

**Report: Baseline Knowledge, Attitudes, Beliefs and
Practices (KABP) Study**

in support of

**A C4D Strategy for Early Childhood Development and
Children with Developmental Delays and Disabilities
for Palestine**

Final Report – September 18, 2019

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This report was written by Andrew Carlson, Ph.D., Associate Professor, School of Communication, Writing and the Arts at Metropolitan State University in St. Paul, Minnesota, and Ms. Chola Lungu, Independent Communications Consultant, Lusaka, Zambia, in 2019.

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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

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Acronyms and Abbreviations

BCC	Behaviour Change Communication
C4D	Communication for Development
CRC	Convention on the Rights of the Child
CSO	Civil Society Organisation
DPO	Disabled Persons Organisation
ECD	Early Childhood Development
ECE	Early Childhood Education
FGD	Focus Group Discussion
GUPD	General Union for Persons with Disabilities
KAP	Knowledge, Attitudes and Practices
KII	Key Informant Interview
MoEHE	Ministry of Education and Higher Education
MoH	Ministry of Health
Mol	Ministry of Information
MoJ	Ministry of Justice
MoSD	Ministry of Social Development
MoRA	Ministry of Religious Affairs
PA	Palestinian Authority
PCBS	Palestinian Central Bureau of Statistics
ROI	Return on Investment
SCT	Social Cognitive Theory
SoP	State of Palestine
SCT	Social Convention Theory
SEM	Socio-ecological Model
SoP	State of Palestine
SLT	Social Learning Theory
TPB	Theory of Planned Behaviour
UNICEF	United Nations Children’s Fund

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II. Executive Summary

Children with developmental delays and disabilities in the State of Palestine are often severely marginalized in their communities. They and their parents/caregivers may struggle with stigma and discrimination from those around them, and they also struggle with the challenges of living in a country in which many aspects of life are impacted by the political situation and the Occupation. Respondents report that they often struggle with the most basic task – transporting their children to receive services – as a result of lack of funding for assistive devices such as wheelchairs, poorly built or damaged roads, and an inability to pay for transportation services. Once a child arrives at a care facility, they may find that the services for which they have come are not available, or may be too expensive for the parents to afford. Nonetheless, parents/caregivers, extended family of children with developmental delays and disabilities, and many community members, leaders, and others express strong support for the rights of these children to receive an education and participate in social and cultural life of their communities.

It is in this context that this report presents the findings of a baseline Knowledge, Attitudes, Beliefs and Practices (KABP) study on children with developmental delays and disabilities and their parents/caregivers. The study was designed to inform the development of a C4D strategy for UNICEF State of Palestine that will promote Early Childhood Development (ECD) behaviours, increase demand for services among parents/caregivers of children with developmental delays and disabilities, and provide parents/caregivers with the knowledge, beliefs, and skills they need to confront stigma and discrimination when it occurs in their communities. Building on previous research and reports, this document is intended to provide baseline data for a multi-year communication strategy around ECD and children with developmental delays and disabilities.

The research used three methods of inquiry: a quantitative study, which is representative of the entire population of Gaza and the three governorates of Hebron, Jericho, and Nablus in the West Bank; a qualitative study which included Focus Group Discussions (FGDs) and Key Informant Interviews (KIIs) with parents/caregivers (parents and guardians), extended family members, community members, leaders, service providers, and policymakers in both Gaza and the West Bank; and participatory activities, which were conducted with youth with developmental delays and disabilities ages 10-15 in both Gaza and the West Bank and parents/caregivers in each region. The design of the study was based on a review of literature, including key recent reports on the situation of children with developmental delays and disabilities in Palestine. In addition, the study proposed the use of a theoretical framework, the Theory of Planned Behaviour (TPB) that would inform the development of a C4D strategy as a final step in a multi-step process to promote positive change for children with developmental delays and disabilities and their family parents/caregivers in Palestine. The three main concepts in this framework – attitudes, normative expectations, and self-

efficacy – informed the design of the quantitative survey instrument and were further explored in the qualitative inquiry.

A note about terminology used in this report: slightly more than 90% of index children are cared for primarily by their mother; about 8% are primarily cared for by their father; less than 1% are cared for by another immediate family member; and slightly more than 1% are cared for by someone from the child’s extended family. Throughout the report, the term **parent/caregiver** refers to this person, the primary caregiver. The word **practitioner** refers to someone outside the family who provides care for a child, such as an employee of a nursery or preschool or a school teacher. **Service providers** are those individuals who provide a specific service related to health, treatment, rehabilitation, counselling, or other service specifically for a child with a developmental delay or disability.

1. Key Insights and Findings

The percentages of respondents with positive attitudes and normative expectations toward confronting stigma and discrimination are relatively high, but parents/caregivers are not confident in their ability to do so.

Parents/caregivers in both the West Bank and Gaza generally have positive attitudes toward confronting stigma and discrimination when it occurs, and they also tend to believe that others expect them to stand up for the rights of their children. However, their belief in their ability to accomplish this is quite low – less than 40% of respondents in Gaza stated that they believe they can confront discrimination when it occurs. The percentage who believe they are able to do so was higher in the West Bank, where 63% of respondents are confident in their ability to confront stigma and discrimination. Other findings reinforce the findings of previous research; for example, the present study found that 62% of respondents in both regions did not believe that Palestinian law provides children with developmental delays and disabilities with legal rights. Jones et al., 2016, found that nearly 52% of respondents were not familiar at all with the rights of CWDs, and that 88% were not familiar with the Palestinian Disability Law (PDL). These results suggest that lack of awareness of legal protections and services for children with developmental delays and disabilities continues to be a barrier to the demand for better services.

Parents/caregivers confront multiple barriers in seeking and providing services.

The findings of the qualitative research suggested that parents/caregivers face multiple barriers in seeking and providing services for their children, not the least of which is the often dire economic situation in which they find themselves. Many parents/caregivers, who are primarily mothers, find themselves caring for multiple children with disabilities, and without consistent grants or welfare from state agencies, again, to which they are entitled by law. Many rely on immediate family for psychological and financial support, and appreciate opportunities to share their experiences with other parents/caregivers in support groups or informal conversations while waiting for services. Participants in both KIIs

and FGDs noted the deleterious effect that an overall lack of institutional capacity has on their ability to receive services for their children, and for the children of those they work with as social workers or service providers. Participants also noted a lack of expertise for specific disabilities in organizations, and were frustrated by the lack of coordination among institutions, Ministries, and other organizations that are charged with supporting children with developmental delays and disabilities.

There are significant differences across many indicators between Gaza and the West Bank.

In addition to the three theoretical variables of attitudes, normative expectations, and self-efficacy, residents of Gaza are generally less wealthy, more likely to be unemployed, generally have a lower level of education than those in the West Bank, and more likely to report that they do not seek information about caring for their child with a disability because they do not know where to look for it. The differences between the two regions should be considered in the development of the C4D strategy.

Lack of institutional coordination remains a significant barrier to service provision.

Particularly in the qualitative inquiry, lack of institutional coordination was cited as a significant problem in providing effective treatment and other services for children with developmental delays and disabilities. Multiple institutions may serve the same group of children, or certain groups of children may be underserved. This supports results of previous research (Jones et al., 2016) that found that coordination among schools, institutions, government agencies, and UN agencies is weak and has not changed in four or five years between that research and the present study.

Emotional and financial support are lacking for many parents/caregivers.

The challenges associated with lack of financial support has been documented elsewhere (Jones et al., 2016; Sood, 2016) and was repeated in the present study. In terms of emotional support, 35% of parents/caregivers stated that they have no sources of personal support in their reference networks and only 2% of respondents stated that they receive any support from their communities. Those that do have people supporting them are often not likely to receive the amount of support they need; 52% of parents/caregivers in Gaza reported that the amount of support they receive, both emotional and financial, is not enough, compared to 24% in the West Bank.

Participants prefer a combination of interpersonal communication (IPC) and online approaches to communication.

In qualitative activities, participants consistently mentioned that workshops and other face – to – face communication modalities were the ways they preferred to receive information and learn from others. At the same time, online platforms such as Facebook were mentioned again and again as an effective way to get information and support.

The findings suggest a set of recommendations for a multi-year, multi-phase C4D strategy to promote ECD, increase demand for services, and encourage parents/caregivers to confront stigma and discrimination when it occurs. Strategic initiatives intended to increase parents'/caregivers' ability to confront stigma and discrimination should focus on improvements in attitudes, normative expectations, and self-efficacy, which together will contribute to increasing parents'/caregivers' intention to perform these behaviours and increase demand for ECD services. These individual-level behaviour change interventions should be supported by social mobilisation and advocacy activities that increase the ability of institutions to coordinate service delivery and adapt the physical environment to accommodate children with disabilities.

Given the complex nature of the situation surrounding children with developmental delays and disabilities, communication activities should include the three main strategic approaches: Behaviour Change Communication (BCC), social and/or community mobilization, and advocacy. Each of these strategic approaches has a role to play in improving the situation of children with developmental delays and disabilities: BCC to encourage individual parents/caregivers to demand services, perform caregiving behaviours, and confront discrimination; social/community mobilization to identify resources and improve the presence of services at the community level, including gaining buy-in from community leaders and influencing the community dynamic-collective capacity to change, and advocacy, to promote coordination and support from government partners in building systems to support parents/caregivers and their children.

Participants report that projects that increase visible accommodations for persons with disabilities have effects on communities' acceptance of individuals who are differently abled. Many participants in qualitative activities believe that attitudes toward persons with disabilities are improving in Palestine, and this is encouraging for those working to influence attitudes among parents/caregivers to equip them to advocate for their children. However, the lack of coordination among service providers remains one of the most glaring issues facing children and their parents/caregivers. The problems with service delivery were identified in 2016 by Jones et al. and, despite the efforts of several participants in this research in policy making positions, are still considered among the most challenging issues. In order to address this issue, UNICEF, along with partners/stakeholders, must conduct an advocacy and capacity building campaign that will encourage effective Ministerial oversight and guidance to institutions at the governate and community levels.

The C4D strategy that will be developed to serve the needs of UNICEF's programmatic goals related to ECD and children with developmental delays and disabilities should build on the participatory approaches adopted in this research to include parents/caregivers and children with developmental delays and disabilities in the design of messages and activities, the implementation and monitoring of communication activities, and eventually, in the

evaluation of the effectiveness of the intervention. UNICEF itself should expect to play a key role in building capacity at all levels of Palestinian society to create demand for services, increase acceptance among communities, build an accommodating physical environment, and improve coordination among Ministries, service providers, and other institutions.

III. Context and Previous Research

1. Context

This report presents the background, design, and findings from a Knowledge, Attitudes, and Practices study related to Children with Developmental Delays and Disabilities that was conducted in Gaza and the West Bank in March, April and May of 2019. The study will function as a baseline for the development, implementation, and evaluation of a C4D strategy to address stigmatization of children with developmental delays and disabilities and support for their parents/caregivers, and in conjunction with other research, to improve ECD outcomes in Gaza and the West Bank. The document includes details on the population included in the study, the methodology and methods used in the administration of the study and data collection activities, and implications and recommendations for the development of the C4D strategy.

2. Previous Research and Social Indicators for Children with Developmental Delays and Disabilities

Children with developmental delays and disabilities are often the most neglected and discounted groups of children. They are judged and defined by what they lack, rather than what they have, and they experience widespread discrimination. Stigma, which may be defined as “an adverse reaction to the perception of a negatively evaluated difference” (Susman, 1994) affects children with developmental delays and disabilities, their parents/caregivers, service providers, and members of their communities, although in different ways and with different effects. Children with developmental delays and/or disabilities are not only concerned with their disabilities, but also with the stereotypes and prejudice from others regarding their condition (Corrigan & Watson, 2002).

Discourse around disability falls into two major categories: medical and social. The medical model emphasizes diagnostic labels, while the social model centralizes unaccommodating social structures, including both the physical presence of accommodations and the willingness of social acceptance of those with differing abilities. The social model provides a frame for parents to use as they challenge disability stigma, while the medical model's focus on individual “improvement” more closely aligns with stigma deflections (Manago et al., 2017).

Stigmatization is part of everyday life for parents of children with disabilities (Manago et al., 2017). Stigma towards children with developmental delays and disabilities starts at a young age. When children see a peer who differs from them, they often label them “weird” or “different” and this rejection towards people who are unlike them grows with them as they age. The social stigma that a child with developmental delay or disability is subjected to tends to be harsh and cruel. This is one reason that persons with disabilities often try to hide their condition, for the prejudice and discrimination they receive from their fellow humans as a result is unforgiving (Thornicroft, 2006).

In fact, stigma can be so severe that individuals with disabilities claim that alongside the stigma, the discrimination they are subjected to is worse than their differing abilities (Thornicroft, 2006). Stigma and fear of rejection prevent them from seeking help, and in the case of a non-visible disability or illness such as depression, disclosing to loved ones their psychological condition. Avoiding treatment usually makes the condition worse. For example, if steps to early intervention are not taken to treat the symptoms of depression, the person's mental state would gradually decline, and soon it will be even more difficult to treat. Unfortunately, even though there is treatment available for those with a mental illness, especially in highly developed countries, two thirds of people worldwide with a known mental disorder do not seek it, primarily due to stigma and social discrimination (Thornicroft, 2008). Across all types of disabilities, but particularly in the case of hidden disabilities and developmental delays, the main reason for the unwillingness to seek treatment is self-stigmatization: diagnosed individuals begin to believe internally what society says about them, that they are a disgrace, as well as less valued and important than others (Corrigan & Watson, 2002). Young children, who are not equipped to seek their own care, are also affected by their parents' or parents/caregivers' internalization of the narrative of unworthiness, as those who care for them tend to prefer to keep them hidden from the view of the community.

a. A model for stigma

While the existence of stigma is well known, it is only recently that researchers have begun looking for the causes of stigma. Stigma is a complex phenomenon that is modified by the culture and contexts in which it occurs, and therefore there is no generally accepted 'unitary theory' of stigma. Link and Phelan (2001) conceptualize stigma as a model with four interrelated component actions by those performing the stigma:

1. Distinguishing and labelling differences, in which differences between individuals are recognised as being important to consider;
2. Stereotyping, in which identified differences are connected to negative traits;
3. Separating, in which the differences are used to create a "normal" and a labelled group; and,
4. Discrimination and loss of status, in which the separated people are devalued, rejected, or excluded.

The ways in which these four components are performed vary based on social and cultural context. Stigma therefore represents a complex interaction between social science, politics, history, psychology, medicine and anthropology (Smith, 2002). For this reason, effectively confronting stigma requires socially and culturally specific approaches that fit within a particular context. There is no "one size fits all" approach to confronting stigma.

b. Parents/Caregivers and Responses to Stigma

Parents/caregivers of children with disabilities are challenged with the stigmatization of their children and themselves. Parents/caregivers may engage in stigma confrontation (Thoits, 2011), but this is not always the case. Studies conducted outside Palestine (green,

2003; Manago et al., 2017; Corrigan & Watson, 2002) have shown that stigmatization is linked to lower quality of life and affects parents'/caregivers' self-esteem, social support, ability to find positive meaning in caregiving, and may also create affiliate stigma, which is internalized, or self - stigmatization. Green (2003) notes that "controlling for the effects of salient maternal and child characteristics and the daily hassles of caring for a child with a disability (objective burden), maternal perceptions that individuals with disabilities are devalued and discriminated against (stigmatized) by others *increases* maternal distress (subjective burden)" (p. 1361). Children of mothers who perceive high levels of stigma interact less frequently with age peers in the informal settings of homes and neighbourhoods. Perceived stigma increases the subjective burden, which Green (2003) defines as "embarrassment, guilt, shame, resentment, worry and other emotional upset" (p. 1362) that mothers perceive in their caregiving tasks. Subjective burden decreases the frequency with which children interact with age peers, because it causes some parents to limit their children's exposure to social contexts that they believe may cause their children harm. Stigma also exerts a direct effect on peer interactions when subjective burden and preference for interactions with wise individuals are controlled (Green, 2003).

Manago et al., (2017) examined 117 instances of stigmatization from 40 interviews with 43 parents, and document how parents respond. Results of the study shown that parents invoke medical and social meanings in ways that serve diverse ends, sometimes centralizing a medical label to challenge stigma, and sometimes recognizing disabling social structures, but deflecting stigma nonetheless. The difference between stigma deflections and stigma challenges is the way each relates to the social structure. Parents of children with disabilities use both medical and social models to address issues related to disability in the everyday lives of their families (Manago, 2015).

c. Global Research on Stigma

Stigma is present in every country in the world, but the majority of previous research on stigma has been conducted in western countries. One example is a study that was done in the United States, with 5,555 college students from thirteen diverse universities (Eisenberg et al., 2009). This study examined mental health help seeking attitudes of students in the United States. The results showed that the race, gender, age, and socioeconomic status of a person all affect the stigma they perceive. Culture plays a significant role in stigma, and so does family status. Furthermore, it is believed in many cultures, specifically collectivist societies, that the disability of a relative can greatly affect the rest of the members of the family. For example, if a girl has a relative with a mental illness, the chances of her getting suitors for marriage would be compromised (Corrigan & Watson, 2002). Severity may also increase the stigma towards a person with a disability, as differences and stereotypes are more easily identified and labels connected to a set of "undesirable attributes" (Link & Phelan, 2001, p. 377). The separation into an "us" and "them" becomes subsequently easier.

Lack of knowledge on the definition and importance of mental health is also one of the main causes of stigma across the globe. Thornicroft (2006) reported that it was discovered from over 12,000 surveys across several European countries that many people had, for example, mistaken conceptions of the mental illness schizophrenia, associating the disease with a “split-personality” (p. 19). These types of misunderstandings contribute directly to the stigmatization of people with mental illnesses, for whom stereotypes are common. On the other hand, those who were knowledgeable about disability tend to be less fearful and more trustworthy of those who had a history of a psychological disorder (Thornicroft, 2006).

Religious beliefs also play a huge role in seeking professional treatment for a disability. Often, families prefer to ask a religious healer for help, as in some cases disabilities are thought to be associated with lack of faith in the person. This could explain why families may like to keep children with disability a secret: they fear society will come to believe that are not pious (Heath, Vogel & Al-Darmaki, 2016). Therefore, many youth are discouraged from self-disclosure and seeking help, as it would not only affect the family, but also because an individual who seeks help would be perceived as weak, especially if the person was male (Al-Darmaki, 2003).

Some Arab cultures have labelled some aspects of mental illness, such as aggressive or anti-social behaviours, as supernatural, something that is caused or influenced by otherworldly creatures such as jinn (El-Islam & Abu Dagga, 1992). This suggests a severe lack of knowledge on the nature of psychological disorders as well as unnecessary fear of those with a mental illness. Al-Darmaki et al., (2016) explored the level of knowledge female Emirati college students had in regards to mental health and psychological problems and found that while some answers were relevant to the actual nature of mental illnesses, most participants associated it with madness and labelled them as incurable (Al-Darmaki et al., 2016).

Addressing the components of stigma requires a multifaceted approach that addresses attitudes and beliefs that lead to labelling, stereotyping, and discriminating, and at the same time reduces the power of those who perform stigma to perpetuate their attitudes and beliefs (Link & Phalen, 2001). Studies have demonstrated the importance of supporting parents/caregivers across the life-cycle in order to decrease stigma, improve social support and self-esteem and improve subjective wellbeing (Werner & Shulman, 2013), which in turn can provide them with the internal mental and emotional conditions they need to promote the inclusion of their children in social and cultural life. The amount of social support parents/caregivers receive may be measured by a) defining the reference network for individual parents/caregivers and b) understanding the messages provided by the social support system, i.e., empathy, encouragement, and validation (Werner & Shulman, 2013).

d. [Research on Stigma in Palestine](#)

The Israeli occupation is a major cause of political, social, economic and security unrest in Palestine. The economy in Gaza is under severe economic strain due to factors including

the blockade, and this is coupled with insufficient quality and sufficiency of basic essential services including health and education facilities, access to water and sanitation, food and housing. In addition to the economic challenges, there have been consistent reports of children killed or disabled by Israeli soldiers during the Great March of Return protests (UN Commission of Inquiry, 2019). In the West Bank, there is a lack of basic essential services for the population, including health and education facilities, access to water and sanitation, food and housing insecurity and access to water and sanitation. According to SOLIDAR¹, the Israeli policy of displacement and dispossession, coupled with the increasing geographical fragmentation of Palestine, growing settler violence and the human rights violations by the Israeli authorities, remain the most urgent issues to be tackled (Solidar, 2016).

Disabled Persons' Organizations (DPOs) are a relatively recent phenomenon in Palestine; according to Kaur et al. (2016) the General Union of People with Disability (GUPWD) was founded in 1993, although the organization's website indicates that it was founded in 1991. Kaur et al. (2016) reported that DPOs are "growing in number and capacity" (p. 21) but tend to be based in urban areas, be led by people with physical disabilities, and to lack a common agenda, all of which affect their ability to participate fully in policy deliberations.

Marginalisation of women, young people, and persons with disabilities including children, the lack of universal coverage in social protection programmes, as well as restrictions on freedom of association for CSOs and trade unions have been significantly worsened by the internal division between the West Bank and Gaza. Persons with disabilities have limited access to health services, due to the closure of numerous centres in Gaza, hours-long electricity cuts in care and rehabilitation centres and the absence of assisting devices. Limited opportunities for health professionals in Gaza to attain new medical techniques and the travel restrictions for health staff, as well as a chronic shortage of pharmaceuticals and supplies. In addition, persons with disabilities face serious challenges in terms of gaining equal access to basic and higher education, and access to funding to support higher education and universities in both the West Bank and Gaza (Solidar, 2015).

There is a high percentage of people with disabilities found in Jenin, where 4.1% of the population of the area has disability with regular tasks (Jones et al., 2016). This is followed by the district of Hebron, with a percentage of 3.6%. In the Gaza Strip, the Gaza governate had the highest percentage at 2.3% of children with disabilities (PCBS, 2018). For disability among children, the percentage was 1.5 percent—1.8 percent among males and 1.3 percent among females (Jones et al., 2016). Mobility is the disability with the highest prevalence, comprising nearly half of disabilities in Palestine (Jones et al., 2016).

The most significant barriers and challenges people with disabilities face (in order of percent reporting) are related to financial difficulties related to the disability, difficulty securing assistive devices, difficulty securing needed medications, difficulty securing transportation,

¹ www.solidar.org

difficulty securing rehabilitation services, difficulty in securing maintenance for assistive devices, difficulty staying in school, and difficulty securing recreational activities (Jones et al., 2016). According to the World Bank (2007), about 87.3 percent of all people with disabilities in the Palestinian Territories were not employed; 85.6 percent in the West Bank and 90.9 percent in the Gaza Strip.

In collaboration with four Palestinian ministries including the Ministry of Social Development (MoSD), the Ministry of Education and Higher Education (MoEHE), the Ministry of Health (MoH) and the Ministry of Labour (MoL), Palestine has adopted a number of strategies targeting persons with disabilities in order to provide them with accessibility, availability, accountability and affordability of the services. These strategies include the provision of all basic and vital services for the persons with disabilities as a right to enjoy a decent living, access to education, availability of appropriate infrastructure, Technical and Vocational Education and Training (TVET) and economic empowerment (World Bank, 2007).

In 2016, the situation and services assessment for people with disabilities in Palestine conducted by the World Bank (Kaur et al., 2016) stressed the need to go beyond traditional definitions and approaches in relation to persons with disabilities. The stress must be increasingly placed on the reduction of stigma and prejudice. According to the assessment, one must be able to identify barriers to full and equal participation as well as have the tools to remove obstacles. Soliciting input directly from persons with disabilities facilitates the identification and removal of barriers and development of accommodations. Sustained positive interaction with persons with disabilities may also serve to lessen stigmatization, while conversely, a lack of understanding of the experiences of persons with disabilities may foster prejudice and lack of action.

The World Bank assessment conducted by Kaur et al., (2016) described the basis for the inflation of persons with disabilities to the level of heroes and then the regression or removal of that status as time passed. The assessment notes:

In the 1980s, the Intifada raised a sudden interest in disability. The number of persons with permanent disabilities due to war injuries rose and those who were injured were regarded as 'heroes'. However, while people's perceptions of war-disabled persons were and still are positive, exclusion of and discrimination against other persons with disabilities prevail. Despite changes in the social attitudes toward disability in the last two decades, large social segments still attach stigma to disability, especially intellectual and mental disability. Degrading terminology and charity-based notions are still common. Coupled with the many environmental obstacles, these attitudes make it difficult for persons with disabilities to join educational institutions, access services, and apply for jobs/earn an income and prevent them from obtaining their rights to political participation (Kaur et al., 2016, p. 2).

