about how to better support children with disabilities.

Tape recorder – just for the purpose of taking notes.

Number of participants: 6-10 children per FGD. Single sex groups.

Total of 10 FGDs – 2 per governorate with children with specific disabilities (6); 2 with caregivers of children with mental/ learning disabilities; 2 with siblings of children with disabilities to discuss issues of stigma, time and care burdens (one with sisters, one with brothers).

Two age categories: 12-13 years; 14-17 years – achieving balance across FGDs

Venue: check if it will be accessible (e.g. community centre/ specialised school). We will cover transport costs and also provide snacks.

Questions for children with disabilities

1. Tell us about your home: who do you live with, how many siblings do you have; how is your house? (this is intended as an ice-breaker, so that they start talking, but some of the information they provide might be important, so listen in case you can then draw on it)
   a) Next focus is on who provides you with the most support – use drawings/ cards/figurines of the family
   b) What sort of support do these family members provide? Why is this important to you? Can you give us an example?
2. Could you please draw a simple map of the key places in your village/neighbourhood – with school, health centre, community centre, mosque, playground, NGO focused on disability.
   [not with children with visual impairment – but could just some sort of clay to build something creative]
   a) Based on the map, ask children 'How do you access these services? Where do you like going and why? Are some places difficult for you to visit? If so, why/why not?
   b) Who helps you access these services outside of your family? (friends, teachers, social workers, imam) – for younger age group use facial expressions [*except for visually impaired*]. Are there any people who are not supportive?
   c) Can you tell us about a typical day when you might access some of these places – from when you wake up, until when you go to bed?
3. Have you ever been taught that you should be treated the same as other children irrespective of your disability? Who taught you this? (e.g. parents, teacher, NGO)
   a) Have you heard about the language of 'rights'? What do you know about them (you can write them down in a flip chart as they mention them).
   b) What about right to go to school? (do your teachers treat you like other children? What about your peers?)
      i. To get good health treatment? (do doctors/ nurses treat you like others?)
      ii. To get supportive devices?
      iii.To participate in leisure activities?
      iv. To be treated well by other people (e.g.. other children at school, teachers) irrespective of your disability?

0. When you use specialised services you need for your disability (*e.g. rehabilitation, special transport, special schools*), how do people providing those services treat you? (*prompts: well, bad, with respect - please explore their answers)*

- Is this situation different for girls than for boys? Why do you think this is?
- Can you yourselves do anything about these barriers?

1. Do you face any other challenges? E.g. excluded from activities you would like to take part in? Please tell us more about this. How do you feel about it?
2. Do you think girls or boys are differently excluded? Please give examples. Why do you think this is?
3. Are some of the services you access "inclusive", that is, they are specifically adapted so that you can participate along other children who do not have the same disabilities that you have. Please tell us what they are? Do you like this? Why?
4. 6) Are you able to participate in family life in the same way as your siblings? (explain why/why not) Do girls participate differently to boys?
5. Do you have access to means of communication and information such as TV, phone, computer, etc? (ask who has which)
   a) If yes: In what ways do they help you? How do you use them? What do you use the most?
   b) If no: Do you think that having access to these would help you? How do you think you could gain access to these?
   c) Do children who do not have disabilities have better access to these? Or is it a general problem for children your age?
6. What would you need to improve your situation? (*prompts: more support from adults; access to services for children with disabilities; more resources; more information, greater respect from others, etc)*
   a) What other services or support would it be helpful for you to have to meet your needs? (make sure to take separate responses from girls / boys)
   b) Try to agree on the 3-5 most important things that should be changed among the group

For children affected by the conflict with Israel:

- How was your life before the conflict and after the conflict?
- In what ways has the new disability affected your life? (*Probe*)
- What would you need now to improve your life situation?

Questions for children who have siblings with disabilities (siblings who are mid/older adolescents – ie. 14 years and above).

1. Please tell us about your family. What sort of disability does your sibling have? What care do different family members provide? What do you do? What do you like doing? What do you find more challenging?
2. What sorts of support does your sibling get? What are the main challenges that your family faces in providing support to your sibling?
3. Are you or other family members treated the same or differently to children/ families who do not have a family member with a disability? If differently, how does this make you feel?
4. Do you have other friends in the same situation as you with whom you can discuss your experiences/ concerns/ etc.?
5. What sorts of changes/ additional support or services would make life better for your sibling and for your family?

Questions for caregivers of children with disabilities

1. Please tell us about your family. What sort of disability does your child have? What care do different family members provide? What do you do? What do you like doing? What do you find more challenging?
2. What sorts of support (from government/ NGOs/ religious organisations) does your child get? What are the main challenges that your family faces in providing support to your child?
3. Are you or other family members treated the same or differently to families who do not have a family member with a disability? If differently, how does this make you feel?
4. Do you have other friends in the same situation as you with whom you can discuss your experiences/ concerns/ etc.?
5. What sorts of changes/ additional support or services would make life better for your child and for your family?

Annex 6.3 Individual interviews with caregivers

Individual interviews with children with disabilities and caregivers

Instructions for interviewer

This is a guide for a semi-structured interview. So while some questions might be asked directly, it is desirable for the interviewer to engage in a discussion with the interviewee which might cover additional issues that stem from the responses to some of these questions.

This guide is aimed at caregivers. While the main aim of our qualitative research will be to get their views of children themselves, it will be important to also get the view of caregivers, using the following guide.

In households visited for IDIs where child is unable to respond, use this guide to get the opinion of caregivers. Overall we are hoping to get representation of caregivers of children with diverse disabilities, different ages and genders, and also caregivers coping with multiple children with disabilities.

Introduction

We are conducting a study on behalf of UNICEF to better understand what the needs of children with disabilities are. We want to get your views and opinions about things you like and do not like in your child's, and what you think they need to make their life to better. There will be no direct benefit from participating in the interview, but your views will be very important in terms of feeding into a national report and policy dialogue about how to better support children with disabilities and their families.

Questions

1. Please tell us about family and your children.
2. In the case of your child with a disability, at what age was the disability detected? How did you react? What about other family members?
3. What kinds of support /care do you need to provide your child with on a daily basis? Do you get help from other family members in providing that care/ support?
4. Does your child have difficulty with self-care such as feeding or dressing him/herself?
   - If you have to help, how much of your time do these activities take? Does it give you the time to do other things? (work, domestic activities, social life)? Do you have any support?
   - Did you have to give up any prior activity or work in order to care for your child?
   - Would you like your child to have independence / be self-sufficient? How could this be achieved? (what type of support would you need for this to happen)
5. Does your child normally need help in getting in and out of the house?
   - Does this keep her/him from going out? If so, what you require to help her/him be able to get out more easily?
   - Because of your child's condition, do they require adapted or modified building features to attend school? Or other services / activities?
   - Are these available to them? If not, have you requested that these are made available? What has been the response?
6. Can you afford the costs of taking care of your child's special needs with the household income?
   - If not, how do you manage?
   - What about support outside of the family? Do you have access to services/programmes? (prompt: please have information about the programmes and services available in the locality and mention these to see which ones they now about / have access to)
   - If not, what are the barriers that prevent you from accessing them
   - If yes, what is your opinion about these services and programmes? How can they be improved?
7. What about access to cash / in kind transfers from the government to support your family in relation to your child's situation? Do you know about these? Do you access them? Why/why not?
8. How satisfied are you with the current policies, services and programmes available to meet the needs of your child?
9. Do you feel that your social group / community discriminates against your child or your family? In what ways? (give examples – e.g. attending weddings or other social occasions; access to leisure activities).
10. What three positive things can you identify about your/your family's life with your child?
11. Overall, what are the three greatest challenges you/your family experience as a result of your child's disability?
12. Does your child feel sad, worried or angry at times? Is this often? Are there situations that trigger this sadness? Please explain. Are you able to help him/her? Do they need additional support to cope with these psychological stresses?