To overcome stigmatization, one must go beyond consultation and shared understanding. According to Kaur et al., (2016), one must be able to identify barriers to full and equal participation as well as have the tools to remove obstacles. Qualitative factors such as whether political support for the vulnerable groups differs, whether earmarked transfers will empower members of vulnerable groups within their households, and whether special programs would be more or less stigmatizing than general social assistance are also significant factors in the decision (Kaur et al., 2016).

i. Health Services Provided to Persons with Disabilities in Palestine

In Palestine, there are four health care providers: (a) The MOH provides primary, secondary, and tertiary care; (b) Local NGOs provide primary, secondary, and some tertiary services; (c) The UNRWA provides health services for refugees through primary health centres and facilitates access to secondary and tertiary; and, (d) the private sector provides private hospitals, pharmacies, and rehabilitation centres (World Bank, 2007). There are many forms of care services offered for persons with disabilities in Palestine. Such services include out-of-home rehabilitation services through available care centres. They provide day care services, accommodation, rehabilitation, physiotherapy, speech and hearing therapy, psychosocial rehabilitation and others (Ministry of Social Development, GOPA, and ARWAD 2019).

Persons with disabilities, as well as children with developmental delays and disabilities in Palestine face different challenges represented by limited availability of services, a limited number of rehabilitation centres targeting disabilities, difficult access to various services, and weakness in financial capabilities of families of persons with severe disabilities. All these challenges restrict the ability of these people and their families to access treatment, rehabilitation, support and counselling. In many cases, it is difficult for persons with severe disabilities to move to and from the rehabilitation centres due to the nature and conditions of the disability or the distance from the service Centre. As a result, families (particularly women) who care for persons with severe disabilities are suffering, particularly those who are living far away from the cities where most of the services are concentrated (Ministry of Social Development, GOPA, & AWRAD, 2019).

ii. The ODI/UNICEF Report on Children with Disabilities (Jones et al., 2016)

Palestinian children with developmental delays and disabilities experience significant levels of cultural stigma directed at their disability. The 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. The report pays attention to different sociodemographic factors including age, gender, disability type and family characteristics (Jones et al., 2016). The report details the ways in which children with developmental delays and disabilities in Palestine are marginalised and excluded. They face difficulties in meeting their rights and contributing to the identification of mechanisms that 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.

Palestinian culture tends to silence children generally, but especially those with developmental delays and disabilities (Jones et al., 2016).

The Palestinian 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. 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 (Jones et al., 2016).

Jones et al., (2016) found that families with one or more children with developmental delays and disabilities were extremely likely to be poor. Nearly 40 percent had monthly incomes that were about half of the extreme poverty line. About 10 percent of children with developmental delays and disabilities have multiple disabilities; 41.8 percent had more than one type of disability. Of all the households included in the study, 41.4 percent had at least one person with disabilities in addition to the sampled child with a disability. 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 persons with disabilities was another child. Families in Gaza were especially likely to have more than one child with a developmental delay and/or disability (Jones et al., 2016).

Palestinian children with developmental delays and disabilities are regularly denied access to the services guaranteed to them by law and are often poor; 53 percent live in families that receive some cash assistance from MOSD, and this assistance tends to be inadequate to meet all of the family's needs. In the extreme poverty in which they live, very few receive any sort of disability-targeted assistance or disability-related education. Many of the children who required the most expensive devices, such as wheelchairs and hearing aids, were simply forced to do without. Families in the West Bank reported difficulty accessing quality education for their children with developmental delays and disabilities. Children with vision and hearing impairments experience relatively less difficulty than children with other sorts of disabilities. Children with cognitive and multiple disabilities are particularly likely to be denied an education, as are girls once they reach puberty (Jones et al., 2016).

Jones et al., (2016) also report that children with developmental delays and disabilities face tremendous stigma in the community. For example, only 23 percent of participants in the study felt that members of their mosque or church were supportive. In addition, only about 50 percent of families were aware of rights for children with disabilities and 92 percent had no awareness of the Palestinian Disability Law. The study cites many discriminatory practices, such as:

- 33 percent of children with disabilities reported being called names related to his/her disability that s/he doesn't like; and,
- Less than 12 percent of children with disabilities are aware of disability related forums.

Some children with developmental delays and disabilities are especially likely to be discriminated against:

- Those who were born with disabilities are more stigmatised in the community than those injured in conflict because they are not seen as heroic.
- Those from wealthier families may be more stigmatised within the family than those from poorer households—because of the threat they pose to familial reputation.

From the above, it is clear that stigma and discrimination are significant factors in the day to day life of children with developmental delays and disabilities in Palestine. They are a significant barrier to the ability of these children to gain fulfilment of their human rights according to the CRC and laws of Palestine. Coupled with financial constraints and the inability to invest in services for children with developmental delays and disabilities, stigma and discrimination are pernicious, deeply rooted realities in the day to day life of children with developmental delays and disabilities in Palestine.

e. [Key Takeaways from the Review of Literature](#)

There are several factors identified in the literature review that may be responsive to C4D programming. First, it is apparent that attitudes toward people with disabilities are rooted in cultural and social norms, which vary among communities and between areas. Shifting such norms may require long term interventions that include anti-discrimination behaviours and outreach to communities through mass/social media. Concurrently, stigma is a complex phenomenon that is best confronted from the perspective of the child with a developmental delay or disability or their caregiver, rather than from an institution or organisation. The capacity of parents/caregivers to confront stigma and discrimination using strategies and approaches appropriate to their contexts must be built. Institutions and organisations can play an important role in providing children with developmental delays and disabilities and their parents/caregivers with the tools they need to confront stigma and discrimination. Parents/caregivers benefit from positive messages of empathy, encouragement, and validation received from those around them, and institutions and organizations can contribute to these messages, supplementing personal reference networks. Despite the positive benefits of institutions and organisations that work with children with developmental delays and disabilities, there are not enough of them and those that do exist are under-resourced, an issue that requires sustained advocacy efforts.

The causes of disability vary, and children who have been injured as a result of the Occupation are considered differently than children born with a disability or who develop it from an illness or other cause. This will have to be considered in the design of the C4D

strategy, as parents/caregivers of these children may need to adopt different approaches to improving the inclusion of their child in social/cultural life.

Gender plays a significant role in the current situation in the State of Palestine related to caring for a child with a developmental delay and/or disability, with mothers generally bearing the brunt of the load of caregiving.

Finally, accessibility in the State of Palestine is a significant barrier to participation and inclusion of persons with disabilities, and this is a barrier that can be overcome through provision of resources and initiative from decision makers. Addressing this issue through advocacy initiatives may be effective in ensuring enforcement of Law 4 of 1999, which supports equal access to persons with disabilities and children with developmental delays and disabilities.

IV. Rationale, Objectives, Frameworks, and Variables

1. Rationale and Significance

In the ToR for the baseline KAP study, UNICEF State of Palestine notes:

The prevalence of social stigma related to disability remains high, and more than one-third of children surveyed said they avoided participating in community life because of the discriminatory community attitudes. Some families struggled to accept that their child has a disability while others have not been able to obtain an accurate diagnosis or intervention. Almost half of families surveyed were unaware that they were eligible for community-based rehabilitation. Girls with disability, sisters of children with disabilities and mothers of children with disabilities often face gender-specific vulnerabilities. Adolescent girls with disabilities are especially unlikely to attend school or be allowed to socialize. Those same girls-and their mothers-are at high risk of intra-familial violence. (p. 2).

The primary purpose of the baseline study on knowledge, attitudes and practices is to understand the ways in which children with developmental delays and disabilities, parents/caregivers, service providers, and community members perceive the issue of stigma towards children with developmental delays and disabilities in their communities. In addition, the study measured knowledge of positive parenting practices among parents/caregivers and practitioners, and how these individuals' knowledge and attitudes are practiced in caregiving, parenting, and day-to-day interactions.

The objectives of this study are to inform a C4D strategy that will aim to address stigmatization of children with developmental delays and disabilities and equip parents/caregivers and service providers with the information and attitudes they need to implement positive approaches to caregiving, child rearing, and seeking services. In addition, the C4D strategy will include an advocacy component that will support children with developmental delays and disabilities through activities to improve the built environment and provide additional services.

Based on existing literature regarding stigmatisation of children with developmental delays and disabilities in Palestine, as well as previous studies related to early childhood development, this study provides baseline data on attitudes, norms, and self-efficacy among parents/caregivers towards confronting stigma and seeking social support from family and community. Qualitative activities, which included KIIs and FGDs and participatory enquiry, were conducted to deepen understanding of the prevalence, root causes and drivers of stigma and discriminatory attitudes towards disability in the society as well as the level of societal factors influencing nurturing care and positive parenting among parents and practitioners.

The results of this report will inform the development of a C4D strategy that will contribute to influencing parents' and parents/caregivers' attitudes toward confronting stigma, and will

promote the inclusion of children with developmental delays and disabilities in social life. In addition, the report will set baseline levels for attitudes, normative expectations, and self-efficacy related to confronting stigma in order to facilitate future monitoring and evaluation of C4D programming.

2. Information and Research Gaps in Existing Data

As indicated in the previous section, recent research in the Palestinian context has provided background information on the scope and scale of stigma and discrimination towards children with developmental delays and disabilities, including their ability to receive services for rehabilitation and physical therapy when required (Jones et al., 2016; Sood, 2016). These studies may serve as formative research in the development of a C4D strategy to address ECD in Palestine in general and to promote inclusion of children with developmental delays and disabilities in particular.

Despite the excellent research that has been done on ECD and on children with developmental delays and disabilities in the State of Palestine, no studies to date have functioned to assess the current or baseline levels of knowledge, attitudes, and beliefs related to confronting stigma and discrimination against their children with developmental delays and disabilities. This research contributes to filling that gap by specifically focusing on three theoretical constructs related to the behavioural intention to stand up for a child who is experiencing stigma and discrimination: attitudes, subjective norms, and self-efficacy. The study also included questions related to use of media, interaction with service providers, and knowledge about the situation related to disability in the State of Palestine.

3. Objectives of the Study

This study has been conducted primarily to inform the development of a C4D strategy to address stigmatization and discrimination against children with developmental delays and disabilities and their parents/caregivers. Therefore, there are a number of limitations that should be considered when using the data and analytic results of the study. An important limitation will be the generalizability of results across the West Bank; although the three governates of Jericho, Hebron, and Nablus have been sampled randomly, the remainder of the area's governates are not included in the sampling plan. Therefore, conclusions about people outside of these three governates should be made with caution. In Gaza, sampling is intended to include all five governates, but due to the fact that some parents/caregivers prefer to keep their children with developmental delays and disabilities hidden, it was in some cases difficult to attain a perfectly random sample of all children with developmental delays and disabilities. This issue applies to both the West Bank and Gazan governates.

This report will be used in the development of a C4D strategy for ECD and will assist in the creation of useful messaging around developmental delays and disabilities in the State of Palestine. Results of FGDs and KIIs will assist in the development of advocacy plans for policy and decision makers in Gaza and the West Bank, and the participatory activities have provided an opportunity to interact with those directly affected by the issues under

investigation and for C4D interventions to benefit from their guidance.

4. Theoretical and Conceptual Background

The present study provides *baseline* data for the C4D ECD strategy, which will be implemented between 2019 – 2021 and beyond. Baseline data differs from formative data in that it measures the current state of two sets of development-related indicators: behavioural indicators, which are concerned with practices, or “do” indicators; and affective indicators, which are concerned with people’s knowledge, beliefs, and attitudes, including perceptions of social and cultural norms, towards new behaviours or practices.

In C4D, changes in the affective dimension are precursors to changes in the behavioural dimension, and are influenced by communication activities, as in Figure 1.

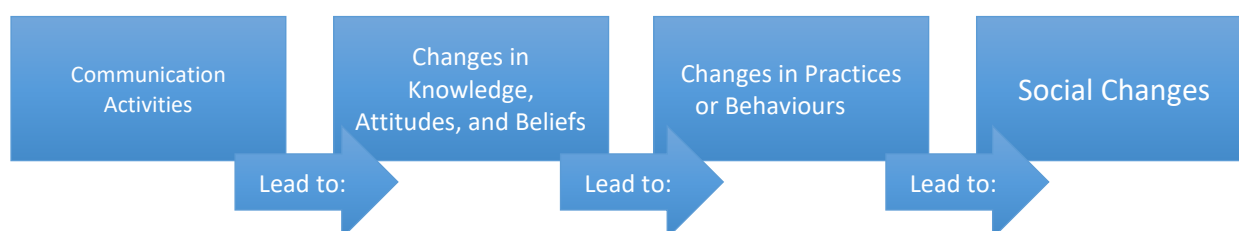


Figure 1: A Theory of Change Approach

This study has been designed using the Theory of Planned Behaviour, which involves increasing the *behavioural intention* of individuals; intention to adopt a new behaviour is highly predictive of the adoption of the behaviour. The concept of behavioural intention and the factors that lead to its increase are included in the Theory of Planned Behaviour (Ajzen, 1991). The TPB suggests that three factors contribute to an increase in behavioural intention:

1. Attitude toward the behaviour
2. Normative beliefs toward the behaviour
3. Perceived behavioural control (self-efficacy toward the desired behaviour)

Figure 2 illustrates the relationship between these factors.

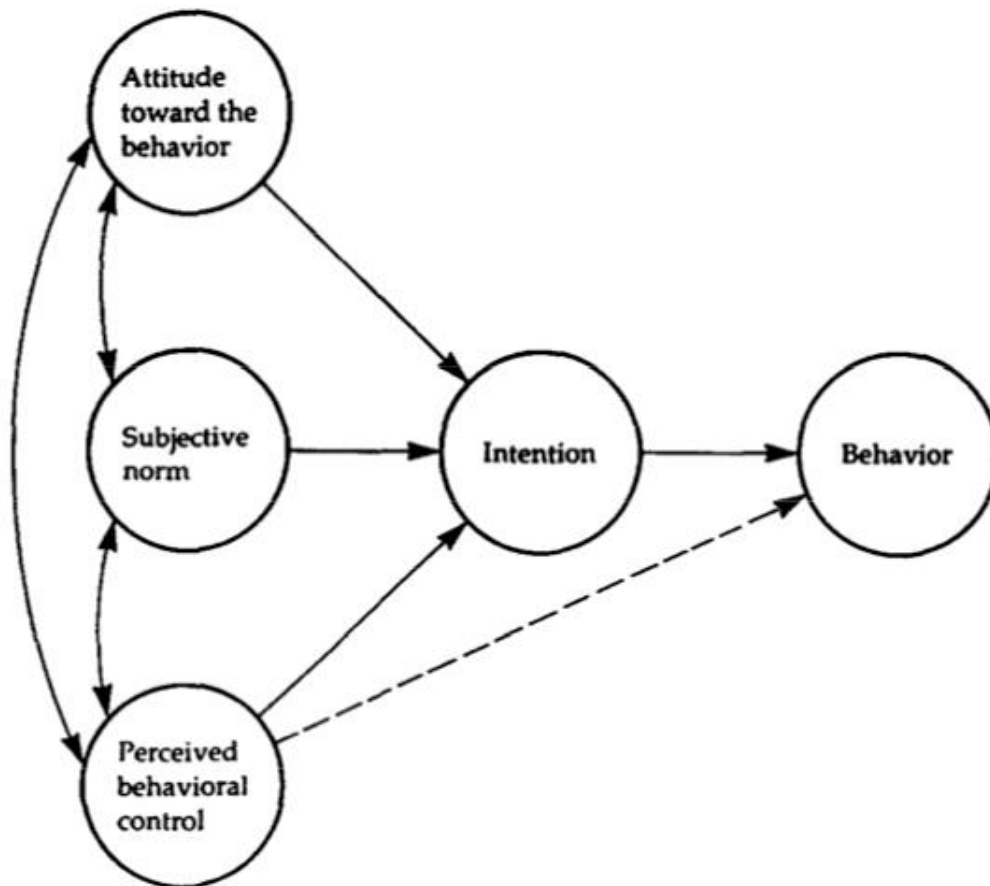


Figure 2: The Theory of Planned Behaviour (Ajzen, 1991)

The baseline study measured the ways in which these three variables – attitudes, norms, and behavioural control – may be influenced to lead to increased intention to adopt new behaviours, including destigmatizing behaviours, positive parenting practices, increased demand for health and rehabilitation services, and demonstrations of support for parents/caregivers and children with developmental delays and disabilities/persons with disabilities. The quantitative instrument included a section on each of these three components, and results are presented in the findings section (p. 28).

An additional theoretical framework that will be applied to the development of the C4D strategy includes social cognitive theory (Bandura, 1989) which suggests that role models are key drivers of updated behaviours. The research included discussions on sources of information and preferred communication channels, which will inform choices of role models and influencers in the development of the C4D strategy.

In addition to immediate actions or practices that may be changed or transformed as a result of C4D interventions, there are significant underlying causes of discrimination against children with developmental delays and disabilities and persons with disabilities, as indicated in the literature review. Primary among these underlying causes is discriminatory norms and practices related to gender in the SoP. Jones et al., (2016) found that caring for children with developmental delays and disabilities is primarily done by mothers and that girl children with disabilities are often treated with hostility by their fathers. The expectation

that the mother is responsible for not only the disability but for nearly all of the care of a child with a developmental delay or disability leaves many of them increasingly vulnerable to stigma, poverty, and exploitation. These factors were supported by the present study, in which more than 90% of children were cared for primarily by their mother. Additional details on differences between Gaza and the West Bank are presented in the findings section (p. 28).

To meet the overall goal of improving the well-being of children with developmental delays and disabilities by reducing stigma and increasing the level of positive practices provided by parents/caregivers and service providers, several new or updated behaviours will be promoted. The review of literature and secondary sources, together with recommendations from UNICEF SoP and other stakeholders suggest that new behaviours related to children with developmental delays and disabilities should be considered across several dimensions and audience groups. Audience groups may be divided in several ways, but research on children with developmental delays and disabilities (Jones, et al., 2016) suggests the following:

- Children with developmental delays and disabilities (and persons with disabilities)
- Parents/caregivers (mothers, fathers, guardians)
- Service Providers, such as counsellors, health care professionals, and social workers
- Community Leaders
- Extended Families (aunts, uncles, siblings, grandparents)
- Social Support Providers (friends, neighbours, community members)

This report presents baseline levels of knowledge, attitudes, beliefs, and subjective norms within the framework of the TPB. In addition, the research has established baseline demographic information for each of the audience groups. C4D programming will then seek to cause change in attitudes, beliefs, subjective norms, and perceptions of behavioural control within audience groups.

Addressing stigmatization of children with developmental delays and disabilities must also be supported through advocacy activities. Recommendations for advocacy activities are presented in the final section of this report.

5. Key Study Variables

This baseline study contributes to the development of a C4D programme that will equip parents and parents/caregivers with the knowledge, attitudes, skills, and confidence to confront stigma and discrimination. Building on previous research, the programme will also increase demand for ECD related services for young children. The study therefore focuses on several key variables related to C4D programming:

- Demographics, including location of the household, education level, employment status, and household income;
- The number of children with a developmental delay or disability 0-8 years of age who live in the household and the type of disability present among them;
- Use of media, communication preferences and information seeking patterns;
- General knowledge of disability in the State of Palestine, including prevalence;
- Attitudes toward disability, confronting stigma and discrimination, and inclusion in social and cultural life
- Normative expectations toward confronting stigma and discrimination, care seeking and inclusion in social and cultural life;
- Self-efficacy surrounding confronting stigma and discrimination, care seeking, and promoting social and cultural inclusion;
- Support and reference networks and the types of support that parents/caregivers receive; and,
- Perceptions about the best ways to promote positive parenting and anti-discrimination behaviours in the State of Palestine.

These variables are described in detail in the subsequent sections of this report. Both quantitative and qualitative enquiry was conducted on the variables in order to gain both broad and deep understanding of their role in promoting pro – child behaviours.

Box 1: Profile of the Typical Survey Respondent

<p>Mothers: 80%; Fathers: 15%; Grandparents: 3%; Other relatives: 2% 30% Receive MoSD benefits; 70% do not 64% of households have income < 1974 NIS/month 10% have a disability; 90% do not</p>

V. Research Design

The study used three primary methodologies: first, a quantitative survey administered to a sample of parents/caregivers of children with developmental delays and disabilities in five governorates of Gaza and three in the West Bank. The survey quantitatively measured the current knowledge, attitudes, normative expectations, and self-efficacy of parents/caregivers at the household level.

Second, the research included qualitative inquiry in specifically targeted communities within districts. These qualitative approaches included Key Informant Interviews (KII) and Focus Group Discussions (FGDs) with individuals and groups, including service providers, community leaders, parents' groups, and other stakeholders. These research activities were specifically designed to deepen understanding of the theoretical components of the C4D strategy, i.e., attitudes towards new behaviours, subjective norms, and perceptions of behavioural control.

Third, the research included participatory approaches, specifically among children with developmental delays and disabilities. Participatory activities included interviews in which children with developmental delays and disabilities used appropriate tools, such as sketching/drawing, photography, mapping activities, and other participatory approaches to facilitate conversations about their abilities, opportunities, and the barriers they face, and how they affect their ability to take part in life in Palestine. Overall, 1,087 people participated in this research, divided approximately equally between Gaza and the West Bank.

1. Participatory Approaches

A critical component of this research is the use of participatory methods that were conducted with children with developmental delays and disabilities. Participatory research is an important part of C4D programming because it allows programmers and community members themselves to gain a deeper understanding of how individuals experience the issue to be addressed by a C4D strategy.

Key issues that were explored in participatory activities included:

- People's perceptions of stigmatization and discrimination as they related to children with developmental delays and disabilities;
- Their susceptibility to stigmatization and discrimination; and,
- Their knowledge about how to address or confront stigma and discrimination when it is experienced.

The participatory portion of the research included two groups of respondents in each region; two in Gaza and two in the West Bank for a total of four participatory activities. The two participatory groups for each region consisted of 8-12 children with developmental delays and disabilities in each area who are between 10 and 15 years of age, and a second

group of 8-12 parents/caregivers, who were either recruited from other qualitative activities or who were parents/caregivers for the children who participated in the children’s group. The activities provided an enabling, safe and uninhibited space for them to express their views and provide recommendations for a C4D strategy appropriate for Palestinian society. While the activities with parents were fully appropriate for parents who represented families that face challenges due to varying disabilities, it was more difficult to organize activities with children who had different types of disabilities and varying levels of severity. In the future, it will be important to increase the number of activities to target each type of disability. The two groups of participants took part in activities such as outcome mapping, cognitive mapping, and social network analysis, participatory sketching and social cartography.

2. Quantitative Research Design

The quantitative portion of the study included respondents from the two regions of the State of Palestine, Gaza and the West Bank. All five governorates of Gaza were included in the study, and three governorates in the West Bank were included. The cross – sectional survey followed a multistage stratified random sampling design proportional to population size. Each governorate was sampled according to population size based on the detailed sampling distribution presented in Annex I, from which the required number of households were chosen at random. The required number of respondents in each of the selected governorates were chosen, to the extent possible, at random from a list provided by MOSD and organizations working with children with developmental delays and disabilities.

a. Sampling Design

The quantitative portion of the KAP study included the administration of survey instruments to parents/caregivers of children with developmental delays and disabilities in three governorates in the West Bank and five governorates in Gaza.

The appropriate sample sizes for representivity in each governorate were calculated using the formula

$$n_0 = \frac{Z^2 pq}{e^2}, \text{ where:}$$

n_0 = sample size

Z^2 = confidence level (1.96

is used for 95% CI)

Area	Number of citizens in target districts	Residents’ percentage to the population of included districts	Proportional sample sizes
Palestine	4,682,467	n/a	n/a
West Bank	1,149,546	100%	420
Jericho	50,002	4.4%	19 +20
Nablus	388,321	33.7%	141
Hebron	711,223	61.9%	260 - 20
Gaza	1,899,291	100%	420
North Gaza	368,978	19.4%	81
Gaza City	654,597	34.4%	144
Dair Al Balah	273,200	14.4%	61
Khan Younes	370,638	19.5%	82
Rafah	233,878	12.3%	52

Table 1: Sample Sizes for Quantitative Inquiry

p = proportion of population (0.5 assumes maximum variability)

$q = 1 - p$

e = level of precision (0.05 standard for social science research).

This calculation yielded a sample size of 385 individuals per area (Gaza and the West Bank)². The final tally for respondents was 401 in Gaza, and 398 in the West Bank.

As indicated in Jones et al., (2016) there are approximately 14,244 children with developmental delays and disabilities in Gaza, and approximately the same number in the West Bank. General population data, which were used to calculate the proportional sample sizes and select specific communities for sampling, are based on the PCBS 2017 Census (PCBS, 2018).

b. Initial Stratification

Because each household with at least one child with a developmental delay or disability in each governorate has an equal chance of being selected as a survey respondent, and because all five governorates of Gaza are included, this research may be said to represent all parents/caregivers of children with developmental delays and disabilities 0-3 and 4-8 in Gaza. In the West Bank, the research may be said to represent the three included governorates. With this quantitative inquiry as a baseline, a survey conducted after the implementation of the C4D strategy will allow for comparison between the pre and post-intervention knowledge, attitudes, and practices of respondents within governorates².

c. Primary Sampling Units

The inclusion of specific households in the survey, those with children with developmental delays and disabilities 0-3 and 4-8 years of age, required some purposive sampling on the ground due to the lack of a recently updated registration database. The distribution is based on the sample size (gross and net, in table 1, above), detailed population figures and disability figures from PCBS Census 2017, and the rough numbers from MoSD registration. Note that the gross sample number includes additional surveys to account for non – responses; the net sample number will be the minimum completed in each region. See Annex I for the detailed sample distribution.