1. Please tell me what you hope for your child in the future? (prompt only if necessary: education, work, marriage). What support will they need to realise these hopes?

Annex 6.4 Individual interviews with CWD

Individual interviews with children with disabilities and caregivers

Instructions for interviewer

This is a guide for a semi-structured interview. So while some questions might be asked directly, it is desirable for the interviewer to engage in a discussion with the interviewee which might cover additional issues that stem from the responses to some of these questions.

The interview is aimed at the child with disabilities, when he/she can answer and is over 12 years of age. Please ensure you use the facilitation tools indicated to promote a good engagement with the child. If the child is not able to respond to these questions, you can use the tool for care givers.

Estimated duration of discussion with child: Around 45 minutes - no more than 1 hour

Facilitation

Since this is an interview with a child / adolescent, you will need to use facilitation tools, either those indicated here or others which you can draw on from your past experience.

Introduction

We are conducting a study on behalf of UNICEF to better understand what the needs of children with disabilities are. We want to get your views and opinions about things you like and do not like in your life, and what you would need for your life to be better. There are no right or wrong answers –so please feel to express your views.

Questions

1. Tell me about your life (*they can start by describing a typical day*), including things you like and don't like:
- In your family
- At school
- In the community

Which family members help you to different daily activities? How important is this support? Why/why not?

For younger children, you could use drawings to depict the time of day.

(Based on responses for each category, probe) Why do you say this? *(Do not ask explicitly: "as a result of your disability" as it can be leading, this may or may not come out explicitly from the response, but we want to hear their own views on their lives).*

In case of child with hearing disability, ask them to draw different parts of their day (what they do) and include in the drawing what they like most about their lives (it can be school or family or community, and what they like the least). If they don't want to draw and prefer to explain, that is fine as well).

2. How do you feel health wise? What would you need to feel better?
3. Please tell us a story about your life, about something that happened to you or your family that made you feel very sad or that you did not like.
4. Now please tell us a story about something that happened in your life that you liked very much or that made you feel very happy.
5. What about when you have worries or concerns – is there someone with whom you can talk – either in the family or outside the family?
6. Do you have access to means of communication and information such as TV, phone, computer, etc?
- If yes: In what ways do they help you? What do you use the most.
- If no: Do you think that having access to these would help you? Which one would help the most? In what ways?

7. What do you think about the services and programmes available to you in order to meet your needs? (*help them think through some of these: e.g. rehabilitation, school, health, school clubs, counselling, etc*). Please tell us three things that you like about these services and three things you don't like about these services *(you can focus on two of the services used the most, e.g. school and another one*)
8. What other services would it be helpful for you to have to meet your needs?

9. When you use specialised services you need for your disability (*e.g. rehabilitation, special transport, special schools*), how do people providing those services treat you? (*prompts: well, bad, with respect - please explore their answers)*
10. Do you participate with other children your age in community activities? e.g. Do you play? Do you have conversations?
    - If yes, tell us about these. How do other children interact with you? (prompt: the same as with other peers, don't interact as much, are welcoming; are distant)
    - If not, why not? how do you feel about this? How do you think this can change? Do you think this is the same for boys/ girls?
11. Are you able to participate in family life in the same way as your siblings? (*explain why/why not*)
12. Have you ever been taught about your rights as a child, and specifically your rights as a child with disabilities? If yes, where did you learn about rights? Please also tell us what you know about your rights? Did this knowledge help you – why/why not?
13. What changes would you like to see in your surroundings that would help you achieve a better life? Please prioritise the most important ones.
14. What are your plans for the future / your aspirations? Do you have a role model (someone you admire/ find inspirational)? If so can you describe who they are and why they are inspirational to you? Do you identify any barriers that might prevent you from doing this? Which ones? How can you overcome these barriers? What support would you need to overcome these barriers?