² Israel, G. D. (1992). Determining sample size. Program Evaluation and Organizational Development, IFAS. University of Florida, PEOD-6.

²There are a number of important caveats to this statement. First, it can be very difficult to isolate communication-related variables for pre and post comparison. Second, when variables are measured it can be difficult to conclusively attribute changes in knowledge, attitudes and practices to one particular communication intervention. Finally, there are many factors that influence people's decisions to adopt new behaviours, many of which take long periods of time to shift. In addition, it is possible to compare, for example, the results of a communication intervention or activity in one area with another area in which no communication intervention was conducted. The calculated sample size represents a 95% confidence level and a confidence interval of 5%, which is typical for social science surveys at this level.

d. Selecting Households and Individuals for the Survey

The survey of parents/caregivers was intended to capture the realities of children with developmental delays and disabilities and their families from the closest lens and in detail. They were selected randomly from the lists kept and maintained by the Ministry of Social Development and other service providers in a sample of communities from the targeted governorates. Parents/caregivers of children with developmental delays and disabilities from 0 – 3 and 4 – 8 were randomly selected from the lists provided in Annex I. Respondents were chosen for inclusion based on whether the household included at least one child under the age of 8 with a disability documented by a caregiver or diagnosed by a medical professional. Slightly more than 92% of children in households surveyed had a developmental delay or disability that was formally diagnosed by a medical professional. Piloting of survey instruments was conducted March 20 – 21, 2019. Results of the pilot study are presented in Annex V.

e. Quantitative Data Analysis

Data collected during the quantitative portion of this study have been analysed using StataIC 15.1. The analysis process has identified baseline levels of knowledge, attitudes, beliefs and destigmatizing practices about the developmental delays and disabilities in the categories corresponding to the theoretical framework described previously (the Theory of Planned Behaviour).

In quantitative research, bias is often injected into research through the lens of the researcher, whose perspectives on the issues influence the design of survey instruments and experiments. In this research, there are no operational activities to be conducted in the research process, such as Trials of Improved Practices, or TIPS (for example, see Shivalli, Srivastava, & Singh, 2015). In the present study, bias has to some extent been addressed by drawing on well-established and previously tested research instruments, the Attitudes Towards People with Disabilities scale (Yuker, 1970) as well as the theoretical perspectives on C4D and design (Ajzen, 1991; Bandura, 1989). These factors, as well as review from stakeholders and international experts, indicate that the results presented in this report are reliable and valid.

3. Qualitative Research Design

The qualitative portion of the baseline study was designed around FGDs and KIIs with parents/caregivers, family members, community leaders, and representatives from DPOs and other service providers. Details on the number of KIIs and FGDs are provided below.

a. Qualitative Participants and Setting

Qualitative research was conducted in Gaza and in the West Bank, as in the quantitative research.

i. Focus Group Discussions

Community members, parents, field social workers and service providers participated in the FGDs in all the targeted regions in the West Bank and Gaza Strip. The FGDs provided a safe space for these groups to express their points of views and provide their insights through discussion with others with varying opinions. They were selected from lists of made available by the relevant ministries, community organizations and service providers' organizations. The final selection of participants was made based on the preset methodologies and criteria described in the study protocol. Their views were important to shed light on the lived reality of children with developmental delays and their families within their communities and in relation to the work of community-based organizations. While their insights brought the study closer to the reality, the reality of children with developmental delays and disabilities from the point of view of the closest impacted individuals was captured through the participation of parents and the children themselves. It was also noted that the majority of participating members in the FGDs were women, as parents and social workers who are closely connected to the reality of children with developmental delays and disabilities are women.

In Gaza, a total of nine focus group discussions were conducted with a total of 124 participants. Participants included parents/caregivers, extended family members, community members, social workers, and representatives of DPOs. Participants were recruited from Gaza City, North Gaza, Khan Younis (near the confrontation area at Khuza'a border), Deir el-Balah, and, for DPOs and social workers, from those organizations working throughout Gaza. These are noted as Overall/Central.

In the West Bank, qualitative activities were conducted in Hebron, Jericho and Jordan Valley, and Nablus. A total of eight focus group discussions were conducted with 91 participants. Focus group discussions were conducted in locations chosen by the facilitator and which were convenient for the participants; generally, these were at associations or other organizations with which participants were familiar and which provided services to children with developmental delays or disabilities in their communities. These locations also provided participants with a familiar place in which to interact with the facilitator and each other. A list of FGDs conducted in each region is provided in Annex VI.

ii. Key Informant Interviews

This study was designed to include KIIs with community leaders, service providers, and policy/decision makers. In Gaza, a total of 12 KIIs were conducted: three with service providers, five with community leaders, and four with policy/decision makers. In some cases, these categories overlapped. Key informants were instrumental in shedding light and providing analysis of the reality of stigma in relation to the situation of children with disabilities and development delays. They provided data and analysis concerning policies, programs and services available to children with developmental delays and disabilities and their families. They also provided insights to the reality of the various interventions targeting children with developmental delays and disabilities, the gaps and opportunities in

the field. They were selected from relevant government and non-government actors including ministries (e.g., Social Development, Education, Health), service providers (e.g., Palestinian Red Crescent, YMCA, Medical Relief Committees and other CBR programs), advocacy and lobbying organizations (e.g., General Union of Palestinian Persons with Disabilities) and professionals including social workers and academics. While their analyses and points of views were instrumental in deepening the analysis of the realities and the future needed actions, they represent the point of view of the policy setters and influencers as well as service providers (supply side). This had to be complemented by the views and analyses of the children themselves, parents and community members, captured through other tools including FGDs and participatory activities.

In the West Bank, a total of 12 KIIs were conducted: seven with service providers, one with a community leader, and four with policy/decision makers. As in the FGDs, KIIs were conducted in locations chosen to maximize the ability of the participants to discuss issues related to children with developmental delays and disabilities; usually, this was the individual’s office or workplace. A list of KIIs is available in Annex VI.

b. Qualitative Instruments and Facilitators

Qualitative instruments included FGD and KII guides. These were developed based on the review of literature, the application of the theoretical framework, and the requirements of the C4D strategy design process, particularly the requirement for an in – depth understanding of both barriers and motivators for changes in attitudes, social norms, and self-efficacy surrounding the reduction of stigma and discrimination and achieving full participation of children with developmental delays and disabilities in Palestinian society. The guides were reviewed by UNICEF and AWRAD, and revised appropriately. The final versions of FGD guides included areas of inquiry as described in table 2 below.

Table 2: Focus Group Discussion Guide Design – Primary Parents/caregivers

Areas of Inquiry
Meaning & Types of Developmental Delay and Disabilities
Developmental Delays and Disabilities in Families/Community
Participation in Cultural and Social Life
Responding to Stigma
Social Network Mapping – Communication with others about Caregiving for Children with Developmental Delays and Disabilities
General Communication Practices and Sources of Information

The number of areas included in the Primary Parents/caregivers tool made it somewhat difficult for facilitators to complete the discussions in less than two hours, which was problematic for some groups. In these cases, facilitators generally chose to reduce the amount of time they spend on the social network mapping exercise. Table 3 indicates the

structure of the tool used for extended family and community members, DPO representatives, and social workers/counsellors.

Table 3: Focus Group Discussion Guide Design - Extended Family and Community Members, DPO Representatives, and Social Workers/Counsellors

Areas of Inquiry
Meaning & Types of Developmental Delay and Disabilities
Developmental Delays and Disabilities in Families/Community
General Communication Practices and Sources of Information

Specific questions in each section were adapted to the participants, but the overall structure of the discussion focused on the areas of inquiry presented in table 6. The number of areas of inquiry in this tool allowed facilitators to complete the discussions according to the guide. The key informant interview guides included questions and probes related to perceptions of disability, challenges of caring for a child with a developmental delay and disability, strengths and weaknesses of parents/caregivers, the participant’s perspectives on the current levels of support for parents/caregivers, the prospects for changing attitudes and behaviours towards children with developmental delays and disabilities, and the most effective ways to implement change in communities. All KIIs followed this basic structure, and were adapted by facilitators depending on the responses of participants.

Facilitators from AWRAD were experienced in qualitative data collection and were briefed on the purpose of the KAP study. They were provided with the research guides ahead of time for familiarization and review.

c. Qualitative Data Collection and Processing

FGDs and KIIs were conducted in April and May 2019, following training and pilot testing in March 2019. Facilitators generally followed the FGD and KII guides closely, but were able to follow up with additional probing questions when opportunities for more detailed explanations appeared. Encounters were recorded and notes were taken by facilitators and dedicated note takers. Recordings were later transcribed in Arabic and subsequently translated into English for analysis.

d. Qualitative Data Analysis

Data from the research was analysed using Atlas.ti qualitative management software, and a grounded theory approach was applied initially, which included the generation of codes that represented concepts from the transcriptions (Glaser & Strauss, 1967; Corbin & Strauss, 1990). Because there were several pre – defined theoretical concepts involved in this research, as well as research guides that were developed with the intention to seek specific data about the experiences of parents/caregivers of children with developmental delays and disabilities in Gaza and the West Bank, groups of codes reflecting these concepts and categories emerged immediately. These codes were grouped into thematic groups, and

were supplemented by additional codes and code groups that emerged from a close read of the data.

Initial coding of the qualitative documents, both FGDs and KIs, yielded a total of 368 codes. The code groups that resulted from subsequent analysis and thematising yielded nine thematic areas. These are listed below in table 4.

Table 4: Code Categories

1	Acceptance and inclusion
	Discussions by participants about the ways in which children with developmental delays and disabilities are accepted by their families, communities, institutions, schools, and other organizations.
2	Support
	Discussions by participants that describe the types of support parents receive from other people, institutions, schools, family, community, and society, and the types of support that they believe would be most beneficial to their situation.
3	Barriers and Challenges
	The types of barriers parents, parents/caregivers, and service providers face when it comes to getting support, seeking and receiving services, and caring for a child or children with developmental delays and disabilities, and the perceptions of participants of the barriers to integration of their children in society.
4	Influence
	The influence parents and parents/caregivers and others feel they have to improve the situation or to promote the inclusion of their children in Palestinian society, and their perceptions of the best or most effective ways they would attempt to influence those around them.
5	Communication, Information, and Information Preferences
	Trusted and untrusted sources of information and preferences for communication.
6	Roles for Parents and Parents/caregivers in Addressing Stigma and Discrimination
	The roles parents, parents/caregivers, service providers, and advocates believe they can play in addressing stigma and discrimination in their communities and Palestinian society.
7	Structural and Institutional Issues
	This category refers to entrenched norms and underlying causes of stigma and discrimination, and the institutional and societal barriers to change.
8	Intention to confront stigma and discrimination
	What parents say about the likelihood that they will confront stigma when it occurs, or how they plan to do so.
9	Contributions to the C4D Strategy
	Responses to questions about messaging, activities, and other communication – related inputs, such as workshops and capacity building programmes, that may be incorporated into the C4D strategy.

Each of the above code categories is explored in additional detail in the Findings section. As with all qualitative research, there are additional codes that are descriptive of experiences of participants related to caregiving and promoting inclusion of their children that are not

included in these categories. These are also described in the Findings section when appropriate to the overall results of the qualitative inquiry.

4. Ethical Considerations of this Study

Ethics in this research were guided by the UNICEF Procedure for Ethical Standards in Research, Evaluation, Data Collection, and Analysis (UNICEF, 2015). This document provides details on procedures in research related to four core ethical issues: Harms and Benefits; Informed Consent; Privacy and Confidentiality, and Compensation and Payment. The relationship between this study and these four issues is described below. Approval from the Helsinki committee for the conduct of this research was secured on February 4, 2019 and the certification of approval is included in Annex IV.

A training programme for data collectors was conducted on March 19th, 2019, during which field workers were trained on the use of the research tools, including informed consent documents, ethical standards, and appropriate data collection methods.

a. Harms and Benefits

Harms and benefits refer to the consideration of any “potential harms and benefits for participants, families, and wider community groups” (UNICEF, 2015, p. 10). There were no harms anticipated for participants in this study; although there are lines of questioning that will ask participants to discuss their experiences related to caring for a child with a developmental delay or disability in their community. These lines of questioning were not anticipated to cause harm to participants, and they may decline to answer any of the questions in the research. Data collectors were trained to provide information on social workers or counsellors who could provide assistance to any participant who experienced distress as a result of the research.

b. Informed Consent

Informed consent refers to the requirement for a participant in research to only give their consent to participate in research once they are fully informed of the harms and benefits associated with the research, as well as privacy and confidentiality considerations. In the present study, each participant in the research was read an informed consent document, after which they were requested to provide a signature or verbally agree to continue with the research. The informed consent request is included in Annex VIII.

c. Privacy and Confidentiality

Maintaining privacy and confidentiality is a core component of ethical research. Recruitment of participants in the quantitative portion of the research was done by examining a Ministry of Social Development (MoSD) database in which children with developmental delays and disabilities were registered. However, this registry did not always include parents/caregivers of children 0-3 years of age; in this case, data supervisors were required to identify parents/caregivers of these children through different means, such as an assessment and identification of households in an area targeted for sampling. AWRAD

maintained the privacy of these households by safeguarding the information on a password protected computer. No personally identifying information was collected during any of the research, although FGDs, KIIs, and participatory activities did require the use of first names in order to build rapport and facilitate discussion. These names were replaced with pseudonyms (such as P1, P2, etc.) in all reporting on the research.

Data from questionnaires, FGDs, and KIIs were shared on an as – needed basis within the research team, with the international consultant, and with staff and volunteers of UNICEF SoP as required for transcription, translation, and data analysis. Transcriptions will be kept on password protected computers and deleted as soon as UNICEF requirements allow (not longer than 3 years from the end of the project).

Participants in FGDs were requested not to share the contents of the discussions with others. While there is no guarantee that they will not do so, this request will serve as a reminder to FGD participants that they will be discussing issues related to children with developmental delays and disabilities in the presence of other people.

d. Payment and Compensation

There were no payments or compensation associated with this research, beyond the provision of light refreshments for individuals who took part in FGDs and participatory activities.

e. Inclusion and Exclusion

This research was purposefully designed to include youth with disabilities aged 10 – 15 in participatory activities, and with the goal of including them in the design of the C4D strategy that will address stigma and discrimination. In addition, their parents/caregivers have been included in quantitative and qualitative research activities and are the primary respondents for the quantitative questionnaire.

Other qualitative activities were designed to be as inclusive of a variety of groups as possible: community members, representatives of Disabled Persons Organisations, community leaders, social workers/counsellors/activists, and service providers are all participant groups that will provide critical data and insight for the development of the C4D strategy.

Stakeholders from various Ministerial positions and other DPOs were consulted prior to the piloting of research activities for feedback and comments. Meetings were held with stakeholders in the West Bank on February 25th, 2019, and in Gaza on February 28th, 2019. All data collectors, head of AWRAD, and the international consultant signed the UNICEF Code of Conduct for the Prevention of Sexual Exploitation and Abuse.

f. Conflicts of Interest

The international consultant (Andrew Carlson) has previously declared that there are neither actual nor potential conflicts of interest (as described in the UNICEF financial disclosure and declaration of interest statements, executive directive CF/EDX/2012 – 0003) in the design and implementation of this research protocol, the conduct of the research, and the publication of subsequent reports, documents, or articles.

g. Ethical Review

The research methodology, including the survey tools, interview guides, and sampling plan were approved by the Helsinki Committee at the Palestinian Research Council prior to the start of the research. This approval required the submission of all the research instruments, including the informed consent documents, for review. The consultant and national research agency were primarily responsible for securing ethical approval from the Helsinki Committee regarding the research.

5. The Role of the National Research Organization, AWRAD

The Arab World Research and Development (AWRAD) served as the national research centre supporting the preparation and implementation of the study. The AWRAD team worked closely with the international Consultant throughout all study phases and provided invaluable input and insights on the various aspects and steps of the study. AWRAD tasks included:

- Reviewing the research protocol and methodology.
- Reviewing and providing input on the survey questionnaire and qualitative tools.
- Piloting the questionnaire and providing further suggestions to improve its validity and reliability.
- Meeting with stakeholders, partners, and the Consultant to finalise the study design.
- Providing detailed sampling frames for each region and governorate.
- Translating the research tools for use in the field.
- Training field researchers for the specific tasks and considerations of this study.
- Designing an electronic version of the survey using Open Data Kit.
- Collecting quantitative data through a survey of parents/caregivers.
- Collecting qualitative and quantitative data through FGDs and KIIs with all relevant stakeholders.
- Organizing and facilitating participatory workshops with children with developmental delays and disabilities and their families.
- Transcribing and translating recordings of qualitative activities.
- Ensuring the quality of the data, data entry and cleaning.
- Organizing a validation workshop with relevant institutions and experts and preparing a report on its proceedings and findings.
- Organizing a national advocacy workshop with decision-makers and influencers and preparing a report on its proceedings and findings.

VI. Findings

1. Quantitative Findings

a. Demographics and background

There were 799 responses to the survey, of which 398 were in the West Bank and 401 were in Gaza. As indicated previously, sample sizes for each governorate were calculated according to population size. This section presents demographic information for survey respondents.

Because the sampling for the study was done randomly through a multi-stage process, tables presented in this section focus on percentages rather than frequencies or counts of respondents. When appropriate, frequencies will be included.

The profile of the typical index child is presented below in box 2.

Box 2: Profile of the Average Index Child

Gender: 53.2% male, 46.8% female
Mean Age: 6.4 years
Children Attending an Educational Institution: 40% of male children; 32% of female children

Table 5: Type of Residence, Gaza and the West Bank

	Gaza	West Bank	Overall
Type of Residence*	Percent³	Percent	Percent
City	78	55	66
Refugee Camp	14	7	10
Village/Bedouin Community	9	38	24
Total	100	100	100

(*p < .05)

As indicated in the table, the majority of respondents live in cities; however, in the West Bank there is also a significant number of respondents who reside in smaller or migrant communities.

The West Bank, as indicated previously, consists of three administrative areas. The areas in which the majority of respondents reside is Area A (62%), which is administered by the Palestinian Authority. Area B (26%) is co-administered with Israel, and Area C (12%) includes Jewish settlements and is administered exclusively by Israel.

Proximity to risk is a significant issue that affects a caregiver's ability to seek health and rehabilitation services, provide care, and deal with the additional stress that may accompany caring for a child with a developmental delay and disability. While the majority of participants in this study did not live or reside near a conflict area, eight percent of Gazan respondents reported that they live near the border or confrontation areas.

³ Totals may not equal 100 due to rounding.

There was no statistically significant difference between Gaza and the West Bank in terms of the number of children under the age of 8; overall, 39% of households had one child under eight, 31% had two, and 23% had three. The number of children in the household was also not related to other variables such as household income, education level, or occupation.

First children tend to be slightly older, while as a second, third, fourth, and fifth child are added, they become younger. There were 61 fourth children in the sample; 95% of them were under the age of 5. There were only eight fifth children in the sample; one of them was over 5 years of age.

In terms of education, there are significant differences ($p < .01$) between mothers' and fathers' education level; while more fathers have completed primary school (34% vs. 26%), more mothers have completed Bachelor's degrees than fathers (18% vs. 11%), and more have completed the Tawjihi than fathers (26% vs. 24%). Education level of parents may be connected to behaviours, such as the ability to seek services, confront stigma and discrimination, and communicate with schools.

The differences between regions in employment status are noteworthy. For example, fathers in Gaza are much less likely to be involved in paid employment than fathers in the West Bank (36% vs. 78%); fathers in Gaza are much more likely to be unemployed, having previously worked (53% vs 11%). Most mothers report themselves as home carers (95% vs. 88%), and while a small percentage are involved in paid employment, more than 90% of all female respondents reported that they have never been employed.

Monthly income levels vary significantly between regions, with 99% of respondents from Gaza reporting income in the lowest bracket. Household income in the West Bank is more evenly distributed, with the largest group in the middle income bracket. Household income is significantly related to other study variables, the details of which will be presented in subsequent sections.

There were no significant differences between regions related to the percent of children whose developmental delay or disability had been identified by a caregiver.

Table 6: Child in Which a Developmental Delay or Disability was Diagnosed by a Medical Professional

Child No.	Overall Percentage Diagnosed
1	92
2	90
3	86
4	87
5	n/a

Table 6 indicates the percent of children whose developmental delay or disability had been diagnosed by a medical professional. The values in the table suggest that the percent of children who are diagnosed decreases as a family has additional children.

There are no significant differences between regions in the presence of specific disabilities diagnosed by a medical professional. Physical disabilities are the most prevalent, with multiple disabilities highly prevalent.

Analysis of the multiple disabilities reported by respondents and additional factors suggested that there may be analytical benefits to grouping particular disabilities into categories. This was done by the researchers during the data analysis process; the updated categories are indicated in table 7:

- Category 1: Physical Disabilities
- Category 2: Autism, Learning Disabilities, Psychosocial Disabilities, Intellectual Disabilities, and Downs Syndrome
- Category 3: ADHD/Speech and Language Disabilities
- Category 4: Blindness/Low Vision/Deafness/Hard of Hearing
- Category 5: Multiple Disabilities
- Category 6: Other

Table 7: Disability Category Diagnosis

Disability Category Diagnosis	Overall
	Percent
Physical Disabilities	22
Autism, Learning Disabilities, Psychosocial Disabilities, Intellectual Disabilities, and Downs Syndrome	23
ADHD/Speech and Language Disabilities	7
Blindness/Low Vision/Deafness/Hard of Hearing	17
Multiple Disabilities	23
Total	8

These categories will be used in subsequent sections to test relationships between disability type and other variables, when appropriate. Overall, the study found that there are many families in which there was more than one child with a disability; 61% of families had two; 31% had three, eight percent had four, and one percent had five children with some type of disability.

Table 8: Households Receiving Cash Benefits from the MoSD

Receive Benefits*	Gaza	West Bank	Total
	Percent	Percent	Percent
Yes	48	12	30
No	52	88	70
Total	100	100	100

(*p ≤ .01)

The ability to care for a child with a developmental delay and/or disability depends on whether there is adequate financial capacity in the household. This in turn may depend on whether or not the household receives funding from the MoSD. There was a highly significant difference in the percentage of households in Gaza and the West Bank which receive MoSD benefits. In Gaza, 48% of households included in the sample receive cash benefits, while in the West Bank, only 12% receive them. Despite receiving benefits, many families, particularly in Gaza, report that they struggle financially.

b. General Attitudes and Awareness Indicators

This section presents detail on a number of general attitude and awareness indicators which were included in the instrument. These are separate from the three theoretical constructs included in the framework of the Theory of Planned Behaviour.

There was no significant difference between regions in the percentage of respondents who had heard of child rights. The overall result suggests that 74% of respondents are aware of the concept. Likewise, there were no significant differences between regions in the way that respondents reported the treatment of children with the developmental delays and disabilities by other adults in the household.

In terms of extended family, there were no significant differences between regions in the way that respondents reported the treatment of children with the developmental delays and disabilities by adults in the extended family. However, 40% of respondents mentioned that their child(ren) with a developmental delay or disability received inferior treatment from extended family members. For treatment in their communities, the overall percentage of respondents who reported that their children receive inferior treatment is quite high – 56% - which suggests that the purpose and objectives of this study are well founded in the reality of the treatment of children in communities in Gaza and the West Bank.

The quantitative instrument included questions related to general attitudes and knowledge/awareness across several important parenting, efficacy, and demand areas⁴. Responses were categorized into strongly agree/agree (a positive valence); strongly disagree/disagree (a negative valence) and undecided. Most questions measured attitudes, knowledge/awareness positively. Statistically significant findings from this set of questions

⁴ The quantitative survey instrument is available online at www.abcde.com.

indicate that the relationship between positive parenting techniques such as playing games, singing songs, and reading are not well understood by many respondents. There was a significant difference between Gaza and the West Bank in terms of support for caregiving from family, and there is an overall low percentage of parents/caregivers who regularly attend a support group. The results suggest relatively low levels of self-efficacy related to finding professional help for caring for a child with a developmental delay or disability, and this value is significantly less in Gaza than in the West Bank. The recommendations section of this report provides some ideas about how incorporating the differences between regions and addressing the areas in which children will benefit from shifting ideas about certain ECD practices (such as reading to children, whether they have a developmental delay and disability or not).

Table 9: Key Responses to Attitudes and Knowledge/Awareness Questions

Question		Gaza	West Bank
		A/SA	A/SA
		Percent	Percent
21F	{Index child} benefits from playing games, singing songs, and other playful activities at home/surrounding community*	58	65
21G	{index child} benefits from reading or being read to at home/surrounding community*	35	40
21H	Members of my family assist me in providing care for my child**	63	79
21I	I participate regularly in parent support groups with other parents of children with developmental delays and/or disabilities	35	31
21J	I feel confident I can find professional help for a child with a developmental delay and/or disability*	37	54
21L	There are professional organizations in my community who can help me take care of a child with a developmental delay and/or disability*	52	28
21N	Reading to {index child} can help them catch up if they are diagnosed with a developmental delay*	35	44

* $p < .05$; ** $p < .01$

A final question in this section indicated that there was no significant difference between regions when it comes to the use of assistive devices; however, the overall percentage of children who use them is quite low (28%).

c. General Knowledge Indicators

This section was primarily concerned with knowledge related to causes of development delays and disabilities and knowledge about rights of women and children in the State of Palestine.

Respondents were asked whether marriage of an extended family member, such as a first cousin, increased the risk of a child being born with a developmental delay or disability. While 93% of respondents in the West Bank responded that it does, only 72% of respondents in Gaza responded that it does ($p < .01$). Although the C4D strategy on ECD is not specifically intended to address this issue, when appropriate it may be part of discussions at the community level.

On the question of whether Palestinian law allows women the right to choose their husband, there was not a statistically significant difference between the two regions. However, only 57% of respondents believe that women have this right. The next series of question asked respondents if they were aware of rights of women related to divorce, separation, and other issues connected to gender and property. There was no significant difference between regions in the overall response, but one question, on whether women have the right to divorce, did indicate a statistically significant difference between Gaza and the West Bank (85% vs. 98%), with nearly all respondents from the West Bank stating that a woman had the right to divorce.

The next questions were concerned with respondents' knowledge related to the rights of children with developmental delays and disabilities. While there were no significant differences on any of these factors between the regions, what is striking about this result is that overall, 62% of respondents did not believe that children with developmental delays and disabilities had Palestinian legal rights at all.

Table 10: How Many Children in Palestine Have a Disability of Any Kind?

Response	Gaza	West Bank	Overall
	Percent	Percent	Percent
Less than 10%	11	16	13
10%	2	7	4
20%	3	10	7
30%	6	8	7
More than 30%	66	46	56
I don't know	12	13	12

When respondents were asked how many children in Palestine are affected by a disability, most respondents believed that the rate is greater than 30%. According to Jones et al. (2016) the national rate of disability in Palestine varies between 2.7% to 6.9%, depending on whether the narrow (a lot of difficulty or cannot at all) or the wide definition (which includes some difficulty) is used. It is therefore interesting that respondents (who are all parents/caregivers for children with developmental delays and disabilities) generally perceive such a high prevalence of disability.

d. Attitudes Toward Disability

The quantitative survey instrument included three subscales based on the theoretical framework of the Theory of Planned Behaviour: attitudes toward disability, subjective norms related to caregiving for a child with a developmental delay or disability, and self-efficacy toward positive behaviours related to caring for a child with developmental delays or disabilities, such as confronting stigma, seeking care, and getting support from others. In this section, the results of each subscale are presented.

Seventeen items were included in the attitude section of the instrument. An initial assessment of internal consistency (Cronbach's Alpha) was calculated based on all 17 items and was found to be acceptable (0.62). While acceptable, the internal consistency suggested that a review of the items was indicated. Based on initial exploration, one item was dropped from the subscale. The item dropped was question 44K:

- Because {index child} has a developmental delay or disability, his or her siblings are treated differently than other children in school or the community

While important, this question was reported not as an attitude but as a perception of the current situation. Results were reported in a previous section.

Factor analysis was conducted to determine whether the items were measuring a single attitude construct or different dimensions of attitudes. The eigenvalues indicated that the items were measuring three dimensions of attitudes: Factor 1 includes items G, H, I, L, M and N and is related to provision of services and rights; Factor 2 includes items E and J and is related to autonomy and independence of the child. Items not included in these two factors were dropped, leaving a total of 8 items in the subscale for continued analysis. The internal consistency of the new attitudes score focusing on rights and autonomy was calculated and the Cronbach's Alpha was 0.72, indicating that the internal consistency had improved.

An attitude towards rights and autonomy score was generated which was the sum of the recoded scores from the 8 items described above. This score was found to be skewed (kurtosis=2.8). A final categorical attitude variable was created based on the attitude towards rights and autonomy score, in which scores from 6 – 16 were coded as positive and from 17 – 40 coded as negative.

Overall, 78% of respondents had positive attitudes across the eight items in the subscale. There was a significant difference between Gaza and the West Bank ($p < .01$) in the percentage of positive attitudes; in Gaza, 68% of respondents had a positive attitude score while in the West Bank, more than 89% of respondents had a positive score.

Other demographic factors also showed significant variations. For example, households in the lowest income tier (0 – 1973 NIS per month) were significantly less likely to have a positive overall attitude score ($p < .01$). The father's occupation was also significantly associated with differences ($p < .05$), with those who were previously employed or never employed less likely to have a positive attitude than those who were involved in paid employment or operating a business. Because the vast majority of respondents were mothers (80%), it is likely that many rely on the father's occupation and are more likely to have a positive attitude toward the situation if the father is working regularly. Mothers themselves are significantly more likely to have a positive attitudes score ($p < .05$); 75% for mothers vs. 60% for fathers).

Mother's education level, father's education level, and mother's occupation were not significantly related to a positive attitude score, nor was the particular disability with which the child had been diagnosed.

Additional items significantly related to a positive attitude score included whether the child used assistive devices of any kind; those respondents whose child used an assistive device were significantly more likely to have a positive attitude score (84% for those who do vs. 77% for those who do not; $p < .01$). Those who had access to the Internet were also more likely to have a positive attitude score (82% with Internet vs. 70% without; $p < .05$); the platform identified was not significantly associated with a positive attitude score. Finally, those who thought that marrying within their family (such as a first cousin) could contribute to developmental delays and disabilities were much more likely to have a positive attitude score (82% vs. 63%; $p = .01$).

e. Normative Expectations Regarding Disability

Eleven items were included in the normative expectations section of the survey instrument. The questions were intended to determine the degree to which parents/caregivers believed that people around them who they admire had expectations of them to undertake positive actions related to caring for their child with a developmental delay or disability.

An initial assessment of internal consistency (Cronbach's Alpha) was calculated based on all 11 items and found to be acceptable (0.67). While acceptable, the internal consistency suggested that a review of the items was indicated. The reliability calculation indicated one item that was reverse coded (question 45H) and this was recoded to align with the remaining items.

Factor analysis was conducted to determine whether the items were measuring a single normative construct or different dimensions of normative expectations. The eigenvalues indicated that the items were measuring two dimensions of normative expectations: expectations of support for the child and expectations of the social and cultural life of the child. Factor 1 includes items F, G, I, and K, and factor 2 includes items B, C, and D. Items in the subscale not included in these two factors were dropped, leaving a total of 7 items in the revised subscale, which had an improved level of consistency ($\alpha = .75$).

As in the attitudes subscale, a normative expectations score regarding support and social and cultural inclusion was generated which was the sum of the recoded scores from the 7 items described above. This score was found to be skewed ($\text{kurtosis}=2.7$). A final categorical normative expectations variable was then generated using the range of positive responses, in which scores from 7 – 14 were coded as positive and 15 or greater coded as negative. A positive score on the subscale indicates that a respondent believes that those around them expect them to undertake positive behaviours related to caring for their child. The modified subscale includes items B, C, D, F, G, I and K, which are:

Factor 1 (social – cultural inclusion):

- [45B] People I look up to expect me to be sure that {index child} attends school
- [45C] People I look up to expect me to be sure that {index child} prays
- [45D] People I look up to expect me to be sure that {index child} plays with friends

Factor 2 (care seeking and support):

- [45F] People I look up to expect me to seek health or rehabilitation care for {index child}
- [45G] People I look up to believe that {index child} should be treated the same as other children in my family and community
- [45I] People I look up to expect me to stand up for {index child} if he/she is not being treated fairly
- [45K] People I look up to expect me to provide financial support for my child, even if the child has a delay or disability

Overall, 60% of respondents had a positive score on the normative expectations subscale; the difference between Gaza and the West Bank did not reach the level of statistical significance.

As with the attitudes score, other variables were examined to determine whether significant differences were related to other factors. Again, households in the lowest income tier (0 – 1973 NIS per month) were significantly less likely to have a positive normative expectations score ($p < .05$), with those in the lower tier less likely to have a positive score than the other tiers (56% vs. 68% vs. 68%). The father's occupation was also significantly associated with differences ($p < .05$), with those who were previously employed less likely to have a positive attitude than those who were never employed, in paid employment or operating a business (47% vs. 71%, 67%, and 60%, respectively).

Mother's education level, father's education level, and mother's occupation were not significantly related to a positive normative expectations score. However, the disability with which the child had been diagnosed was significantly related to a positive normative expectations score, with parents/caregivers for children diagnosed with autism, learning disabilities and intellectual impairments less likely to have a positive normative expectations score ($p < .05$).

Additional items significantly related to a positive score included access to the Internet; those respondents with access to the internet were more likely to have a positive score (64% with Internet vs. 51% without; $p < .05$); the platform identified was not significantly associated with a positive score for normative expectations. The difference between those

who thought that marrying within their family (such as a first cousin) could contribute to developmental delays and disabilities and those who did not was not statistically significant.

f. Self-efficacy Regarding Pro – Disability Behaviours

Seven items were included in the self-efficacy subscale and were related to the respondent's belief in their ability to take a particular action related to caring for a child with a developmental delay or disability.

An initial assessment of internal consistency (Cronbach's Alpha) calculated based on all seven items and was found to be acceptable (.75). Once this calculation was performed, items in the scale were recoded so missing values did not affect the calculation and reliability was again checked and found acceptable (0.71). The internal consistency calculation indicated no items were reverse coded.

Factor analysis was conducted to determine whether the items were measuring a single self-efficacy construct or different dimensions of self-efficacy. The eigenvalues indicated that the items were measuring only one dimension of self-efficacy. Therefore, the entire set of items was retained. The questions for this subscale included the following:

- 46A I feel confident that I can provide good care for {index child} at home.
- 46B I feel confident that I can find professional services for {index child} if I need them.
- 46C I feel confident that {index child} can take part in activities in the community, like school, play, religious services, and visiting friends
- 46D I feel confident that I can get support from my family, neighbours, or community if I need it
- 46E I feel confident that I can stand up for {index child} if he/she is not being treated fairly (discrimination) or if he/she is experiencing disrespect (stigma)
- 46F I feel confident that I can convince my family/spouse that my children should not marry someone from our immediate family (first cousin)
- 46G I feel confident that I can create a plan for addressing discrimination or stigma ahead of time

An overall self-efficacy score was generated which was the sum of all the scores of the 7 items described above. This score was found to be skewed (kurtosis = 2.9).

A final, categorical self-efficacy score related to quality of care, inclusion, and pro – child behaviours was then generated in which scores from 7 – 16 were coded as positive and 17 or greater coded as negative. Overall, 47% of respondents had a positive self-efficacy score, which was markedly lower than the overall scores for the other two subscales (73% and 60% for attitudes and normative expectations, respectively).

The greatest and most striking difference in the self-efficacy score was between Gaza and the West Bank ($p < .01$). While 63% of respondents in the West Bank had a positive self-efficacy score, in Gaza only 37% had a positive score. Although a typical report on statistical results would simply label this significant, the magnitude of the difference is actually quite notable. Given the situation on the ground in Gaza, perhaps it is to be expected that parents/caregivers would be much less confident in their ability to undertake actions related to seeking care, confronting discrimination, and inclusion in social and cultural life.

As with the previous scores, other variables were examined to determine whether significant differences were related to other factors. Again, households in the lowest income tier (0 – 1973 NIS per month) were significantly less likely to have a positive self-efficacy score ($p < .05$), with those in the lower tier less likely to have a positive score than the other tiers (45% vs. 68% vs. 66%). The father's occupation was also significantly associated with differences ($p < .001$), with those who were previously employed or never employed less likely to have a positive self-efficacy score than those who were in paid employment or operating a business (40% and 45% vs. 60% and 54%, respectively).

The type of diagnosed disability was not significantly associated with self-efficacy score, nor were mother or father's level of education. The use of assistive devices was also not significantly related to the self-efficacy score. Respondents who sought information about caring for a child with a disability were more likely to have a positive self-efficacy score than overall (61%; $p < .01$). Those who had access to the Internet were more likely to have a positive self-efficacy score (61% with Internet vs. 39% without; $p < .01$); as with the other scores the platform was not significantly associated with a positive self - efficacy score. Those who thought that marrying within their family (such as a first cousin) could contribute to developmental delays and disabilities were much more likely to have a positive self-efficacy score (57% vs. 36%; $p < .01$).

The findings on the three subscales associated with the theoretical framework of this research indicate that particular attention should be paid to self-efficacy in future C4D work around confronting stigma and discrimination; the attitudes and normative expectations scores are quite a bit higher and while intervention may be beneficial, do not have the same urgency as increasing people's belief in their ability to act.

g. Reference and Support Networks

The survey instrument included four questions (47, 48, 49, and 50) on reference and support networks, which included questions about how many people provided support, what type of support they provided, respondents' perceptions about the amount of support they received, and who provides support. There was no significant difference between Gaza and the West Bank in terms of support network, but overall, 35% of respondents reported that they had no one who provided support on a regular basis (every day or several times

per week). For those who did receive support from at least one person, the types of support they identified were as indicated in table 11 below.

Table 11: Type of Support Identified

Type of Support	Gaza	West Bank	Overall
	Percent	Percent	Percent
Financial	64	80	73
Logistical	52	65	60
Emotional**	82	92	88
Caregiving	69	84	78
Other	2	2	2

(**p < .01)

While financial, logistical, and caregiving support did not indicate any statistically significant difference between regions, emotional support, which is arguably the most important type of support that can be provided to a caregiver in the form of supportive messages and encouragement, did indicate a strongly significant difference between Gaza and the West Bank, with parents/caregivers in the West Bank reporting receiving such messages at a rate nearly ten percentage points higher than those in Gaza.

Table 12: Supportive People in the Network

Providers of Support	Gaza	West Bank	Overall
	Percent	Percent	Percent
Immediate family	83	86	85
Extended family	14	12	13
Community	2	1	2
Other	0	2	1

Table 12 indicates that most parents/caregivers who do receive support get it from members of their immediate family. Only two percent of parents/caregivers report that they receive regular support from members of their community.

Respondents were asked whether the amount of support they received was too much, the right amount, or not enough. There was a statistically significant difference in responses between Gaza and the West Bank, with significantly more respondents in Gaza reporting that they did not receive enough support from people within their networks (52% vs. 24%, p < .01). Respondents in the West Bank were much more likely to be receiving the right amount of support.

h. Access and Use of Health Care and Education

The final set of questions (51 – 76) involved access to, use of, and perceptions related to health care and education services. Respondents were asked a series of questions about their child’s use of health care services, barriers to accessing and using these services, and questions about their child’s school.

Overall, only 37% of respondents report that their child is receiving any type of professional health service (rehabilitation, physical therapy, or other health services received on a regular basis). The likelihood of receiving health services was not significantly related to the diagnosed disability. The majority of those who received regular health services were satisfied with them (68% overall).

The next question asked parents to identify where they had heard about the health facility where they received services. The largest response category was “referral from doctor or nurse” (42%), followed by information from family at 18% and neighbours and friends at 17%. There were no significant differences between the regions in response to this question. These responses suggest that health care professionals play the key role in sharing information about appropriate health facilities and services with parents/caregivers; family, neighbours, and friends also play a role in providing information about health care facilities.

Many children seem to have difficulty accessing the health care facility, as indicated in table 13 below.

Table 13: Does the Child Have Difficulty Accessing the Facility?

Difficulty Accessing the Facility	Gaza	West Bank	Overall
	Percent	Percent	Percent
Yes	58	38	47
Lack of accessibility*	6	33	18
Lack of transportation*	57	51	54
There is no one to take him/her*	15	11	13
No	42	62	53

(* p < .05)

Nearly half (47%) of children have difficulty accessing the health facility at which they receive regular services. The difficulties reported vary significantly between Gaza and the West Bank, with those respondents in Gaza more frequently reporting that there is a lack of transportation and those in the West Bank reporting that the facility is not accessible to their child.

The next question asked whether the child had difficulty using the facility once inside. Most did not (78%); there were no significant differences between Gaza and the West Bank regarding the difficulty the child faced once inside. The major issue reported on using the health care facility once inside had to do with lack of medical devices like crutches, beds, or other therapeutic materials. Once connected with the facility, 67% received counselling services. There was no significant difference between the two regions in terms of receiving counselling services.

Respondents were asked whether they had received a referral to another health, education, or support services from the facility. Most children (57%) had not received a referral to

another facility and there was not a significant difference between the two regions. The type of disability also did not have a statistically significant effect on whether a respondent reported receiving a referral. The type of referral varied, but the vast majority of referrals were received for assessment and medical care (82%). There was one significant difference between regions, which was for rehabilitation, where a greater percentage of respondents in the West Bank had received referrals for rehabilitation than in Gaza (74% vs. 59%, $p < .05$).

The final set of questions included the child's attendance at education facilities such as nurseries, schools, or other facilities.

Table 14: Does Your Child Attend an Educational Facility?

Attends Education Facility	Gaza	West Bank	Overall
	Percent	Percent	Percent
Yes, nursery	1	1	1
Yes, preschool	11	6	9
Yes, school	18	24	21
Yes, another educational facility	6	5	6
No	64	64	64

There were no significant differences between regions in responses to this question; the majority of children in the sample do not attend any type of educational facility at all.

When the diagnosed disability was initially included, there was no significant relationship between the likelihood of attending an educational facility and the diagnosed disability. However, when the types of disabilities were categorised into six groups, rather than 12 distinct disabilities, a statistically significant difference appeared in the likelihood of attending an educational facility. Those children diagnosed with ADHD and speech and language disabilities (56% attending) and children diagnosed with sensory disabilities (blindness/low vision/deafness/hard of hearing; 56% attending) were more likely to attend some type of educational facility, while those children diagnosed with autism, learning disabilities, psychosocial disabilities, and Down syndrome were less like to attend (32% attending). Children with physical disabilities, multiple disabilities, and other disabilities were also less likely to attend an educational facility (38%; $p < .05$ for all categories).

Next, respondents were asked whether they were satisfied with the education that their child's school provided. Most respondents were satisfied with the education provided by the school that their child attended (68%) and there was not a difference between Gaza and the West Bank. In the next question, family and friends were identified most frequently as the source of information about the school (34% and 22%).

The next two questions asked about difficulty children had attending the school. While there was no difference between regions in the response to this question, there was a

significant difference in response depending on the diagnosed disability category, as indicated in table 15.

Table 15: Does your Child Have Difficulty Attending School?

Difficulty Attending School*	Yes	No
	Percent	Percent
Physical disability	43	57
Autism, learning disability, psychosocial disability, Down syndrome, intellectual disability	21	79
ADHD, speech and language disability	10	90
Sensory disability (blindness/low vision/deafness/hard of hearing)	16	84
Multiple disabilities	44	56
Other	55	45
Overall	29	71

(*p < .05)

Those children with physical disabilities, multiple disabilities, or other diagnoses are significantly more likely to have difficulty attending school than their peers with other categories of disabilities. The main difficulty that the child encountered when attending school also varied significantly between regions, as indicated in table 16.

Table 16: Main Difficulty Attending School

Main Difficulty Attending School*	Gaza	West Bank	Overall
	Percent	Percent	Percent
Lack of accessibility of the building such as ramps, curb cuts, and other physical accommodations	8	45	23
Lack of assistive devices such as screen readers, Braille texts or markers, or other assistive devices	12	9	11
Lack of accessible toilets for {index child} to use	29	21	26
Transportation	20	9	16
Attitudes of people at school toward {index child}	22	12	18
Teachers' knowledge of {index child's} delay or disability	4	0	2
Other	4	3	4

(p < .05)

Accessibility is a major barrier for children with developmental delays and disabilities when it comes to attending school. Transportation also is an issue. When asked whether their child received the same quality of education as other children in their school or educational facility (question 67), only 35% of respondents stated that they believe that their child receives the same quality of education as other children at their school.

The next set of questions asked about communication with school teachers and administrators. In Gaza, 85% of respondents report that they communicate regularly with their child's teachers or parents/caregivers; in the West Bank, 95% do (p < .05). Face to face meetings are the most prevalent form of communication with children's teachers (88%); those respondents in the West Bank were also more likely to identify electronic

communication such as emails (6% vs. 0%, $p < .01$) and telephone as communication methods (77% vs. 62%, $p < .05$).

There were no significant differences between regions in terms of the frequency of communication; most parents/caregivers communicate with their child's teacher between once a week and once a month (44% and 40%, respectively). A majority of parents/caregivers would prefer more frequent communication with their child's teacher. Only 35% of respondents agreed that the amount of communication they received was adequate for them. In terms of communication with school administration, most respondents reported that they do so both formally and informally (52%). There were no differences between regions in responses to this question.

Respondents were asked to rank how they felt about certain interactions with teachers, school administration, and educational outcomes, from very important to useless. The responses were grouped into three categories: important, undecided, and not important. Overall, 88% believe that it is important that teachers recognize them as experts on their children. On the development of a learning plan and follow up on milestones, there were significant differences between Gaza and the West Bank; 80% of respondents in Gaza believed that development of a learning plan was very important vs. 97% in the West Bank ($p < .05$), and 78% of respondents in Gaza ranked follow up on milestones as very important, compared to 97% of respondents in the West Bank ($p < .05$).

The final three questions asked respondents to consider whether they trusted their children's teachers and school with their children's safety, academic development, and emotional and social development. There were no significant differences between regions in responses to any of three questions. Most respondents completely or mostly trust their children's schools and teachers with their children's safety (84%), academic (80%) and emotional and social development (80%).

Subsequent sections of this report present findings of qualitative enquiry and the participatory activities.

2. Qualitative Findings

This section presents the results of the qualitative data collection and analysis, as described in the previous section. Results are presented across nine thematic areas, as indicated in table 4 on page 24.

a. Acceptance and inclusion of Children with Developmental Delays and Disabilities

In the context of this analysis, *acceptance* of a child with a developmental delay or disability refers to several concepts. First, that a child with a visible disability can go from place to place within their community and not be shunned, given unwanted attention, or be subjected to verbal or physical abuse. The experiences of participants in their communities

varied significantly: some reported that their communities are not accepting of their child, and that their children are subject to abuse when they travel, while others reported that they are able to move freely without difficulty. For example, a primary caregiver from Nablus noted:

'I did not experience this from the community and I never faced any problems. Those who are around us never made us feel less, but I think as mothers, we always see our children as "different" from their siblings, especially in the mornings when they go to school and need help getting ready.'

On the other hand, many parents/caregivers report that they and their children still face stigma and discrimination from those around them. An example is a caregiver from Khan Younis who stated:

'...my son is with developmental delays and he gets bullied in the community and they call him "midget" and other terms which caused deterioration in his physiological condition'

A second characteristic of acceptance is related to all children with developmental delays and disabilities, visible or not, and the willingness of those around them to allow them to take part in social and cultural life. The severity of the disability plays a large part in whether a child in this situation is allowed to attend religious, social, or cultural events, and schools in particular stood out to participants as places where their children had the greatest potential to be marginalized, stigmatized, or discriminated against. For example, a mother in Hebron noted:

'None of the schools accepted to take in my daughter because of her physical disability, although she does not suffer from any mental disability and she is very smart. I asked them to move the classrooms to the ground floor but they refused. The Yatta Rehabilitation Centre and MoSA got involved, but none of the schools accepted her. She is 8 years old today and is illiterate.'

Another mother, also from Hebron, stated simply that "[t]he community does not provide emotional and psychological support at all, except some very close family members, mainly our sisters." A participant from Khan Younis said simply "the disabled (*sic*) are always disabled in the eyes of the community no matter where they go."

These statements are contrasted by several participants who reported that those around them are able to be supportive once they have come to know their children better. For example, a caregiver from Deir al-Balah noted:

'...when I take my son to the mosque, he keeps on moving and going to the books corner and they used to tell him "do not play here" but now they are used to him and they love him.'

Extended family, most notably uncles and aunts, were frequently mentioned as being strong sources of support for children with developmental delays and disabilities. When discussing the ways in which their children are treated by extended family, most participants indicated that aunts, uncles, and grandparents are supportive, at least psychologically, and treat their children well. A caregiver from Khan Younis noted:

'Thank God my son is so much better right now and his uncles support him. They used to treat him with pity, but after they saw that he got better their attitude became much better especially since my child is funny and loveable.'

Discussing support from communities, an interviewee from Nablus stated:

'There is still a negative attitude but it's mild. Things have changed, even when you walk in the streets a child in a wheelchair does not catch your eye like before. Even when we pass a child with special needs [they] do not catch our eye anymore and it's normal. Every day we see someone in a wheelchair, especially electronic ones. We see the child with hearing aid and it's normal for us. Things are different and people started accepting persons with disabilities and special needs.'

This sentiment was reflected by other participants. In an FGD with community leaders from Nablus, a participant stated that "I say previously people were ignorant but now people are much better as we have organizations that care about people with disabilities and there are trainings for parents...before it was as if the person with disability is considered shameful for them."

Although these participants' statements are positive, parents/caregivers experience stigma and discrimination differently depending on their child's situation. Those who care for children with more severe and visible disabilities are more likely to experience significant social barriers to the inclusion of their children. However, one area in which most parents/caregivers experienced significant challenges with acceptance of their children, no matter their situation, was in schools.