For children affected by the conflict with Israel:

- Tell us about your life before the conflict and after the conflict?
- What changed (physically)?
- In what ways has that affected your life? (*Probe*)
- What would you need now to improve your life situation?

Annex 6.5 Key informant interviews with organizations working for, with or in areas linked to children with disabilities

This is a guide for a semi-structured interview. So while some questions might be asked directly, it is desirable for the interviewer to engage in a discussion with the interviewee which might cover additional issues that stem from the responses to some of these questions.

This is a comprehensive guide of possible questions for KII but the interview should be tailored to what the specific key informant might be able to answer based on their experience and position.

Duration of the interview: 1 hour to 1.5 hours

General

1. Can you tell us about what your organisation does for children with disabilities? What is its main focus?
    a) How many children/ households do you serve?
    b) How do children and their families find your organisation's services?
    c) What is going well and what are the challenges?
    d) For CBOs – which umbrella organisation are you part of (e.g. Red Crescent, Union etc.)?
2. The 1999 Law for Persons with Disabilities provides a legal framework to protect the rights of children with disabilities.
    a) To what extent are government service providers aware of this Law? And are they aware of the conditions in the law? (including 5% quota in government agencies).
    b) To what extent do you think related legislation, policies and programmes have been put in place by State agencies to guarantee the enactment of the law?
    c) In what areas (sectors) do you think policies and programmes are more / least effective in fulfilling CWD's rights? (for example: education, health, social protection, community support services, etc).
    d) Can you please provide examples of why you think this is the case?
    e) For those who know about social protection, was it better before the unified cash transfer programme in 2010?

0. Do you consider that there are differences in the situation of children with disabilities in different parts of the West Bank/ Gaza, for example with respect to inclusive services available for CWD, rehabilitation services; quality of services, accessibility, social environment (discrimination), social norms stigmatising CWD etc?
    a) (probe: what regions? Why these differences? How are they manifested?) Probe especially on Area C; areas close to Separation Wall (Jenin); proximity to settlements in Hebron; Bedouin Community?
    b) What about the centralisation of specialist services in Ramallah? To what extent is this a problem?
    c) What are the underlying causes of inequalities among the disability community? Are there any specificities that affect children more / less than the disability community as a whole?
1. Are there services for families/ parents that provide support to the caregivers – support networks? Are there examples of good practice?
2. What about challenges for late teens – given that support for children is only up to 18 years is this a challenge? Is there a need for transition support services towards ensuring independence for pwds as they become adult? E.g. employment, education.

How can these linkages be made – e.g. links with UNICEF and other UN agencies – rather than being limited to age silos?

3. With respect to social interactions and life in the community, how are families with children with disabilities treated? What are community attitudes like towards children with disabilities? Towards their families? What forms of deprivation and exclusion do families that have members with disabilities face?
- How do you think this affects children in particular?
- What about other siblings? Are they affected? Are there differences between girls and boys?

4. Are there community level interventions taking place to reduce these forms of exclusion?
- If yes: what types of interventions, by whom, how do they work?
- On day of disability, are they invited? To general NGO events are they invited?
- Invited to recreation events – families and the children with disabilities? (e.g. UNRWA initiatives)

Enabling environment

5. What social, institutional and political factors could potentially support the creation of an enabling environment for the realization of the rights of children with disabilities? (e.g. social norms, institutional capacities at all levels of government, accountability and coordination mechanisms, policy and legal frameworks)
- What do you think this “enabling environment” would look like? What factors would it need to include to improve the situation of all children with disabilities so that they have the same rights and opportunities as other children?
- What agents would need to work together to promote this?
    - (prompts:) Government agencies (which?);
    - NGOs (which?);
    - CBOs (which?) ;
    - Religious institutions (which?) – e.g. Zakat Committees? Are there any challenges/ barriers to religious organisations focusing on disability issues? Are there differences in inclusion of children with disabilities in the govt school system versus the madrasa system?
    - What about coordination across key disability-focused organisations? Would an umbrella organisation/coalition be useful? What are the challenges in this?
- How can families, including children and their parents, be involved in contributing to this enabling environment? (please give your ideas, and possible examples if this is happening already). What are the existing mechanisms for consulting with families with disability? For those on the cash transfer programme and those not? Where might there be opportunities for interacting with the system?
- What about the role of the private sector in supporting people with disabilities? Is there coordination? Or is it more ad hoc sponsorship? (could meet Jawal to learn more about this). (E.g. through schools, health centres).

6. Please identify the main barriers to the well-being of children with disabilities to access and utilize basic social services and other critical resources?
- Prevention – awareness raising about how to avoid preventable disabilities – e.g. spina bifida, cerebral palsy, genetic counselling
- Prevention - in terms of changing discriminatory social norms – for children, families, girls/women on the marriage market
- Support for children with disabilities
- Support for the family /caregivers of children with disabilities

7. Do budgetary allocations from the government to relevant sectors / ministries / implementing agencies constrain the provision of these services? (probe on the importance of budget constraints compared to lack of coordination, compared to attitudinal barriers).

- Is there a challenge with respect to overall government allocations to the sectors?
- Do different government agencies earmark resources to address the needs of children with disabilities (eg: MOSD, MoE, MoE, etc). Or are they centrally managed by MOSD?
- Are the resources sufficient? Have they increased over time? Are they effectively and efficiently spent? Is there funding ear-marked for working on disability issues?
- What other agencies provide financial support to improve the provision of services for CWD? (e.g. donors (and which donors), NGOs, local religious organizations, other country governments, etc).

Supply

8. What human resource capacities exist at national, sub-national and community levels to provide essential services and address inclusion of children with disabilities more broadly? In terms of rights, psycho-social support, specific disabilities, coordination of services in complex cases, referrals?
9. Do you think that general services are inclusive of children with disabilities (e.g. schools, community centres, public transport, etc)?
10. Can you please mention the main programmes providing support to children disabilities? In your opinion, how well / poorly do they work?
11. How do you think the PNCTP (cash transfer) has contributed to the wellbeing of children with disabilities? Does it face any specific challenges in supporting these children?
12. What other social protection measures exist that are inclusive of and reach children with disabilities and their families?

- Please tell us what your impression is about how they contribute to the wellbeing of children and their families. Is the distribution of resources – e.g. accessible cars – equitably carried out? Are there clear criteria? What about monitoring and follow up?

13. To what extent is the physical environment in Gaza and the West Bank accessible for people with disabilities? What needs to be improved?
14. Are communications and information systems, including internet, accessible for children with disabilities (for example, if there is public internet in public libraries, are these accessible to CWD, etc)? How could it be improved? (what resources, support, capacity building, etc would it require)

- To what extent is internet a source of support for other children and caregivers living with disabilities? Are children linking with others in similar situations? What about caregivers?

Quality

15. How can problems of quality of services be improved going forward? (please probe around the following factors: more resources; more training of providers; more sensitization about disabilities; more equipment; more accountability and mechanism for beneficiaries to voice their complaints?)

West Bank

- Emergency action for children who have conflict-related disabilities – how prevalent is this? How are children and their families treated? What is your view on the appropriateness of this response (especially compared to families whose children have non-conflict related disabilities?

Gaza

a) Can you please tell us about the situation of children who incurred long-term injuries and other debilitating conditions during the conflict in Gaza two years ago?

b) Have these children been able to get the treatment, rehabilitation and care they need?

- If yes: who has provided this support? How has it been funded? (probe: which children have and which haven't - perhaps there is difference by locality, status, etc)
- If no: How are families coping? What is needed at this stage to support these children?