Participants often reported that schools were difficult for their children to access. This supports the findings of Jones et al., (2016) who also reported that children with developmental delays and disabilities struggled to access education due to lack of accessible facilities, poor attitudes among teachers, and lack of capacity to include and integrate children with developmental delays and disabilities. Participants in this study reported the same barriers for their children; for example, a caregiver from Nablus stated:

'Older students with complex disabilities receive worse treatment than those with moderate cases. For example, I asked the principal of the school to allow my son to enter the resource room, but she replied that it is only for young students and those who have a chance of getting better. I told her that my son is not "nothing"...I sometimes visit him at school to find out that other students abuse him but none of the teachers had done anything to stop it. I had to file a complaint at the MoE and requested that my son spend time in the resource room.'

Another caregiver from Jericho stated:

'My child is in the fourth grade and he doesn't know 'till now how to write his name and he is being taught bad behaviour at school. There is no education and no care giving in the schools, there must be a specialized school for those conditions who can bare such responsibility.'

The experiences of parents/caregivers and their children have led many of them to abandon the idea of school altogether, despite their belief in the right of their child to receive education.

One component of the challenge of attending school is the treatment that children with developmental delays and disabilities receive from other children. Participants frequently reported that children in schools or their neighbourhoods are verbally or physically abusive. Sometimes children may feel that teachers focus too much on those with developmental delays or disabilities, as was reported by this participant from Hebron:

'My child (girl) got home from school one day and asked why do teachers care [so] much about the girl with the physical disability in class? Children are often bothered by the special treatment of their classmates who have specific disabilities.'

The lack of capacity to integrate children with developmental delays and disabilities in schools is a significant issue and the above quote suggests it also affects other children, who may begin to resent students who need accommodations to successfully integrate.

Although participants did report ill treatment from other children, there are also examples of children with developmental delays and disabilities being treated as equals by other children, particularly those in their family. A mother from Deir Al-Balah noted:

'Since he started going to the new school, I felt that he became a normal person. He started reading simple words, his behaviours changed and he became better. Even in the future if I want to let him sell in a small trolley he can manage. His brothers treat him as one of them and not as inadequate.'

Acceptance of persons with disabilities has other effects on families that have been described elsewhere and are supported here. For example, parents/caregivers of children with developmental delays and disabilities worry that the child's siblings will not be able to marry or will be treated poorly by others in their community; they worry that they spend so much time with their child with a developmental delay or disability that their other children will feel neglected or jealous; they often experience psychological burnout and stress from constantly having to provide intensive care for their child; and in some cases feel shame at bringing their child out in public. What may be more discouraging is that many have given up believing in the ability of institutions such as the General Union for People with Disabilities (GUPD) and the government. A participant in an FGD with representatives from Disabled Persons Organizations noted:

'The majority of individuals with disabilities started losing hope in the institutions and even in the GUPD. There are certain things that institutions cannot achieve due to governmental restrictions, which leave the ministries as the only available option. Ministries, however, are not very reliable and rarely deliver on their promises.'

Participants acknowledge the importance of inclusion, and desire that their children be included in social and cultural life, but struggle to find ways to do so. In some cases, participants confront stigma and discrimination directly, and in others, they retreat into their homes. Strategies for dealing with these issues will be discussed in a subsequent section.

b. Support

Qualitative guides included questions that solicited participants' thoughts about ways that they could be supported by people and institutions in their communities and in Palestinian society more generally. There were three types of support that were most frequently identified by participants that would improve their ability to support their children with developmental delays and disabilities: financial support, psychological support, and dedicated spaces and facilities for services and activities for their children.

Participants suggest that financial support should take the form of fee payments for the provision of services, free or reduced costs for education, and allowances that assist them in the caring for their children or maintaining their households. In other cases, participants requested financial support for institutions that provide care for their children. Some participants expressed frustration at the lack of support from official channels. For example, a caregiver from Nablus stated:

'We don't only want to attend meetings, we need financial support. I went to the MoSA to ask them to cover for my children's expenses, but they decided to cut the aid.'

There should be an exception for difficult cases. We need their compassion and help, not only meetings and workshops.'

This caregiver's statement suggests frustration with intangible types of support, and for many participants the need for financial support is often stated as the most pressing requirement.

However, when asked what could be done by organizations and institutions to support the participation of children with developmental delays and disabilities in social and cultural life, the responses given by participants often varied significantly. For example, in an FGD with extended family and community members in Khan Younis, participants said the following:

- *treat them well without mocking them or being abusive.*
- *provide specialized educational centres, especially for autistic children.*
- *offer entertainment and recreational activities.*
- *take into consideration the nutritional aspect of children with disabilities.*
- *[provide for] their needs in terms of rehabilitating and developing schools to accommodate children with disabilities.*
- *provide the necessary treatment free of charge.*
- *create cultural centres to raise the awareness of the society.*
- *provide psychological support for parents and children with disabilities.*
- *eliminate corruption and nepotism in governmental institutions providing services for children with disabilities.*
- *[increase] the number of projects that provide psychological support and recreational projects.*

This FGD included 16 female participants and no male participants. All identified themselves as "housewives" when asked what type of work they were engaged in, and several care for children with developmental delays or disabilities. The range of responses, which vary from providing psychological support to providing treatment free of charge and eliminating corruption and nepotism in institutions, demonstrates not only the wide and varied need for support for families caring for children with developmental delays and disabilities, but the high levels of knowledge of parents/caregivers and community members of potential interventions that could make a difference in the lives of children and their parents/caregivers.

Psychological support was also frequently mentioned as an important form of support that should be provided to both parents/caregivers and children. Participants noted that many parents/caregivers suffer from burnout or high levels of stress due to the burden of caring for children with developmental delays and disabilities and that they should be provided with support that can help them cope with these stresses. A participant from Hebron suggested:

'Support the mothers so they can deal with all the talk they hear from relatives and the community...strengthen them physically and psychologically.'

When asked how family or community members provide support for parents/caregivers, a community leader in Nablus noted:

'through supporting them and standing by their side and caring for their emotions, providing financial, moral and social support. Through nice words that alleviates the suffering of the parents and helps the child to grow.'

Moral and social support may provide significant benefits for children and their parents/caregivers, particularly as they adopt new behaviours that promote this inclusion of their child in social and cultural life. Providing psychological support may also be supported through the development of communication programs that build support among communities for children and their parents/caregivers.

Many participants also mentioned the need for communication initiatives in their communities that would promote the rights of children with developmental delays and disabilities and reduce stigma and discrimination. For example, a participant from Hebron stated:

'The surrounding community needs awareness and the issue of disability needs to reach out to the community in a different way other than media; that this individual is like everyone else and has needs and rights'

Another participant from north Gaza stated simply that "we need to change the society's perception of people with disabilities and raise awareness in schools about how to deal with them." Participants also stated that such communication campaigns should include children as well as adults, children with developmental delays and disabilities themselves, who are often unaware of their rights and do not currently have the ability to confront stigma and discrimination directly, and parents/caregivers of children with developmental delays and disabilities themselves, who must adopt new behaviours to integrate their children in social and cultural life.

A need for support for parents/caregivers and children with developmental delays and disabilities was also expressed by participants' desire for spaces and facilities that could serve their particular needs. Some participants expressed the need for tangible improvements, such as elevators, accessible streets and buildings, and dedicated service windows for people with disabilities at businesses such as banks. Other expressed a need for intangible improvements, such as classes that are appropriate for children with certain disabilities, workshops or training programs that will help parents prepare to care for a child

with a disability, and the provision of specialists and counsellors for treatment and rehabilitation.

One KII participant, who works in the MoSD, stated the following regarding support for parents/caregivers and children:

'Practically speaking, it's [about] preparing the mother father and the family and the prior preparation of them. The first people who will practice discrimination against the child are his siblings, the preparation of the scene is key. Because it's not enough to tell the parents they will have a child with these symptoms and do this and that to make the child feel normal, you have to tick and work on all life squares that the child spans...[t]he issue of stigma is about preparing the playground before and after and continue doing it. The second thing is much more complicated and needs more adjustments; all the facilities related to children should be adapted because you can't constrain the child in one place.'

One possible approach to confronting stigma and discrimination is through the *social model* of disability, which suggests that it is the environment, rather than the person, that needs adjustment to function in society. Participants noted that psychological support and acceptance of children (and people) with developmental delays and disabilities would come following the adaptation of the environment to accommodate them, rather than the other way around. A community leader from Nablus explained it this way:

'The negative attitudes will not change unless there is an understanding of persons with special needs through more awareness and inclusion in the community and for them to become part of the public sphere. The sidewalks in the city are not designed to be used by persons with disabilities and this is not a result of the negative attitude but because it seems that the vision of the municipality does not see them as part of the community who deserve these services. When I walk on the sidewalks, I started noticing why are there some slopes; because part of the community is those with disabilities and it comes to my mind that these people are living with us and some easements are made for them. These public places need rehabilitation through municipalities and institutions providing services; they must include audio signs or braille language...the unavailability of these facilitations will not enable the normal citizen to understand the needs of these people. When you see these facilitations every day and grow up with them you start respecting this category. You understand that they have rights and they are being met in the streets and it becomes part of your personality. As a result of not having these facilitations this group becomes absent in my life.'

A person with a disability from Gaza, Khan Younis, echoed this social model of disability sentiment, stating that:

'From my personal experience, once the supervising doctor said that I could not go to a practical training because of my disability. However, I went and proved myself and abilities to overcome the difficulty. The society is disabled not us.'

If the environment in both Gaza and the West Bank is adapted to accommodate the needs to persons with disabilities (including children) it is more likely that members of the public will begin to understand their presence is valued and acknowledged, which will lead to greater acceptance and inclusion for those with developmental delays and disabilities. Communication programmes serve an important role in the meantime, and should be supplemented with advocacy initiatives that promote the development of public spaces with appropriate accommodations for those who need them.

Finally, some parents/caregivers noted that it can be difficult to ask for help. One parent from Hebron stated, “[f]irst of all, there is no support from the extended family. It is very hard as our pride prevents us from asking for help.” There are always barriers to seeking support, and it is important to recognize that parents/caregivers must be provided with support in ways that maintain their dignity and pride.

c. Barriers and Challenges

It goes without saying that people with disabilities face significant barriers and challenges around service provision, education, mobility, and stigmatization and discrimination. Participants described many barriers and challenges to inclusion and integration, and also to simply providing care for their child. Some of the most frequently mentioned barriers include the physical environment, transportation, and financial difficulties; other barriers include lack of capacity among service providers and institutions, and the ever-present stigma that many parents perceive from their communities.

As mentioned in the previous section, the physical environment is a significant barrier for many children with developmental delays and disabilities. Even if a child has full mobility, the lack of accommodations for this with low vision or those with hearing loss can present challenges outside the home. For example, a parent from Gaza stated:

'The school is close to us but I have to get a taxi (paying a significant amount of money) to take my daughter to school and not to walk in the streets. The environment I live in is harsh and is not suitable for my daughter with sandy streets.'

Speaking generally about the situation in facilities in the West Bank, a participant from Hebron noted:

'The streets, educational institutions and ministries should be adjusted to accommodate persons with disabilities. I am surprised how an institution providing medical services is not suitable for persons with disabilities.'

Beyond the challenges imposed by the physical environment in which parents/caregivers and their children find themselves, many participants also noted that lack of transportation plays a significant role in whether or not their child is able to receive services, attend school, or interact within their community. A primary caregiver from Nablus stated:

'We suffer a lot, especially as mothers, from transportation. We cannot leave our house every day to go to the centre and pay for transportation and sessions. At least help us with transportation.'

This was seconded by another participant who followed up, noting that:

'The MoSA used to cover our transportation to sessions, but now that the number of cases has increased, so they cut the aid. I don't understand why they stopped covering it. What can people do when they have more than one case at home?'

An additional barrier/challenge is financial; this supports what participants said about support in the previous section. In Palestine, the financial barriers are also complicated by the political situation, as suggested by a service provider from Hebron:

'The political situation in which we live affects all organizations in terms of financing their work. The MoSD has yet to pay us for our services, and the limited financial situation of the PA affects our work as well as theirs.'

The financial constraints are felt by most participants: there are costs for services, costs for transportation, costs for assistive devices, and costs for school fees. Most of these costs are borne by the family, who perceive that their governments, whether Ministries or another institution, should provide them services, education, and transportation without cost. However, policy makers themselves note that they are underfunded and under-resourced in terms of human capacity. A decision/policy maker from Nablus stated:

'The weakness is that there are no budgets and the funding is insufficient and we continue our work through networking with other institutions. There must be a larger budget allocated for these people to fulfil their needs. In our work the weakness is having no budgets that cover the needs of people with disabilities.'

Together with the financial challenges that constrain the provision of services, facilities, and transportation, the lack of resources also leads to a lack of coordinated approaches to serving parents/caregivers and their children. Many participants mentioned that institutions need to coordinate their activities, and in doing so would preserve gains made in service provision and rehabilitation efforts and allow for greater specialization. For example, a service provider in Hebron stated:

'Organizations could improve their work by specializing in one domain, and by communicating with local citizens because they are our biggest supporters. We can collect donations and introduce our work to the public. This way they are familiarized with our work and will be more willing to support us. We could also depend on local resources. Furthermore, coordination is needed between the organizations when it comes to external funding through working together on different projects that will benefit our citizens, and through putting pressure on the new government to play a bigger role.'

The idea of coordination between institutions was echoed by community leaders in Nablus:

'I say on the level of the town the organizations' work should be consolidated and every one should take care of the cases and not each person works alone. Based on a study there should be cooperation among organizations! To form a committee out of all organizations, that works with all people with disabilities and not each organization working according to its goals.'

This type of coordination is a goal of policy makers, some of whom mentioned that they have attempted to create opportunities for institutions to work together. For example, a decision maker from the Ministry of Social Development in Gaza reported:

'We always seek to unify the efforts between us and other institutions. This role takes a lot of effort to convince institutions whether civil or international. We gather the institutions in several meeting on a yearly basis, in addition to supporting them receive projects and providing easements.'

Institutional capacity itself is an issue that was mentioned by several participants. Although some of the lack of institutional capacity stems from lack of coordination, it is also exacerbated by a lack of financial resources and a dearth of trained specialists. For example, a participant in an FGD with primary parents/caregivers from Hebron stated:

'There aren't any centres that provide workshops or advice on how to deal with children with delays and disabilities. The available TV programs are not enough, we need specialized people to diagnose our children's cases, and there aren't any programs for rehabilitation and development. The only available centre is the Yatta Community Centre.'

In addition to the lack of specialists, there is a lack of trained individuals who can provide generalized services for children with developmental delays and disabilities. For example, this decision maker from Jericho stated:

'In Palestine and with all the institutions, we talk mostly about the shortage of staff in terms of quality and technicality. Institutions do not have sufficient number of staff that is compatible with the number of disabilities. This shortage affects the quality and type of services, when you do not have the capacity to accommodate the cases you receive each day. There is a lack of qualified staff and shortage in the number of staff and also assistive tools.'

An additional challenge to the provision of support in Gaza is the resources that have been diverted to care for those injured in the Return protests; a social worker from Gaza stated:

'Most projects are for the injured in the Return protests; even rehabilitation projects. There has been marginalization of children with disabilities since the start of the Return protests. There are people who need physical therapy on a continual basis and the current economic situation is poor.'

Those injured in the Return protests often require extended care and treatment, which takes away from resources available for other children. In addition, donors have prioritized funding for those injured in the protests, thus reducing the base of funding for other children who may require treatment or services.

Challenges are slightly differently conceived in this analysis than barriers. A challenge implies a difficulty that may be overcome with effort on the part of a participant, institution, or organization, while a barrier can often seem insurmountable without outside assistance. Participants identified several challenges of caring for children with developmental delays and disabilities, including:

- Lack of a representative body that advocates effectively for people with disabilities and tracks assistance;
- Characteristics of children with developmental delays and disabilities, whose special needs are often perceived as challenging by parents/caregivers. These challenges have been explained elsewhere (see Jones et al., 2016); and,
- Poverty and lack of financial resources, which can make it extremely challenging for parents/caregivers to provide effective treatment for their children; coupled with the lack of a representative body and the lack of coordination among institutions, poverty can make it extremely difficult for parents/caregivers to receive the support they need.

When asked what in their community was particularly challenging for children with developmental delays and disabilities, one community leader from Nablus noted:

'The unavailability of a collective national body or authority in order to organize the services for children with disabilities. Luck plays a role sometimes as you might know

about an institution that provides the services needed for your child. Some of these institutions also request fees, so how much are you willing to pay to receive this service? The MoH and the MoSD which represents the government is not providing enough services for these children.'

This was echoed by a policy maker in Jericho who stated that there is “[p]oor vocational guidance for children with disabilities and the weak role of the GUPD.”

As indicated previously, many participants discussed the lack of financial resources at their disposal in the context of considering what type of support they needed. Poverty, however, is a condition which affects many aspects of life for parents/caregivers of children with disabilities and developmental delays. These challenges include transportation, paying fees for treatment or services, being unable to afford clothes, assistive devices, sanitary items, and other material needs. The presence of poverty also affects families’ ability to take part in social and cultural life, particularly if their child requires mobility support or other assistive devices.

In some cases, particularly in Gaza, participants noted that the dire economic situation there had pressured their children to take part in the Return protests. This has led directly to the child being injured and requiring additional care, thus further straining the family’s resources. A caregiver from north Gaza, Jabalia, noted:

‘It is because of our difficult economic situation and the psychological and neurological pressure we endure, that our children decided to participate in the March of Return protests. We ask for financial support. We need support programs for basic needs for my son and for all mothers.’

In sum, the barriers and challenges that participants must face in the process of caring for their children are significant. Addressing these barriers and challenges will require a complex, nuanced approach to communication programming that includes not only behaviour change communication, but social mobilization and political advocacy.

d. Influence

Influence refers to the ability of parents, parents/caregivers, and other stakeholders to advocate for the children in their care and for themselves. The concept aligns, to some extent, with the theoretical concept of self-efficacy in the TPB, although in the context of the qualitative inquiry it appeared more broadly as a thematic element. The main areas of discussion related to influence included the power of collective action, the ability of people to advocate for themselves, and the feeling of powerlessness that parents and parents/caregivers often feel to change their situation.

Collective action was discussed as one of the most effective tools that parents/caregivers might have to create change. This collective action could be targeted at NGOs or other

institutions, or at government agencies themselves such as Ministerial departments. For example, two participants from Khan Younis identified collective action as influential tactics:

'Collective work contributes to pressuring the institutions to improve the lives of the children with disabilities.' (participant 1)

'To boycott the activities and projects that do not meet the needs and interests in the community, and to influence them to replace those projects with one's meeting the needs and are beneficial.' (participant 3)

In north Gaza and elsewhere, participants identified the importance of the 5% law, which:

'Oblige[s] governmental and non-governmental organizations to absorb a number that is not less than 5% of its staff among the disabled in a manner that conforms to the nature of activity in these organizations while making workplaces suitable for the use of the disabled.' (Palestinian Territory, Law #4 of 1999).

Collective action was seen as a way to pressure government organizations into meeting their legal requirements under the law; one participant stated that collective action could "activate the 5% law, and organize protests to add more pressure on the government."

Beyond the influence that collective action could have on the government, it was also seen as a way to unite parents and parents/caregivers in a common goal, such as improving service delivery and understanding among community members. A community leader in Nablus stated:

'Through lobbying and advocacy and through uniting all parents to influence the NGOs in order to design a program to improve the lives of the children with disabilities and through awareness campaigns. Because it's possible that any person could have in his family a child with disability and the children are parts of this community.'

While several participants mentioned that collective action is or could be an effective form of influence, others noted that collective action often had little effect or was futile, given the economic and political situation in Gaza and/or the West Bank. For example, a primary caregiver from Jericho stated:

'We tried to influence them in all the ways we could but there was no benefit, we filed reports and appeals in a collective manner, but we did not benefit at all. In our opinion nepotism plays a great role and if we knew someone or used nepotism, we would get what we need to help our children.'

Advocacy with governmental bodies may also play a role in influencing the situation for parents/caregivers and their children. In such cases, participants were sometimes likely to call on international organizations, such as UNICEF, to support them in their efforts to improve service delivery. For example, when asked how family and community could support parents/caregivers, one extended family member from Gaza stated:

'To firstly put pressure on the government for it to do its duty especially the Minister of Health. We want our voices to be heard by associations so you can help us and voice out our problems to officials.'

Another family member from Hebron stated "[y]ou as an institution should deliver the voices of these organizations and the parents to the highest level." Others had different ideas about ways to conduct advocacy. For example, an extended family member from Gaza suggested that UNICEF/AWRAD could:

'...[c]reate an online platform that gathers parents of persons with disabilities so their voices can be heard and to present their issues and communicate with each other and benefit from the different experiences.'

This effort could be supported by an effective registry of children with developmental delays and disabilities; while there is already significant ministerial/governmental capacity in this regard, service providers and policy makers stated that more could be done to maintain it effectively. For example, a policy maker in Ramallah stated:

'Part of the challenge that we have been talking about for years is the data base and how to update it. [Participant] has helped a lot in this because he gave us the names and the addresses, but we have a big problem that we faced is that the researchers (social workers) are going to the wrong places, the ages (young and elderly). There is an aspect that has to do with the data base and the fact that it is not updated in regard to this issue. In order for us to connect the real information with the system how can you do that if you provide it with information that I doubt is correct? How to work on connecting it directly to the work of the ministry? This is also an important issue when you ask the MoE.'

Parents, parents/caregivers, extended family members, and other participants not directly connected to a Ministerial position occasionally mentioned that a better enrolment system or database would assist them in receiving services. There are several factors that are likely to increase parents' self-efficacy around advocating for themselves and their children; one is the existence of a regularly updated database that is connection to other Ministries, particularly the MoE, so that parents are assured that if they take their child for school enrolment they will find a place. A second thing that might assist in this regard is some form of identification; a services card, for example, that specifies which services or assistance a

child and/or caregiver is entitled to receive. These issues will be further explored in a subsequent section.

All told, influence is a complicated factor that could be improved through capacity building activities but also through institutional factors that promote the ability to parents and parents/caregivers to seek and demand (and receive) services for their children with developmental delays and disabilities.

e. [Communication, Information, and Information Preferences](#)

One of the questions in the FGDs with parents/caregivers asked them to identify those in their social circles who they are able to rely on for support, the type of support they receive from these people or institutions. They were also asked about who they found the most difficult to talk to or gain support from. Unfortunately, in some FGDs there was not sufficient time to complete this section of the discussion. However, participants' thoughts about trusted and untrusted sources of communication were also identified from other parts of the FGDs and KIIs.

In general, participants identified immediate family members as trusted sources of information. In some cases, this circle was limited to women, as noted by this participant from Gaza (Jabalia):

Facilitator: 'What stood out to you about the people you talk to about caring for your children? Are they mostly family, peers, community members, or from institutions or organizations? Are they mostly female, or male?'

P1: 'The green circle. They are all females. I think of men as a source of anxiety not of safety. Most of the people I trust are family members (my mother, sisters). My red circle [of untrusted sources] is the government and neighbours and uncles, who are not genuine about their concern regarding my children. They are just pretending to care.'

In many cases, trusted sources of support also include husbands; but as the above quotation indicates, some parents/caregivers do not perceive men as helpful sources of support. Another participant from Jericho noted that:

'When I talk with someone who has the same case, I'm comfortable talking to them because they face the same hardships I face in the family and they share the practices they adopt to deal with their children. We resort mostly to females because they are more compassionate and closer to children.'

Male parents/caregivers, who were a small minority in the FGDs with parents/caregivers, nonetheless also agreed that men could be difficult to talk to about disability. A male

participant from Jericho, for example, noted that he is not comfortable talking about his son to his own father (the grandfather).

Another potential way to provide support for parents/caregivers is through support groups, which were mentioned by participants as potentially useful sources of support. But these seem to be connected to project timelines, rather than ongoing; some participants noted that they lasted for the duration of a particular project and then disbanded. This was the case in Hebron, where the facilitator reported that:

‘Some of the attendees had participated in parental support groups, but the meetings had stopped when the project came to an end. There wasn’t any following up with the mothers after the end of the project. One of the mothers stated: “at least these support groups uplifted my spirit and helped me and my son to understand that he is equal and similar to all other children.”’

Another participant from Nablus noted that “I sometimes meet and discuss the problems I am facing with other mothers at the association while we wait for the sessions to be over.” While this is a beneficial outcome of treatment sessions, the informality of the discussion suggests that participants may not be able to rely on these discussions.

Support groups have benefits, according to participants. Several parents/caregivers in an FGD in Deir Al Balah stated this, as indicated below:

P1: ‘We do lift each other in these meetings.’

P2: ‘These meetings are uplifting and we benefit.’

P3: ‘We discover that we are not the only ones with a problem with their child. We find that everyone else has a problem.’

P4: ‘It becomes easier to talk about our problems because others also face the same difficulties.’

Information about caring for a disability is also an important component of support. There are several sources of information, but most participants who discussed seeking or wanting information mentioned two sources: first, social media or the Internet, particularly Facebook, and second, interpersonal communication in the form of workshops or meetings with knowledgeable people such as specialists. When participants mentioned social media, they frequently mentioned the potential of a Facebook group to provide support and information that they could not get elsewhere; the Internet in general was also mentioned by several participants in multiple FGDs. For example, when asked how they would prefer to receive information, an FGD participant from Hebron stated:

'To have a Facebook page and group that combines all parents with children with disabilities, the children themselves, institutions and centres to communicate and send messages and have discussions to receive information.'

Workshops and seminars were also mentioned as important sources of information and as preferred communication methods. Participants believe workshops provide opportunities for them to interact with specialists who will provide them not only with the knowledge they may need to more effectively care for their children but also the opportunity to ask questions that they may not feel comfortable asking in other contexts, or for which the answers are not readily available elsewhere. In Khan Younis, an FGD participant stated:

'My favourite method is seminars, because it provides experts with information and expertise that are far more important.'

Other communication channels mentioned by participants included mass media, such as television and radio; schools; centres, organizations, and associations; and persons with disabilities themselves. A service provider from Hebron also suggested:

'[w]e could make use of the Friday prayers, schools, radios and even organize summer camps that address the negative attitude and the ill-treatment of the disabled and further spread awareness. It is also important to have consistent awareness programs and meetings.'

Participants value both Facebook and face to face workshops for the same reason: they both provide them an opportunity to interact with others who will be able to answer questions they have about caring for their children with developmental delays and disabilities, and will provide those responses in an atmosphere that is non – judgmental or stigmatising. Support groups also fulfil this function because everyone participating has their own experience to share.

f. Roles for Parents and Parents/caregivers in Addressing Stigma and Discrimination

Many participants agreed that they have a role to play in addressing stigma and discrimination and in ensuring that their children with developmental delays and disabilities are included in social and cultural life. The process of encouraging inclusion of children with developmental delays and disabilities begins with the family, who have the ability to influence the path of the child from birth, depending on their attitudes toward disability. A policy maker from Ramallah explained the process this way:

'The first objective is real and humanitarian in fighting the stigma issue, first the family should accept that the child is a human being and to deal with him in a good way. This person has a problem but it might have a solution, the issue of the stigma might determine the path of the child either a dramatic path or it might save him.'

A participant from Hebron explained the role of a parent/caregiver as follows:

'What matters the most is that the child is included in activities and we have to be smart in choosing a suitable activity for the child. To build the space that he integrates into the most and learns and has fun. This must be initiated by the family and to prepare the child before taking him out. As a mother I can provide the child with the confidence in himself no matter what type of disability he has. What matters is taking him to the right places and if he hears a comment, he would be able to at least defend himself and not be affected after I give him the strength in all aspects of life.'

Beyond these types of caregiving, participants also suggested that parents/caregivers also have a role to play in changing others' minds about how they treat their children. For example, a participant from Khan Younis stated that parents should be:

'providing guidance and teaching the un-disabled [sic] children how to treat their disabled siblings...[and]...raising the awareness of their peers in school in terms of the way they treat their colleagues with disabilities.'

Some parents/caregivers described the ways in which they confronted stigma and discrimination; for example, parents/caregivers in an FGD from Deir Al-Balah stated that they would stand up to mockery:

P1: 'Through confrontation.'

P2: 'Through intimidation. Saying that this word upsets me and upsets the child and that if it was repeated this would not be good. However, if the person is more understanding we can talk to him/her in a more meaningful way.'

P3: 'I want to confront everyone, this might happen again, he might be going to his uncle's house and the same will happen again. If I do not say anything, they will keep on saying the same bad words.'

P4: 'It must be known among the family members that they should always defend the child.'

One participant from the same FGD went on to say that "[i]f you stay silent when your kid is wronged and do not confront who did that, they will keep on doing it." Some participants felt very strongly about the need to stand up to mockery or bullying. One participant from Gaza stated:

'I faced a situation at the end of Ramadan in which our neighbours with a child with disability were making fun of him. I'm the type of person in which persons with disabilities are a red line for me. When I see someone with a disability being mocked, I defend him/her and at the same time I blame his mother. She knows that her child has a special condition so why would you confine him to a certain place or let anyone mock him? I personally advised my children to defend him whenever they see him and to protect him. People like this need special care.'

Other participants were less willing to confront stigma or discrimination; they sometimes felt that it was not worth the trouble that it might cause, such as this participant from Deir Al-Balah:

'For me, my daughter is deaf and if she was subjected to such situation, I would bring her home and would not let her go out to see her aunts again.'

This was echoed by a participant from Hebron, who stated:

'My son wears a hearing headset and cochlear implant and both are very visible. When I take him to events I am always very afraid of what might happen to him if he falls or if other children bother him, so eventually I decide not to go to events, even to weddings and funerals.'

The physical burden of mobility often precludes parents/caregivers from taking their children to social and cultural events; for those children who do not have access to assistive devices and may have lower mobility levels than others, this is a significant challenge that directly affects their ability to confront stigma and discrimination. This fits together with participants' discussion of the need for consistent transportation, but is even more specific. For example, a participant from an FGD in north Gaza (Jabalia) stated:

'We are very glad that our son finally has a wheelchair. It was very difficult for him before because every time he wanted to move we had to carry him. He was constantly in need of help, especially when he wanted to go to the restroom.'

In cases such as these, parents are doubly burdened; first, by the literal weight of carrying their child from place to place, and second by the weight of stigma and discrimination from the community. Parents and parents/caregivers can play a role in confronting stigma and discrimination, but it is much easier when the physical burden of caregiving is lessened by the provision of assistive devices or accommodations. A policy maker from Jericho stated this as follows:

'For families to be more accepting it should find a society that accepts their child and is not dismissive either in the streets or centres or the school or any other place. The existence of acceptance outside the family strengthen their commitment to the child, and enhances their ability to defend the rights of their son and for him to live like any other Palestinian child.'

Acceptance of the child outside the family means, in many cases, the provision of rehabilitative services, assistive devices, environmental accommodations such as ramps and

appropriate traffic control devices, and other accommodations. A community leader from Nablus described one way that the process of making these changes is occurring:

'In An-Najah University we have a special office called "Computer Unit for Persons with Visual Disability" and is managed by a blind person who prints materials for children in schools and in the university using the braille language. What is also new is that recently the banks printed their forms using the braille language so the blind can go to the bank and read the contract and can apply for a loan and complete the financial forms. They now do that not only through hearing, but they sign the braille forms and they now read and understand completely their rights and duties.'

Each accommodation and adjustment to the physical world will have the effect of increasing the opportunity for inclusion of children with developmental delays and disabilities. As indicated previously, small changes can play a significant role in addressing stigma and discrimination, as those children who require accommodation are provided with it, and are therefore present in society and viewed as being valuable enough to accommodate. Part of the role that parents and parents/caregivers will play in the process of increasing the number of accommodations will be through advocacy and collective action, as described in the previous section.

g. Structural and Institutional Issues

Structural and institutional issues refer to the underlying causes of stigma and discrimination; they are often unseen contributors to maintaining a particular status quo or marginalization of certain groups of individuals in a society. Because these are often unspoken, it can be challenging to identify them. There are also risks and benefits to these issues being described by outsiders: in some cases, those outside a particular culture or language group are unable to identify the nature of these issues; on the other hand, they may be more visible to outsiders, who do not generally inhabit the cultural spaces in which these structural and institutional barriers reside. This section, therefore, presents one interpretation of results of the FGDs and KIIs that may identify structural and institutional barriers to the progress of children with developmental delays and disabilities.

The main issue involved in the institutional challenges facing children with developmental delays and disabilities is the overall lack of institutional capacity. Much of this lack of capacity stems from the ongoing occupation and the economic challenges it brings, particularly the ability of the PA to provide funding for Ministerial initiatives to support treatment and rehabilitation services. As indicated in previous sections, there is also a lack of coordination among institutions that leads to duplication of effort and, conversely, a likelihood that many children with developmental delays and disabilities will fall through the cracks of institutional care. This was described by a community leader in Nablus:

'For example, a women's society works with a person with disability and the Red Crescent works with the same case leaving other cases without care. There are cases that are marginalized and do not take their right [have their rights fulfilled] in care.'

Institutions themselves were reported, in some cases, to be driven by a profit motive rather than a service motive. However, given the economic situation in the State of Palestine, perhaps this is not surprising. The lack of Ministerial funding, coupled with a genuine desire to keep an institution operating at some level may lead managers to focus on funding issues as a primary imperative. But the barriers to fulfilment of children's rights to services are significant and commonly perceived among parents/caregivers. A KII participant from Nablus noted:

'I wish that these institutions working with children with disabilities are not for profit and are free of charge. Each child has the right to be treated and they have the right to receive a salary, in addition to receiving education, either through schools or universities. Children with disabilities have the right to receive special aiding devices because they are very expensive and the government should cover these expenses, especially cochlear and cornea implants.'

In Jericho, the situation with institutional capacity was described as one of the main parts of the challenge of providing services for those with disabilities by a KII participant (with the other significant barrier being transportation):

'The problem of disability in Jericho is twofold: the first is the lack of centres providing services for people with disabilities. There are only two institutions, the Red Crescent Society and the Jericho Community Centre. This means lack of services and capacities for developmental delays and disabilities. Also, some of the disabilities are not covered such as professional rehabilitation for autism. The capacities of these institutions cannot cover all the needs for mental and intellectual disabilities. They do not have the capacity or sufficient staff to cover the needs in Jericho.'

Again, these barriers or issues are reflected in the lack of coordination among institutions, as described by a policy maker in Ramallah:

'On the policy level, and in our opinion, there are no connections or networking among the interventions needed for this category, everyone just sits and waits and prays to God that this problem is not at their end, and that it is a problem at the MoH, for example, and if so, he closes the file of the case and turns his back to the child and the family.'

While many of these issues stem from lack of financial capacity within institutions and their funders, such as Ministries, they are also connected to the challenges with maintaining an effective registry and representation at the Ministerial level. In a previous section,

participants from Ramallah described the data base they have created to track service provision to those with disabilities living in the West Bank. However, despite the existence of what could be effective MIS systems, a lack of Ministerial coordination contributes to ineffective use of resources and lack of positive outcomes. The participant from Ramallah who described this situation stated:

'The other issue that I want to talk about - on the country level - is the fact that everything that is cross-sectoral paralyzes the work and impedes it. And this is killing us in the country, when things are distributed...everything as gender, youth and early childhood are scattered. There are at least three Ministries with the biggest budgets, staff and size – MoEHE, MoH, and MoSD - if you go there and see how the projects are implemented, you will find that everyone works on his own.'

The lack of Ministerial coordination is reflected in the lack of institutional coordination at the community/governate level, which affects parents/caregivers by causing them to lose faith in the institutions that are supposed to represent and support them. When this is coupled with a lack of follow up from institutions, organizations, and even parents/caregivers themselves, it means that services are not provided and that any positive outcomes for children with developmental delays and disabilities are not sustained.

The underlying structural challenges that face parents/caregivers and children with developmental delays and disabilities in Palestinian society consist of two components: the first is the impact of gender on the caregiving process and the fact that so much caregiving falls exclusively on mothers and women. This component of the situation is unlikely to change soon, as mothers are generally valued for their roles as parents/caregivers. Fathers do play an important role in providing care for their children, but it was described by participants as advocating, following up with schools, taking their children to the mosque for prayer, and other activities outside the home. While they are supportive, they are not generally involved in caregiving at home. A service provider from Hebron noted:

'The best support system to the child is the mother. From our experience, we see fathers once a year, but mothers, they are always the main support to their children.'

However, some organizations are working to change the role that fathers play in providing care; for example, in Gaza, participants described a training they had done with fathers:

'We also worked with fathers to "activate" their role as caregiver and encourage them to be active participants in the process. We were successful in these attempts, especially with fathers who are unemployed and spend more time at home.'

Nonetheless, the lack of overall support from fathers in the daily function of caregiving places a burden on women in Palestine, who complain of both psychological and physical symptoms that have resulted from the stress of caring for their child or children.

The second component of the issues facing parents/caregivers and children with developmental delays is reflected in customs related to marriage, which, of course, is also related to gender. Most participants mentioned or agreed that consanguineous marriage is a cause of developmental delays and disabilities in children, in both quantitative and qualitative inquiry. Anecdotally, consanguineous marriage is common in Palestine, and research in Gaza has found that the rate of consanguineous marriage is 40% (Sirdah, 2014). Jones et al., (2016) have explored consanguineous marriage as a cause of disability and suggest that efforts for preventing disability should include “investments in pre – marriage genetic testing – using religious leaders to promote increased uptake” (p. 89). Normative expectations regarding confronting stigma and disability were included in the quantitative portion of this research, and the high prevalence of participants in qualitative activities who suggested that consanguineous marriage is also a cause of disabilities suggests that this may be a useful consideration for communication interventions.

Marriage also plays a role in promoting stigmatisation of children with developmental delays and disabilities within families, because siblings of those children are considered at risk of not receiving a marriage proposal. One caregiver from Gaza stated:

‘Having a child with disability can affect the marriage of the girls in the house. If people come over to ask for a girls’ hand in marriage, they tell us not to take him out so they won’t reject the girl.’

A community leader from Nablus noted:

‘The issue here is that they are suffering and are afraid of the shortsighted community. Meaning that we must be brave, but families with a disability case are affected on a social level. It is hard for unmatured people to say that they want their son to be engaged to a sister of a person with disability.’

With these two examples in mind, it is notable that marriage possesses significant importance in Palestine; it influences the situation with regard to disability and yet perpetuates stigmatization of children with developmental delays and disabilities.

While these two cultural components of Palestinian society may be seen as underlying causes of some of the difficulties parents/caregivers face, it is worth mentioning that culture also plays a critical role in ensuring support for parents/caregivers, particularly support from immediate family. Designers of communication programmes should take care to develop

initiatives that promote positive aspects of culture (support, community, accountability, education) and challenge negative aspects (gender bias, outdated marriage practices).

Socially, many participants stated that Palestinian society still suffers from stigmatizing attitudes and behaviours and that they are often unwilling to take their children out of the house for fear of being mocked, shouted at, or discriminated against, as described above. However, several participants also noted that they are seeing shifts in attitudes towards children with developmental delays and disabilities and that people's increased contact with either the children themselves or accommodations which are being made for them has had a positive effect on the likelihood that they are accepted by those around them. Participants in both Gaza and the West Bank gave examples of their children attending prayers, being taken to social events, and going to school. Parents and parents/caregivers were also frequently likely to challenge stigmatization of their children, be it at school or in the street. One community leader from Nablus said:

'I do not agree that there is a negative attitude or ill treatment of children with disabilities. This is very limited and only comes from uneducated people and thank god our society today is educated. I see a lot of empathy in general in the community, and I do not count on negative people who are shortsighted towards the rights of humans.'

Similar to this, a caregiver from Deir Al-Balah stated:

'People started to become more aware of the conditions we face as the number of disability cases has increased. The situation is better now and everyone minds his own business and feels with others. In the past people did not appreciate the human value.'

The changes in people's attitudes toward those with developmental delays and disabilities are a positive sign that change has occurred. However, while it may be true that a large majority of people are basically accepting of children with developmental delays and disabilities, if a person experiences stigma or discrimination at the hands of a single neighbour, teacher, or official, the result is arguably the same as if all people were discriminatory.

[h. Intention to confront stigma and discrimination](#)

Participants' responses regarding their willingness to directly confront stigma and discrimination when it occurs vary. Most people believe that the root causes of discrimination are not only people's attitudes and beliefs, but also related to lack of institutional capacity and government oversight. They are therefore likely to suggest that they will engage in collective action or other advocacy actions as well as directly confront those who mock or abuse their children.

The theoretical framework that has guided the development of this study and the C4D strategy, the TPB, consists of three separate components that lead to behavioural intention: attitudes toward the behaviour, normative expectations regarding the behaviour, and self-efficacy around the behaviour. The quantitative research indicated that the percent of the population with positive attitudes toward the behaviour and positive normative expectations toward the behaviour are greater than 70% and 60%, respectively, for both Gaza and the West Bank, while the percent of the population with positive self-efficacy around the behaviour is considerably lower, particularly in Gaza (37%). These results are supported by the qualitative research in several ways.

First, many participants talked about the rights of children with developmental delays and disabilities to education, inclusion, and equity. The FGD guide for parents/caregivers included a question related to participation of children with developmental delays and disabilities in social and cultural activities. The question was “what would you say to other children or adults who think that children with developmental delays or disabilities should not participate in these activities?” Participants often expressed that all children have rights, including those with disabilities, and the government, institutions, and other citizens have a responsibility to fulfil those rights by providing services, including children in activities, and not discriminating against them. A community leader from Nablus stated:

‘I say to children and grownups that all children and any person have rights and children with disabilities have the right to participate in different activities; that is considered as one of their rights and not given to them.’

When asked about whether children with developmental delays and disabilities have the same rights as other children, another community leader from Nablus, stated:

‘I almost want to contest this question and I feel that this question is strange, because even the parents who hide their children with disability completely believe in the rights of their children. The issue here is that they are suffering and are afraid of the shortsighted community.’

A primary caregiver from Hebron stated:

‘The community, May god forgive them, has a very unusual and unnatural attitude and understanding towards individuals with delays and disabilities. This is very sad, especially when schools refuse to accept our children, regardless of whether the school is equipped to deal with such cases, they do not have the right to refuse them. Our children have the right to education and schools are an obstacle.’

The qualitative results suggest that participants from all groups believe that children with developmental delays and disabilities have rights that are not being fulfilled. The duty

bearers for the fulfilment of these rights include schools, organizations and institutions, government agencies, and other children and adults in their communities. All of these entities were identified as lacking the ability or the will to fulfil the rights of children with developmental delays and disabilities. The understanding that all children have the right to education and participation and social life fits with the quantitative findings about normative expectations regarding confronting stigma and discrimination. It also supports the quantitative finding about attitudes toward confronting stigma and discrimination – participants feel that it is an important part of their duty as parents/caregivers or community members.

A second way in which the qualitative findings support the results of the quantitative inquiry is in the ways participants responded to questions about how they have confronted stigma and discrimination in the past. Although many or most participants believe in the rights of their children, they are much less likely to report that they have directly confronted discrimination when it has occurred, or that they were effectively able to change the situation for their child. Many participants talked fatalistically about the presence of stigma and discrimination, and the difficulty they would have in changing the situation. For example, an extended family member from north Gaza stated “our community will never change their perception of individuals with disabilities. They will always regard them as such.” In an FGD with primary parents/caregivers from Hebron, the facilitator reported that “one of the mothers said that she was bothered by the treatment, but she was helpless to do something about it.”

Although there is fatalism about stigma and discrimination among participants, many also had positive ideas about how to work with others to overcome negative attitudes toward their children. For example, a caregiver from Hebron stated:

‘Firstly, I do not take my son to any place that makes him feel inconvenient and secondly, I would explain to him why I’m not taking him with me. I would tell him that I did not take you not because there is something wrong with you but because the people there are wrongful and negative. I should also sit with people and make them understand the condition of my son so they can be considerate. We also have to confront the family that stigmatizes my son and treats him negatively so I can fix the problem with the family and the community as well.’

It is unfortunate that there are still many situations in which parents/caregivers feel as though their children will be made to feel “inconvenient” or otherwise unwelcome; however, this caregiver’s approach to interacting with the community suggests that some are willing to confront discrimination and feel capable of doing so.

An associated factor related to a caregiver’s ability to promote the inclusion and integration of their child in social and cultural life has to do with their attitudes toward the self-

sufficiency of the child. As suggested by Green (2003) the burden of caring for a child with a developmental delay and/or disability consists not only of the challenges associated with stigma, but also of the objective burden of care, which is an ongoing drain on parents/caregivers' "time, energy, and money" (p. 1362). Thus, the goal of increasing self-sufficiency among children with developmental delays and disabilities can be considered to have two purposes: first, it fulfils the rights of the child to become an independent, autonomous person with agency and second, it may reduce the objective burden of care for mothers who perform most of the routine caregiving tasks.

When participants talked about ways in which they would increase the self-sufficiency of their children, they used terms such as confidence, empowerment, and reliance. For example, a caregiver from Deir Al-Balah stated "I don't want to tell my son what to do but I want to develop him so he can depend on himself." Those who are too careful with their children were also noted by a caregiver from the same FGD, who said "They pamper him and are scared for him too much and if he even gets a sting by a spur, they take him to the hospital." Other participants discussed giving chores to the child so that they begin to feel included in the life of the family, and of equality in the family. One participant from Hebron stated:

'Excessive care can make them feel incomplete! It's nice for them to be integrated with the family and to feel as if they are like other children, nothing less and nothing more.'

Creating self-sufficient children contributes to the reduction of stigma and discrimination because it may free some parents/caregivers from the burdens of routine care. They may then be able to more effectively confront stigma and discrimination when it occurs in their interactions with others.

These findings suggest that while participants value the rights of children with developmental delays and disabilities, they may struggle with the barriers to the fulfilment of those rights. They may be discouraged by the cultural factors that continue to marginalize themselves and their children, and sometimes feel as though there are no effective ways to change the situation. On the other hand, there are those who are working to increase the self – sufficiency of their children as family members and as citizens, and expect through these efforts to promote the inclusion of their children in family and community life. Parents are not always prepared to directly confront stigma and discrimination when it occurs, but they believe that their children have rights which should be fulfilled.

i. Contributions to the C4D Strategy

Participants had many ideas about the ways in which communication activities could play a role in reducing stigma and discrimination and in increasing the ability of their children to take part in social and cultural life. These included both activities and messages, and generally fell into four categories:

1. Providing workshops, seminars, and other consciousness-raising activities for parents/caregivers and members of the public.
2. Conducting advocacy activities to ensure that the rights and duties related to children with developmental delays and disabilities are fulfilled.
3. Engage in research that will support government initiatives to register and provide services to children with developmental delays and disabilities.
4. Facilitate the coordination of support and treatment activities among institutions and organizations so that all children who are entitled to services receive them consistently.

Each of these types of activities will be considered in the C4D strategy that will be developed based on this KAP report, and will be expanded as appropriate based on the contributions from other stakeholders. Activities would be supported by specific messages that could be shared on social media, as described previously, and through workshops and seminars. Messages suggested by participants include:

- *'There is no place for disabilities when there is hope'*
- *'Despite discrimination/prejudice, I march forward'*
- *'I have a right to education/I have a right to play'*
- *'No giving up'*
- *'I have a right to treatment'*
- *'My disability does not cancel out my freedom'*

(primary parents/caregivers, Hebron)

Another set suggested by participants included:

- *'The word disability should be changed to special needs'*
- *'My son is not disabled; you make him disabled'*
- *'[fulfil] the right of education for the disabled child'*
- *'There should be no discrimination in the way the community treats the children with developmental delays and disabilities'*

(primary parents/caregivers, Jericho)

A third set from parents/caregivers included:

- *'Don't be more disabling than the disability itself.'*
- *'We want actions not rhetoric.'*
- *'Everyone might have a disability or have a child with a disability.'*
- *'Disability is not a stigma and persons with disabilities deserve respect.'*

(primary parents/caregivers, Khan Younis)

The messages suggested by participants are important because they suggest positive engagement with communities; they are about fulfilling the rights of the child and confronting stigma, rather than requesting assistance. They confront the “charity – based notions” described by Kaur et al., (2016, p. 2) as being part of the broader narrative about people with disabilities in Palestine. In general, participants value respect from those around them and many noted that the respect they receive when they try to include their children with developmental delays and disabilities in daily life is gratifying. They also perceive that they are respected for their efforts in ways that they were not previously; that the situation regarding stigma and discrimination is changing and that their work on inclusion is contributing to a better situation for those with disabilities.

Further development of messaging around these issues will be completed as part of the C4D strategy.

3. Results of the Participatory Activities

Participatory activities with parents/caregivers of children with developmental delays and disabilities and children with developmental delays and disabilities themselves, aged 10 to 15, were conducted in Gaza and the West Bank. Participatory activities were designed around a set of five participatory activities that were described in detail in the study protocol, and which included the five techniques described in table 17 below.

Table 17: Participatory Techniques Utilised

Method	Description
Outcome Mapping	<i>Outcome Mapping</i> focuses on outcomes, and considers the programme’s contributions to them (Earl et al., 2001).
Cognitive Mapping	Participants discuss their mental map of their physical environment.
Social Network Analysis	Participants identify their connections to other people in their communities.
Participatory Sketching	Participants sketch a response to a question about something in their lives.
Social Cartography	Participants identify social “hotspots” in their environment.

While previous research around disability in Palestine has used participatory activities and tools, the review of literature suggests that this is the first study in which a separate set of participatory activities has been designed and conducted separate from FGDs and KIIs. Step by step instructions for the facilitation of the activities described in table 21 were provided in the study protocol. Facilitators chose as many of the activities as they could and adapted them to the characteristics of the participants. For youth 10 – 15, this sometimes meant that additional icebreaker activities were added and also that accommodations were made for those participants whose abilities were different than others’.

Four separate groups of participants took part in participatory activities that took several hours to complete. The makeup of the group from Gaza is described in table 18.

Table 18: Participants from Gaza

Youth Participants				Adult Participants			
#	Sex	Age	Location	#	Sex	Age	Location
1	Male	15	Rafah city	1	Female	41	Al Sabra
2	Male	15	Rafah city	2	Female	43	Sheikh Rawdan
3	Male	15	Rafah refugee camp	3	Female	37	Al Shaté
4	Male	15	Rafah refugee camp	4	Female	51	Al Shijayeh
5	Male	10	Al-Sultan area	5	Female	27	Not stated
6	Male	10	Al-Sultan area	6	Female	33	Not stated
7	Male	15	Rafah city	7	Female	34	Not stated
8	Female	14	Rafah city	8	Male		Not stated
9	Female	10	Rafah city	9	Male	42	Tal El Hawa
10	Male	12	Rafah city	10	Female	44	Northern Al - Rimal

The participatory groups in the West Bank included 12 adults (3 males and 9 females) and 11 children, 8 males and 3 females. Children ranged in age from 10 – 14 years of age. Additional details of adult participants were not available.

The activities that were conducted with parents and parents/caregivers in both regions included outcome mapping, social network analysis, and the development of a communication campaign to improve the inclusion of children with developmental delays and disabilities. In Gaza, after introductions and icebreaking, the facilitators conducted cognitive mapping, social cartography and participatory sketching. Youth participants in Gaza were also asked to consider communication campaigns and activities that would reach people who could take action for children with developmental delays and disabilities. Unfortunately, the youth group in the West Bank was unable to undertake any of the participatory activities, primarily due to the challenges in the interaction between the participants and the environment, which was not accommodating to the variation in disabilities among participants.

a. Findings from Gaza

The participatory activities in Gaza yielded rich interactions with participants, both adults and youth, about the nature of their environment, the challenges they face in interacting with their environments, and their anticipation for the results of communication programmes that may contribute to changing their situation for the better.

For their part, children and youth who participated in these activities highlighted the challenges they face in making friends, leaving their homes, and interacting with others in their communities. Most participants expressed that they felt lonely; to some extent this is because their disabilities prevent them from walking or biking to school with other children.

In other cases, the child may be prevented from travelling or attending events due to symptoms of their disability. When asked about the most significant issue that they face, the group agreed that the economic situation in Gaza was their most significant issue; the lack of resources leads to poor living conditions and ambiguity about their future. The participants felt that Palestinian government agencies were responsible for the lack of resources that they faced.

The youth had three main campaign messages for leaders of associations, centres, and institutions, as well as government bodies. These were:

- The government must work on enhancing the economic situation of families with children with disabilities.
- Fulfil the right of persons with disabilities to receive free and continuous medicine and medical supplies.
- Provide working opportunities for families with children with disabilities.

The youth also identified support systems; several noted that they have friends and family with whom they interact at school and at home. For example, one stated:

'...the sand on the street makes it harder to walk in the street but the school's environment is suitable and I have friends to play with. I love to play hide and seek with my cousins but running makes me tired. I love going to my grandparents' house because they have wide land that is suitable for playing. The most person that makes me feel comfortable is my mother and father and they push me to participate in social and cultural activities, and if I face a problem, I approach my mother.' (F., a 10 – year old boy with osteoarthritis)

On the other hand, others struggle to find support, looking to extended family.

'the traffic on the way is very tiring and does not suit me and the school is also not suitable but there is an elevator and they let me use it. However, during recess I don't participate and I stay alone in class. I spend most of my free time on the phone or in the mosque and the house is the place I'm comfortable in. My cousins are the people I feel most comfortable with. If I face a problem, I approach my grandparent.' (M., a 15-year old boy with short – leg syndrome).

Some participants prefer to remain indoors:

'I spend my free time on my phone. I do not go out to the streets unless I'm going to school and I don't like to go out. The house is the only place I stay in. I do have friends but we play together in the house and if I face a problem, I approach my father.' (S., a 14-year old girl with a partial hearing disability).

The participants in these activities overall expressed the desire to be able to interact with other children and play outdoors, rather than having to stay inside or be limited in their mobility. This was expressed during the cognitive mapping exercise. For example:

'I tidy up my bed and I tell my parents good morning; I then wash my face and go to school on the bus. My father takes me to the bus and drops me off. I have a friend with disability and I sit in the first chair in the bus and the other kids hold my bag and what catches my attention the most are the swings; I love them a lot. I wish I had a bicycle and if I was good, I would drive it.' (M., a 10-year old boy with Genu Varum)

'I wish I can run with the guys but I can't due to my disability.' (A., a 15-year old boy with short leg syndrome).

'I wish I can play soccer and parkour. I started training but I didn't continue as a result of bad economic condition and my parents' fear.' (F., a 15-year old boy with a visual disability that was exacerbated during the war, and asthma).

These participants rely heavily on their families for support; they frequently noted that they felt most comfortable talking to their parents about problems or issues they faced. They are engaged with issues such as environmental pollution, housing, migration, and travelling; they expressed concern about these issues based not only on their disability but also on the conditions in Gaza, which they described as uncertain.

Parents/caregivers of children with developmental delays and disabilities in Gaza began their sessions with introductions, in which they described their children with developmental delays and/or disabilities. Several participants in this activity are caring for multiple children with disabilities.

The session began with an outcome mapping exercise, in which participants identified desired outcomes from communication interventions, and agreed on some potential ways forward towards these outcomes. These are presented in table 19 below.

Table 19: Outcome Mapping for Communication Interventions in Gaza

Outcome	Target Audiences	Thoughts & Feelings	Actions that Contribute to the Outcome
Resisting the discrimination in education	<ul style="list-style-type: none"> • Sons and daughters • Student colleagues • Teachers • Counsellor 	<ul style="list-style-type: none"> • The feeling for them is very negative and hostile • Violent feelings • Exclusion, marginalization • The teacher avoids the student and doesn't integrate him in the class • The feeling that he is less than the others 	<ul style="list-style-type: none"> • Integrate children with disabilities in all school activities. • Empower the role of psychological counsellors and social workers in schools. • Changing the curriculum and adapting it to people with disabilities. • Adaptation of all educational process elements to the use of disabled people.

		<ul style="list-style-type: none"> • If the child was not clever the teacher hits him and does not integrate him in class 	<ul style="list-style-type: none"> • Continuous communication with parents • Monitor the misuse that happens in the organizations about the funding
Confronting the psychosocial pressures that the people with disabilities and their parents face	<ul style="list-style-type: none"> • Family • Extended family • Local community • Organizations 	<ul style="list-style-type: none"> • The pressure on the child without the disability in terms of requests, so the child with disability feels that he is different than him, the origin is to integrate them • Discrimination between children • Social isolation • The extra or less care of the child with disability • Some parents, unintentionally, feel that the child with disability is a burden, and the additional care makes the child feel that he is a burden, and the other children without disability feel jealous and hostile against the children with disabilities 	<ul style="list-style-type: none"> • Providing job opportunities for the parents and people with disabilities • Psychological support sessions for the children and parents every week or month for example • Increase the entertainment places for the parents and children with disabilities and for example create a free cart for children to enter these places for free. • Focus on success stories and celebrities • Teach parents how to deal with their disabled children Comprehensive adaptation • Make disabled people participate in different aspects and develop their capacities, as in the UNRWA every staff has a card and they can enter for free, why this applies to them only, we have to do it for the disabled as a priority.
Social integration	<ul style="list-style-type: none"> • All organizations that deal with children with disabilities on a daily basis 	<ul style="list-style-type: none"> • Social isolation • Hostility • Violence • Discrimination 	
Supportive environment (financially and morally)	<ul style="list-style-type: none"> • Inside the house • Public roads • Public organizations such as health and education – related organisations 	<ul style="list-style-type: none"> • Jealousy • Underestimating this person • The organizations do not deal with them as educational opportunities • Misuse and employment in disability 	<ul style="list-style-type: none"> • Full adaptation for the use of people with disabilities

The four outcome areas identified by participants included resisting discrimination in education, confronting the psychosocial pressures that parents/caregivers of children with developmental delays and disabilities face, social integration, and creation of a supportive environment. The group identified potential audiences for communication activities that might influence the situation and considered the ways in which people affected by the issue thought and felt about it. Finally, they considered some actions which would contribute to fulfilling the outcome.

Following outcome mapping, participants discussed their social networks and how their networks provided support. Most participants identified at least three individuals in their network who provided strong psychological support, either for a child or for the caregiver;

these individuals also provided financial support and sometimes provided the child with a trip for entertainment. The networks typically consist of close family members, such as siblings of the child, aunts and uncles, and grandparents. Each of these individuals is counted upon by participants for emotional, financial, and physical support in caring for their child or children.

The final activity conducted with these participants was for them to consider communication interventions that would address their most pressing issues. These are presented in table 20.

Table 20: Communication Issues and Ideas, Gaza

#	Issue	The Role of Communication in Addressing the Issue
1	Communication obstacles	<ul style="list-style-type: none"> • Bring specialized people in treating speech
2	No interaction with the school books (children don't do homework)	<ul style="list-style-type: none"> • Provide special tutors • Provide financial and moral incentives to facilitate their completion of homework
3	Help with transportation	<ul style="list-style-type: none"> • Providing wheel chairs
4	The cost of mobile services	<ul style="list-style-type: none"> • Communication between the responsible person and the society and informing him of the missing needs • Reviewing the issue of the cost • To include new legislation to the law of the people of disabilities that is under preparation now, in a way that services are provided for free for people with disabilities.
5	Electricity alternatives	<ul style="list-style-type: none"> • Providing solar energy and put it at the rooms of the person with disability

Following this activity, participants developed a basic communication strategy to address one issue; in this case it was the high cost of services for children with disabilities. Participants identified potential target audiences, communication channels, and messages they would use to convey their ideas.

Target Audiences:

- Societies and organizations who provide services
- International NGOs as UNICEF and UNRWA and those who fund civil society that works in this sector.
- Higher bodies at the organizations (Ministry of Social development, they should be responsible entirely for persons with disabilities)

Communication Channels:

- Personal direct and indirect relations
- Modern and traditional media tools
- Direct interaction with the funding agency
- Civil society
- Complaints box
- Letter to the manager (of an organization/institution)

- A friend inside the organization

Key Messages/Activities Suggested by Participants:

For UNWRA:

- It is the right of people with disabilities to receive the services for free, make a special card for them and get the service for free.

For policy makers:

- Present evidence-based papers on the issue and problem.
- Policy documents, meaning that the laws guarantee that people with disabilities receive services for free.
- Create a Palestinian centre that is part of the PA that provides all services for people with disabilities, and any organization that wants to fund or donate to be through this centre.
- Create a social and health centre specialized for people with disabilities.
- Providing the needs of the people with disabilities on a continuous basis

The findings from the participatory session with adults suggest that parents/caregivers in Gaza are particularly concerned about service provision, which is also reflected in the other qualitative activities. They also identified communication challenges as a significant obstacle that affects their children and for which they would like a solution. The outcome mapping exercise yielded useful ideas about the ways in which people are responding to the presence of discrimination and stigma in their lives, and their perceptions about some of the best ways to resolve the situation to their benefit.

b. Findings from the West Bank

In the West Bank, eleven children ages 10 – 14 took part in the participatory workshop. As indicated previously, this group faced significant challenges in conducting any of the suggested participatory activities, primarily due to the variation in the abilities and skills of the participants. The facilitator of the session started the session by asking the participants to discuss their cognitive maps (described above), which included considering the ways in which they interact with their environments throughout a typical day. Most children discussed their interest in computer/video games and cell phones; however, the results of specific participatory activities were not captured by the facilitator or were not capable of being facilitated due to the variation in abilities among participants. However, children did discuss the ways in which they confronted ill treatment when it occurred and shared their thoughts on what was important and interesting to them via sketches.

Themes that emerged from these activities included the importance of being Palestinian (several drew Palestinian flags); the ability to play, as many drew playgrounds or other spaces for play, and the home. When asked about how they confronted stigma it was typically to seek help from an authority figure who they trusted, such as a principal or

mother, father, or grandparents. One child said that they were “ashamed” to tell anyone that they were being harassed.

For parents/caregivers, the participatory session began with introductions and a description of the children for whom the participants were providing care. The session then moved on to outcome mapping, in which participants first identified the most significant challenges they face in providing care for their children. After proposing several issues, participants agreed on the following key challenges:

- *There are no existing organizations that provide services, and (if they are available) the difficulty in reaching them.*
- *The shortage of psychological counsellors and the psychological debriefing and support programs to children and their parents.*
- *Changing the negative views of families and the community.*

These three challenges were identified by the participants as the focus of their discussion on outcome mapping. However, in this activity, the facilitator focused primarily on the barriers and difficulties that participants face in caring for their child, rather than guiding a discussion on how to use communication to reach a particular outcome and identifying behaviours that could contribute to the outcome. Therefore, the results of this activity are similar to those of the FGDs that were reported earlier, in that participants identified barriers and challenges, such as lack of institutional capacity and acceptance (or lack of) from community members. Following this discussion, the facilitator asked participants which communication activities and/or tools they might use to change the behaviours of community and family members. Participants stated:

P4: ‘I talked with the teachers to make her participate in everything, I also talk to my daughter and support her, and the important thing is to change the views of the surrounding environment as much as possible.’

P7: ‘For example we go to the organizations that help our children and tell them to choose for them suitable activities, and ask that each child is classified based on his disability and give them activities based on that.’

P1: ‘This category should not be neglected because they might have capacities and capabilities and energies.’

P4: ‘The government should create a suitable environment for them in public schools because it’s difficult for us to register them in private schools that are expensive. Despite the shortage, my daughter is in a private school and it’s not suitable for her. The important thing is to make our children strong and not feel that they lack something or feel any deficiency.’

These results are similar to results reported in the qualitative findings section.

The facilitator then moved on to social network analysis and asked participants to identify the relationships between their children and those around them. Key results from this portion of the activity suggest that most of the children who are cared for by these participants are very strongly connected to their families, but do not have strong connections to their surrounding environments. This activity was intended to allow participants to describe their own reference or support networks, rather than those of their children; however, it is useful (although not surprising or novel) to understand that the parents themselves perceive that their children are not strongly connected to the communities around them.

Finally, the facilitator asked participants to work to develop a basic communication intervention that would address a pressing need. Participants agreed that the issue to be considered should be:

The shortage and lack of psychological counsellors and debriefing programs to support the children and their parents and to change the negative view in families and community.

Participants then suggested several approaches to communicating with the public around these issues, mainly focusing on the second part of the issue, that of changing the negative views of families and communities. Approaches to address the situation included:

- To send SMS messages using mobiles to schools, universities and ministries.
- To lead campaigns on Facebook by specialized students in this field.
- Radio announcements.
- Daily radio programs/small posters on the cars' mirrors.
- Large signs and banners as announcements in the streets.

Participants also agreed on three slogans to address the issue of lack of support:

- *I am productive, forget that I am a disabled person.*
- *My ability comes from my passion to the community....do you know who I am?*
- *I love you more ... do you know me?*

Finally, participants brainstormed ideas about the best ways to undertake communication about the issue they identified. They suggested the following:

- Directly knock on the doors of the decision makers (the governor, mayor, the PMO).
- Participate in marches to request our rights and changing the reality of the services provided to children with disabilities.
- Form a committee of the parents and stay in constant contact to meet and follow up with the responsible persons, to press and to achieve at least simple parts of children's rights.

While the results of the participatory activities from the West Bank did not yield the same depth of results as those from Gaza, they did provide insights into the key issues for parents/caregivers and reinforced findings from the FGDs and KIIs.

VII. Media and Communication Practices and Processes

1. Typical Communication Patterns

A key component of an effective C4D strategy is the use of appropriate communication channels. This section provides information on which channels respondents tend to use to find information about caring for their child with a developmental delay or disability. This section provides details from the quantitative inquiry regarding communication; a previous section presented the results of the qualitative inquiry regarding trusted and untrusted sources of information and knowledge.

a. Quantitative Results

Whether or not respondents had ever sought information about caring for their child was the first question in this section, followed by a question about who or how they had secured the information.

Table 21 presents information on whether parents have sought information on caring for their child with a developmental delay or disability.

Table 21: Parents Who Have Sought Information on Caring for Their Child with a Developmental Delay or Disability

Information Seeking*	Gaza	West Bank	Overall
	Percent	Percent	Percent
Yes	47	68	57
No, because I don't want/need information on this topic	10	5	7
No, because I don't know where to get information about this topic	43	27	35

(* $p < .05$)

The differences between Gaza and the West Bank are statistically significant and suggest that those in the West Bank are more likely to seek information about caring for their child with a developmental delay or disability because they know where to do so. There are no significant differences between regions in the sources of information; paediatricians and health centres are the most often cited sources of information about caring for a child with a developmental delay or disability (76% and 64% of respondents mentioned that they had received information from them, respectively). Parents and spouses are also important, but they are less frequently cited than health care professionals (56% and 52%, respectively). Additional sources of information included social media (43%); community institutions (39%); and peers or others who are caring for children with developmental delays and disabilities (49%).

2. Exposure to Media Channels

This section provides information on which channels tend to be preferred or most frequently used by respondents. Again, qualitative results were presented in section IV above, and are not repeated here.

a. Quantitative Results

This section asked respondents to identify the frequency with which they accessed various traditional or mass media channels, as well as the frequency and method they used to access electronic media, such as the Internet and social media platforms. Few respondents report that they read newspapers with any frequency (12%). Compared to newspapers, a greater percentage of respondents report that they listen to the radio at least once a month (45%); there was no difference between regions. Television is the most frequently used form of traditional (mass) media in Gaza and the West Bank, and is significantly more used in the West Bank. More than 90% of respondents watch TV at least once a month in the West Bank, and more than 80% in Gaza do so.

Mobile phones are highly prevalent in both Gaza and the West Bank, although there is a statistically significant difference between the two regions, with 95% of West Bank residents having access to a mobile for both sending and receiving, and only 82% of residents of Gaza having access. Mobile phones are frequently used to send and receive text messages (97% of respondents use them this way) and access the internet and social media (97% of those who access the internet do so through a mobile phone).

Table 22 indicates participants' access and use of the Internet.

Table 22: Access to and Use of the Internet

Access	Gaza	West Bank	Overall
	Percent	Percent	Percent
Yes**	55	79	67
Facebook	91	90	90
Twitter	8	13	11
Instagram	31	34	32
YouTube	72	84	79
News Sites	48	47	47
Government Websites*	41	25	32
INGOs	21	20	20
Local Organizations	24	31	28
Google*	71	89	82
No	45	21	33

(** p ≤ .01; *p ≤ .05)

There is a significant difference between Gaza and the West Bank in terms of access to the Internet. In Gaza, only 55% of respondents reported that they have access to the Internet, while in the West Bank, the percentage with access to the Internet is 79%. While there are some significant differences in terms of platforms (notably Government/Ministry websites and Google) the overall top platform used equally by Internet users in both regions is

Facebook, with 90% using it. Results in terms of access were significantly different between regions. Those in the West Bank report being online much more frequently than those in Gaza; however, in both regions a large majority of people (87%) are online at least once a day, if not more frequently.

The results of the quantitative survey on communication methods and media suggest that online channels, particularly Facebook, are the most widely used by respondents in both regions. While there are some differences between regions that should be considered, particularly the lower percentage of access to the Internet in Gaza, it is reasonable to conclude that online channels, such as Facebook and YouTube, will be effective at reaching wide audiences. This was supported by the qualitative research, which also identified Facebook as a potentially useful communication channel. Several participants mentioned that online platforms for sharing information and experiences would be beneficial to them.

VIII. Implications and Recommendations for C4D Programming

1. Implications for Communication Interventions

Across many study variables, there are statistically significant differences between Gaza and the West Bank, between the theoretical variables and household or individual characteristics, and between the type of disability and other variables. In addition to the three theoretical variables of attitudes, normative expectations, and self-efficacy, parents/caregivers from Gaza are generally less wealthy, more likely to be unemployed, generally have a lower level of education than those in the West Bank, and less likely to be able to secure information about caring for their child with a disability. These factors must all be considered in terms of their impact on the C4D strategy for confronting stigma and discrimination and increasing demand for ECD services. Both quantitative and qualitative results were useful in providing ideas for the development of activities and messages around reducing stigma and discrimination. Recommendations for the C4D strategy follow this implications section.

The three theoretical constructs (attitudes, normative expectations, and self-efficacy) provide useful insights into potential avenues for communication interventions. In C4D interventions, it is reasonable to consider shifting indicators such as these between 6 – 8 percentage points per year. Overall, attitudes toward positive behaviours related to caring for a child with a developmental delay or disability are positive, with 78% of respondents overall having positive attitudes toward rights and autonomy. In Gaza, 68% of respondents had a positive score, while in the West Bank, 89% did. This suggests that a C4D strategy related to changing attitudes on the items in the attitudes subscale described above could yield excellent results in the West Bank, where a single year program could improve the percentage of parents/caregivers with positive attitudes to nearly 100% in a relatively short timeframe. In Gaza, such a shift will take longer, but in one or two years could increase the percentage of people with positive attitudes to more than 75%. The C4D strategy should include indicators on items in the attitudes subscale that are specifically targeted with key messages and activities and that can be reassessed after an implementation period.

Normative expectations are an important component of the theoretical framework, and there was no significant difference between Gaza and the West Bank on the normative expectations subscale. Normative expectations can be addressed through communication interventions, by communicating with people about what the expectations are related to specific behaviours identified in the subscale described above. Doing so would increase the percentage of people who believe that others have expectations about certain pro – disability (or anti-discrimination) behaviours that they should undertake. Again, indicators based on the final normative expectations subscale should be developed, targeted, and assessed after the strategy is implemented.

The self-efficacy subscale was particularly striking in the difference between Gaza and the West Bank, where respondents from Gaza were much less likely to score positively, with only 37% having a positive score on the self-efficacy scale, compared to the West Bank, where the percentage was 63%. The factors that make it less likely for respondents to feel confident in their ability to undertake specific behaviours are connected partially to demographic factors, as indicated above, but also on structural factors in Gaza, such as proximity to risk, the length of the conflict and occupation, the level of unemployment, and the challenges of day – to – day life likely make it more difficult for residents there to think positively about adopting a new behaviour. Messages about self-efficacy can be relatively simple to create and should include incremental behaviours that will contribute to an overall increase in people’s confidence in their ability to adopt a new behaviour, even if the entire behaviour seems daunting or a large change. An additional component of increasing self-efficacy could also include capacity building, in which parents and parents/caregivers of children with developmental delays and disabilities learn practical ways to confront stigma and discrimination or access ECD services.

While there were no statistically significant findings that demonstrated a relationship between the type of disability and inferior treatment from either immediate or extended family, there was a strongly significant difference ($p < .01$) in the type of disability and the likelihood of inferior treatment from the community, with children with autism, learning disorders, or psychosocial disabilities more likely to receive ill treatment from their communities than those with physical or sensory disabilities. To some extent, this reinforces the findings from Kaur et al. (2016) who noted that children injured in protests (resulting in physical disabilities) were more likely to be treated as heroes.

Recommendations for the C4D strategy are also supported by the qualitative activities, which provided insight into several thematic areas resulting from analysis of FGDs and KIIs. The qualitative results suggest that there is widespread belief in the importance of fulfilling the rights of children with developmental delays and disabilities to education and inclusion, but that parents/caregivers may lack the confidence to directly confront episodes of discrimination when they occur. It also seems that most parents/caregivers lack a personal framework within which to build a response to stigma; while some are willing to sit down with others to discuss their perceptions of people with disabilities, very few talked in terms of medical or social models of disability and how these frameworks are useful in promoting the rights of persons with disabilities. It may be useful to address these issues in seminars or workshops, which many participants stated are their preferred source of learning and knowledge regarding caregiving.

An additional finding from the qualitative inquiry suggests that lack of coordination among service providers is severely hampering their ability to provide cohesive services to children with developmental delays and disabilities, and that increased coordination would lead to much better outcomes in terms of screening and follow up. UNICEF and other organizations

therefore have a role to play in building systems, led by Ministerial stakeholders, that will improve the ability of institutions at the community level to coordinate service delivery. The C4D strategy must therefore include advocacy activities and recommendations for building the capacity at both the Ministerial and community level for coordination of service delivery.

a. Use of Traditional (Mass) Media

Generally, traditional media are not particularly widely used in Gaza or the West Bank. There is almost no regular use of newspapers, and only some use of radio (although not daily, generally). Television is more widely used, with around 56% of respondents stating that they watch TV daily. It seems unlikely that a traditional messaging strategy which relies on mass media would provide good ROI.

b. Interpersonal Communication

When asked whether they had sought information about caring for a child with a developmental delay or disability, 57% of respondents responded that they had done so; on the other hand, 35% of respondents said they had not because they did not know where to seek such information.

The preferred communication channels for information about caring for a child with a developmental delay or disability were, in order of percentage of respondents who mentioned them:

- Paediatrician
- Health centres
- Peers who also care for a child(ren) with a developmental delay or disability
- Social media
- The internet, i.e., websites
- Parents, spouse's parents, and a spouse

These results suggest that UNICEF and partners should continue to work with health care professionals to provide information not only about caring for children with disabilities, but also to discuss culturally appropriate ways to confront stigma and discrimination in the community. These health care professionals may be effective in "leading the way" in a movement that will contribute to an increase in anti-discrimination behaviours.

Qualitative results underscored the value of IPC, and participants were more general in their desire for capacity building activities such as workshops or seminars that would allow them to ask questions of specialists and equip them with the tools they need to improve their ability to care for their children or to seek services.

c. Social Media

The most frequently used communication channels in both the West Bank and Gaza are accessed via mobile devices; and the most frequently accessed is Facebook. Residents of the three regions in the West Bank are more frequently accessing the Internet, but there is no significant difference between the two regions in terms of use of Facebook.

The other frequently used platform, and one in which there is a quite significant difference between the West Bank and Gaza, is Google. This suggests that any communication intervention should consider geographically targeted ads on Google; although this isn't something that is typically included in C4D interventions, it may be a useful way to draw people to Facebook content. Combined with interpersonal communication activities, a strong social media presence would provide those caring for children with developmental delays and disabilities the opportunity to share experiences and make up for some of the lack of social support they identified in their communities.

Qualitative results suggest that participants view Facebook as the most accessible and useful internet platform for finding information and for sharing experiences with other parents/caregivers. The C4D strategy should therefore consider the development of a Facebook group or page that would provide a virtual space for interactions among parents/caregivers, service providers, and other stakeholders.

2. Overall Recommendations for C4D and Communication Programming

In general, communication activities in the C4D strategy should revolve around destigmatization, positive caregiving, and seeking or demanding ECD services, supported by social mobilization and advocacy activities that can lead to increased coordination among institutions and service providers. Using concepts from the Theory of Planned Behaviour as the guiding framework as described in this report and with focus on improvements in attitudes, normative expectations, and self-efficacy, the strategy should contribute to increasing parents' and parents/caregivers' intention to perform anti – discrimination behaviours and increase demand for ECD services.

To meet the overall goal of improving the well-being of children with developmental delays and disabilities by reducing stigma and increasing the level of positive practices provided by parents/caregivers and service providers, several new or updated behaviours should be promoted. The updated behaviours are provided in Annex III of this document. The behaviours fall into several categories related to promoting positive outcomes for children with developmental delays and disabilities and are supported and promoted by changes in attitudes, normative expectations, and self-efficacy as they occur. An additional set of indicators related to ECD was proposed by Sood (2016) and will be included in the C4D strategy on ECD.

In general, C4D strategies and interventions tend to be most effective when they:

- are multi-layered, including more than one strategic approach;

- are consistent in message and content across layers;
- are based on existing and new partnerships and alliances:
- are based on clearly identified roles of government partners and stakeholders;
- consider the ways in which government and influencers can play a role;
- capitalize on small successes throughout the project; and,
- include frequent, common messaging.

The inclusion of these general recommendations will guide the development of C4D activities and strategic approaches. Specific recommendations for the C4D strategy include:

1. Design messages at the community level, rather than nationally. The differences between Gaza and the West Bank, and also between governorates and communities, must be reflected in messaging, audiences, and strategic approaches.
2. Communication efforts should focus on building self-efficacy around several key behaviours, including the ability to confront stigma and discrimination, getting referrals, and communicating with service providers of all types.
3. Many parents/caregivers are unaware of where to find information on caring for their children with developmental delays and disabilities. Communication efforts should build their knowledge of the appropriate and effective ways to learn about caregiving techniques.
4. Communities should play an increased role in providing emotional support for those parents/caregivers who provide care for children with developmental delays and disabilities.
5. It is important to make efforts to shift public consciousness around disability from medical to social models. This implies that messaging should begin to question the barriers to inclusion that are inherent to the physical and social environment of Palestine, and move away from a focus on symptoms, diagnoses, and a focus on the “deficits” associated with disability in medical models.
6. Advocacy efforts should primarily focus on building capacity for institutional coordination.
7. Investments in the physical environment will support efforts to include children with developmental delays and disabilities in the social and cultural life of Palestine. These investments will increase the public’s consciousness of the presence of persons and children with disabilities in their communities.
8. Communication and advocacy should use multiple channels, but are most likely to be successful when they are a mix of face-to-face approaches and online support or resources. These channels should be accessible to people with disabilities.
9. Development of C4D materials should build on the participatory activities included in this research. The relationships developed by the research agency AWRAD, UNICEF, and other stakeholders should be maintained through continued involvement in the C4D process.

A further consideration for the C4D strategy should be the foundational idea that children with developmental delays and disabilities should be included in mainstream social and cultural activities, including education, health services, religious activities, and any additional intervention areas that include the opportunity for inclusion.

Communication activities should include the three main strategic approaches: behaviour change communication, which is intended to encourage change among individuals; social and/or community mobilization, which is intended to identify resources and power within communities and mobilize these resources to specific ends; and advocacy, which should be used to influence the policy and legislative environment around the issue.

Table 23 indicates the strategic approaches typically used in C4D strategies and their purpose in the context of this project.

Table 23: Strategic Approaches and Purposes in the C4D Strategy

Behaviour Change Communication	Social and Community Mobilization	Advocacy
Build capacity to confront stigma and discrimination	Identify resources within communities	Build consensus around coordination of service provision
Increase demand for services and the ability to follow-up on initial treatment or provision activities	Encourage support for children with developmental delays and disabilities among community leaders	Build support for funding and financial support
Build capacity and willingness to provide support to parents/caregivers	Mobilize resources and capital that could provide adaptations and accommodations at the community level	Encourage enforcement of the 5% law and the Law Number 4 for 1999
Encourage fathers to engage in caregiving activities		
Build capacity for collective action or advocacy		

The specifics of messages to encourage change in the affective dimension (attitudes, knowledge, beliefs) will be provided in the C4D strategy and further developed in subsequent programme activities. However, the qualitative portion of the research asked participants to provide some ideas on potential messaging around disability, which were presented in the findings section. These suggested messages may serve as the starting point for message development activities in subsequent phases of this project.

3. Potential Audience Groups

The review of literature and secondary sources, together with recommendations from UNICEF SoP and other stakeholders suggest that new behaviours related to children with developmental delays and disabilities should be considered across several dimensions and audience groups. Audience groups may be divided in several ways, but research on children

with developmental delays and disabilities (Jones, et al., 2016) suggests the following audience groups and the potential strategic approach to be used (table 24):

Table 24: Three Strategic Approaches and Audience Groups

Behaviour Change Communication	Social/Community Mobilization	Advocacy
Parents/caregivers (mothers, fathers, guardians)	Service providers within specific communities	Government departments
Children with developmental delays and disabilities themselves (and persons with disabilities)	Community (political) leaders Religious leaders	Institutions and organizations
Extended families (aunts, uncles, siblings, grandparents)		Representative organizations (GUPD, others)
Social support providers (friends, neighbours, community members)		

Specifics of activities and key messages for each audience will be described in the C4D strategy.

IX. Conclusions, Limitations, and Future Research Opportunities

This study is primarily intended to establish baseline measurements for current attitudes and beliefs around parents/caregivers of children with developmental delays and disabilities. By design, the study focuses on the three components of the TPB: Attitudes toward a new behaviour, normative expectations surrounding the behaviour, and self-efficacy around the implementation of the new behaviour. Because there are numerous, multi-faceted interpersonal communication-related behaviours that surround confronting stigma and discrimination, all potential beneficial strategies for these behaviours were not explicitly queried in the quantitative tool. This has been partially addressed in qualitative activities.

1. Limitations

As a multi-stage, random sample, the quantitative activities were intended to provide representivity across the five governates of Gaza and three in the West Bank (Hebron, Nablus, and Jericho). However, in order to attain the required number of respondents, it was sometimes necessary for the research teams to request information from the community or other sources about households with children with disabilities rather than drawing from the sampling frame described in the protocol. However, it is unlikely that the inclusion of households not drawn from the MoSD's list has biased the sample or results.

Gender is a key component of C4D initiatives. While this study considered gender from the perspective of parents/caregivers, the quantitative study did not identify any significant relationships between the gender of the index child and other study variables such as attitudes, normative expectations, or self-efficacy. Reported treatment from immediate and extended family, as well as community, were also not significantly associated with the gender of the index child. Thus, developing specific communication messages for parents/caregivers will need to be considered during the subsequent phase of the project at the community level.

As with all qualitative activities, results from FGDs and KIIs should not be considered representative of a larger population or group of people. Reports of qualitative results are generally considered valid when they are reasonable *prima facie*, when they are supported through triangulation of methods, and when they can be checked or validated by others from the same community. The reporting of qualitative results in section IV, part 2 of this report demonstrate validity across all three of these categories. The analysis of qualitative data quickly reached saturation, which refers to repetition of common themes by multiple respondents. Therefore, while the qualitative data is not representative of a larger population (as is the case for the quantitative data) it does represent common ideas that are held by parents/caregivers of children with developmental delays and disabilities.

One limitation of the qualitative activities was the underrepresentation of male parents/caregivers; while this reflects the reality of caregiving, it would be useful in future research to specifically include men in FGDs that discussed the situation regarding children

with developmental delays and disabilities in Palestine. It should also be noted that the relatively short timeframe between the conduct of qualitative activities and the completion of this report meant that not all FGD and KII recordings were transcribed word-for-word, and instead relied on facilitators' report of what was said. In addition, not all transcriptions had labelled participants, so in some cases it was not possible to track which participant said what in response to questions. These issues likely did not affect the presentation of the findings significantly.

While not a limitation *per se*, this study's focus on the theoretical concepts of the TPB precluded research into other factors. The study provides results related to attitudes, social norms, and self-efficacy, it did not investigate other factors that may be useful in C4D programming. For example, additional research into community influencers and opinion leaders may have provided additional ways forward for the development of messages. However, details of these specific individuals may be found in a subsequent phase of the project.

As always, future research should take into account the findings of this study, and those that have preceded it. Previous studies on disability in Palestine have described the scope and conditions for children with developmental delays and disabilities in the West Bank and Gaza; the findings presented contribute significantly to understanding of attitudes, norms, and self-efficacy surrounding anti-discrimination actions among parents and parents/caregivers, and the statistical results provide a baseline for future evaluation activities. This study also furthered the research surrounding children with developmental delays and disabilities by including them and their parents/caregivers in participatory activities, which furthers efforts to create C4D strategies that fulfil the human rights-based approach to programming. Organizations working on behalf of people with disabilities were also included in the research, and their perspectives on the issues related to institutional capacity and imperatives were useful in the development of a holistic picture around providing treatment and rehabilitation to children with developmental delays and disabilities.

2. Lessons Learned

The main lesson learned from this study concerns the implementation of participatory activities with children and youth with disabilities. A key lesson from the conduct of the participatory inquiry was the need for facilities and activities that would support a multitude of disability profiles. It may assist organizations and facilitators in future implementation of participatory activities with this population to conduct recruitment well ahead of time, so that profiles of participants can be considered and planned for.

An additional lesson learned from the quantitative research would be the inclusion of a specific question related to the current levels of behavioural intention to confront stigma and discrimination. While this finding was, to some extent, provided by the qualitative inquiry, it may be useful to break intention into a specific question category. However, the

findings related to attitudes, normative expectations, and self-efficacy will be more than adequate to inform the C4D strategy.

While the sample covered the various types of communities in the West Bank and Gaza, very small communities where very limited or no lists were available were not included. These excluded communities must be taken into consideration in future studies as they might resemble a varying pattern than neighboring villages, refugee camps and cities. In addition, the survey targeted parents, and not children, due to the close-to-impossible conduct of a complex and long survey questionnaire with the. This is in addition to other ethical issues that might arise when doing research with children (8 years of less). The closest the study came to capturing the views of children and their parents/caregivers is through the participatory activities.

Finally, the social network analysis conducted in FGDs with parents/caregivers yielded useful insights into the perceptions of parents/caregivers regarding their support systems. However, the length of the FGD guide sometimes precluded the ability of facilitators to complete this activity. Future research on social support systems should either reduce the time spent on other questions or specifically plan for adequate time for this activity.

3. Conclusions

This report provides evidence on the ways in which children with developmental delays and disabilities, their parents/caregivers, extended family and community members, policy and decision makers, and service providers perceive stigma and discrimination in their communities. Evidence about commonly used and preferred communication channels is also provided, as well as details on attitudes and knowledge regarding disability, children and women's rights, and support systems for parents/caregivers. The inclusion of participatory activities that were designed to include children and youth with developmental delays and disabilities and their parents/caregivers provided deep insights into the situation of these individuals in their communities and the State of Palestine in general.

The results of the study, together with previous studies, will also be used to design communication activities and key messages for specific audiences in relation to ECD and children with developmental delays and disabilities. This baseline study therefore contributes significantly to understanding the situation of children with developmental delays and disabilities in the State of Palestine, and will facilitate the development of future communication interventions and activities.

X. References

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XI. Annex I: Detailed Sample Distribution

1. West Bank

a. Jericho/Jordan Valley Region

Population distribution by Type of Residence and Sample distribution

Type of Residence	Population Size	Population %	Gross Sample #	Net Sample #
City/town	20,907	41.8%	17	15
Refugee camp	13,344	26.7%	10	9
Village/Bedouin community	15,751	31.5%	13	12
Total	50,002	100%	40 (20+20)	36

Sample Locations (net sample – each locality (ies) represents a type of residence)

Locality	Population Size	Type	Net Sample #
Jericho	20,907	City/town	15
Aqbat Jaber	8,960	Refugee camp	9
Az Zubeidat	1,679	Village/Bedouin community	6
Al A'uja	5,224	Village/Bedouin community	6

b. Nablus Region

Population Distribution by Type of Residence and Sample distribution

Type of Residence	Population Size	Population %	Gross Sample #	Net Sample #
City/town	156,906	40.4%	56	53
Refugee camp	29,528	7.6%	11	10
Village/Bedouin community	201,887	52.0%	73	70
Total	388,321	100%	140	133

Sample Locations (net sample – each locality (ies) represents a type of residence)

Locality	Population Size	Type	Net Sample #
Nablus	156,906	City/town	53
Balata	14,636	Refugee camp	5
Old Askar	6,537	Refugee camp	5
Beita	11,682	Village/Bedouin community	12
A'sira ash Shamliya	8,813	Village/Bedouin community	12
Jamma'in	7,436	Village/Bedouin community	12

Burqa	4,152	Village/Bedouin community	8
Al Badhan	3,171	Village/Bedouin community	8
Deir Sharaf	2,949	Village/Bedouin community	6
Duma	2,674	Village/Bedouin community	6
Odala	1,566	Village/Bedouin community	6

c. Hebron Region

Population distribution by Type of Residence and Sample distribution

Type of Residence	Population Size	Population %	Gross Sample #	Net Sample #
City/town	464,235	65.3%	156	150
Refugee camp	16,582	2.3%	6	6
Village/Bedouin community	230,406	32.4%	78	72
Total	711,223	100%	240	228

Sample locations (net sample – each locality (ies) represents a type of residence)

Locality	Population Size	Type	Net Sample #
Hebron	201,063	City/town	64
Yatta	63,511	City/town	40
Al Thahriyeh	35,924	City/town	26
Halhoul	27,031	City/town	20
Al Aroub	8,941	Refugee camp	6
Beit Um'ar	16,977	Village/Bedouin community	14
Al Shuyukh	12,052	Village/Bedouin community	14
Kharas	9,139	Village/Bedouin community	14
Ar Rihya	5,754	Village/Bedouin community	12
Karma	1,781	Village/Bedouin community	6
Al Buwaira (Aqbeh Injelyih)	1,532	Village/Bedouin community	6
Zeif	1,061	Village/Bedouin community	6

2. Gaza Strip

a. North Gaza

Population distribution by Type of Residence and Sample distribution

Type of Residence	Population Size	Population %	Gross Sample #	Net Sample #
City/town	314,779	85.3%	64	62
Refugee camp	49,462	13.4%	11	10
Village/Bedouin community	4,737	1.3%	6	5*
Total	368,978	100%	81	77

* A minimum of 5 questionnaires is kept for each type of residence to ensure representation of small/Bedouin communities.

Sample locations (net sample – each locality (ies) represents a type of residence)

Locality	Population Size	Type	Net Sample #
Jabalya	172,704	City/town	34
Beit Lahya	89,838	City/town	16
Beit Hanoun	52,237	City/town	11
Jabalya camp	49,462	Refugee camp	10
Um Al-Nnaser	4,737	Village/Bedouin community	5

b. Gaza City

Population distribution by Type of Residence and Sample distribution

Type of Residence	Population Size	Population %	Gross Sample #	Net Sample #
City/town	590,481	90.0%	130	123
Refugee camp	40,734	6.2%	9	9
Village/Bedouin community	21,382	3.8%	5	5*
Total	652,597	100%	144	137

* A minimum of 5 questionnaires is kept for each type of residence to ensure representation of small/Bedouin communities.

Sample locations (net sample – each locality (ies) represents a type of residence)

Locality	Population Size	Type	Net Sample #
Gaza city	590,481	City/town	123
Ash Shati' camp	40,734	Refugee camp	9
Al Mughraga	11,458	Village/Bedouin community	5
Madenat Ezahra	5,338	Village/Bedouin community	
Juhor ad Dik	4,586	Village/Bedouin community	

c. Deir Al Balah

Population distribution by Type of Residence and Sample distribution

Type of Residence	Population Size	Population %	Gross Sample #	Net Sample #
City/town	169,315	62.0%	37	35
Refugee camp	84,913	31.0%	19	18
Village/Bedouin community	18,972	7.0%	5	5*
Total	652,597	100%	61	58

* A minimum of 5 questionnaires is kept for each type of residence to ensure representation of small/Bedouin communities.

Sample Locations (net sample – each locality (ies) represents a type of residence)

Locality	Population Size	Type	Net Sample #
Deir al Balah	75,132	City/town	15
An Nuseirat	54,851	City/town	10
Az Zawayda	23,841	City/town	10
An Nuseirat camp	31,747	Refugee camp	9
Al Burij camp	28,024	Refugee camp	9
Al Maghazi	9,670	Village/Bedouin community	5
Wadi as Salqa	6,715	Village/Bedouin community	
Al Mussadar	2,587	Village/Bedouin community	

d. Khan Yunis

Population Distribution by Type of Residence and Sample distribution

Type of Residence	Population Size	Population %	Gross Sample #	Net Sample #
City/town	302,335	81.6%	67	65
Refugee camp	41,182	11.1%	9	8
Village/Bedouin community	27,121	7.3%	6	6*
Total	370,638	100%	82	78

* A minimum of 5 questionnaires is kept for each type of residence to ensure representation of small/Bedouin communities.

Sample Locations (net sample – each locality (ies) represents a type of residence)

Locality	Population Size	Type	Net Sample #
Khan Yunis	205,125	City/town	48
Bani Shaila	41,439	City/town	9
Al Qarara	29,004	City/town	8
Khan Yunis camp	31,747	Refugee camp	8

Khazaa'	11,388	Village/Bedouin community	6
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e. Rafah

Population distribution by Type of Residence and Sample distribution

Type of Residence	Population size	Population %	Gross Sample #	Net Sample #
City/town	171,899	73.4%	38	36
Refugee camp	36,550	15.6%	8	8
Village/Bedouin community	25,429	10.0%	6	5*
Total	233,878	100%	52	49

* A minimum of 5 questionnaires is kept for each type of residence to ensure representation of small/Bedouin communities.

Sample locations (net sample – each locality (ies) represents a type of residence)

Locality	Population Size	Type	Net Sample #
Rafah	171,899	City/town	36
Rafah camp	36,550	Refugee camp	8
Al Shokat	16,445	Village/Bedouin community	5

XII. Annex II: Analytical categories and concepts

The following set of analytical categories and concepts is intended to establish a common vocabulary for the development of the C4D strategy that will result from this report. This section also includes a description of key C4D approaches to facilitate understanding of terminology used in recommendations for C4D intervention designs.

a. Supply and Demand-Side Determinants

Constraints and bottlenecks to the uptake of a given behaviour or service can stem from “demand-side” determinants such as the lack of knowledge or motivation on the part of a community member, and can also be the result of a “supply-side” factor such as poor service, absence of supplies (e.g. vaccines or water purifiers) or lack of infrastructure (e.g. a health centre). When considering ECD activities, for example, there are three essential components: ECD programmes (supply), ECD professionals (service) and ECD participants (client). When any one of these elements is lacking, it will be difficult to increase the number of parents who utilize ECD services and, correspondingly, the number of children who benefit from them. From a C4D perspective, “generating demand” can be pursued where and when the other two elements of the ECD equation are present. Wisely choosing the site of an intervention, so that demand is generated where services and supplies exist, ensures that communication is not wasted, and does not lead to frustration on the part of community members.

Advocacy is often most useful on the “outer ring” of the ecological model (Fig. 3) at right, for influencing decision makers, policies and legislation at the “enabling environment” level. **Social mobilization** can help trigger or inspire *community-level action* that is essential when problems are of a communal nature, such as discrimination against children with developmental delays and disabilities, and seeking ECD services, where individual decisions to discriminate against children with developmental delays or disabilities, or the decision to keep a child at home during the first five years of life can have negative consequences for neighbours and the larger community, particularly in the long term.



SOURCE: Adapted from McKee, N. Social Mobilization and Social Marketing in Developing Communities (1992)

Figure 3: Strategic Approaches in C4D

Behaviour change communication (BCC) aims to promote change at the individual level, with community members (parents, for example) and/or service providers (paediatricians, or other health clinic staff for example). BCC works best when individuals can fully control their own actions, as with the decision to quit smoking, the act of boiling unclean drinking water, or providing respectful service to health clinic clients. When behaviours to be

addressed, or actions to be promoted, are related to deeply-entrenched social norms, longer-format C4D interventions are generally more effective, especially when they generate dialogue that can gradually “chip away” at tightly held beliefs (before a norm can change, one has to be able to at least talk about it, which isn’t the case for some norms related to “taboo” behaviours such as consanguineous marriage in some countries). The difference between individual decisions/behaviours and social norms is outlined in the section that follows.

b. Individual Decisions/Behaviours and Social Norms

When considering how to promote a given behaviour, it is important to determine whether the behaviour, action or decision to be promoted is within the control of the individual, or whether individuals perceive they have less autonomy, because the action or behaviour is highly influenced by local social norms. We define social norms as a system that “specifies what is acceptable and what is not in a society or group...often meant to represent a solution to the problem of attaining and maintaining social order.”⁵ A social norm is likely in play if a community member asks themselves, with concern: “What will others in the community think if I act in this way, or make this decision?” If I choose to stop smoking (individual decision) I may not face a social consequence but if I decide to take my child with a developmental delay or disability to a social/cultural event (social norm), there may be some judgement on our family.” The difference between an individual decision and a social norm can have implications for C4D intervention designs. A deeply entrenched social norm may necessitate longer-duration communication formats, such as a multi-year radio serial drama, to generate the level of dialogue that can help chip away at norms over time. The promotion of a one-time behaviour such as birth registration, on the other hand, might be addressed through short-duration information-only approaches, via leaflets or SMS blasts. Knowing whether a C4D intervention is meant to address a behaviour or a norm can help avoid the waste of time and money that can occur when there is a mismatch between problem and approach.

c. Direct and Indirect Communication Impact

Just as a deeply entrenched social norm will be more difficult to influence than an individually-controlled behaviour, some practices related to ECD are impossible to address with communication alone, i.e., without additional material resources. For example, a communication intervention promoting the use of ECD centres will not be effective if people are too poor to afford fees or educational materials. The promotion of school enrolment and retention requires that a school be open, geographically accessible, and with fees local parents can afford. Communication can have direct impact when additional resources are not required for a specific practice to be performed successfully. Exclusive breast feeding, biology permitting, is a practice most mothers can control without additional resources. Parents do not need material resources to avoid disciplining their children with violence;

⁵ Stanford Encyclopedia of Philosophy, [Social Norms, Section 1: Introduction](#)

communication has the potential to have an impact, even if violence against children is an accepted social norm (it just may take longer when a given practice is an accepted norm).

d. Frequency of Action

An additional factor that can affect the potential influence of communication is the frequency and/or regularity of action that is being promoted. An EFP which must be done once (enrol a child in school) is different, from a communication perspective, from one that needs to be done repeatedly or daily. A one-time action might be promoted through an “event-based” activity, such as an “enrolment festival”, whereas something that needs to be done *daily* might require a visual prompt (“wash hands!” sticker) or repeated radio announcements and catchy phrases. With repeated practices, such as hand-washing, communication would aim to promote habits and new, positive social norms.

XIII. Annex III: Updated Behaviours

Topics	Indicators
Rights of Children with Developmental Delays and Disabilities	
Actions	[Public] Confront stigmatizing behaviours appropriately when they occur
	[Parents/Caregivers] Have a plan for how to address stigmatizing behaviour
Interactions with Children with Developmental Delays and Disabilities	
Actions	[Parents/Caregivers] Allow children with developmental delays and disabilities to solve their own problems
	[Public] Show respect for children with developmental delays and disabilities
	[Public] Avoid consanguineous marriage
	[Public] Seek genetic testing if married consanguineously
Gender – Related Issues	
Actions	[Fathers] Resist marrying daughters (both with and without developmental delays and disabilities) before age 18
	[Women] Seek legal protection from GBV
Support for Parents/caregivers	
Actions	[Extended Family] Support parents/caregivers with messages of empathy, encouragement, and validation
	[Neighbours, Community] Support parents/caregivers with messages of empathy, encouragement, and validation
Support for Families	
Action	[Community, Extended Family] Support relatives and neighbours who care for children with developmental delays and disabilities with messages of empathy, encouragement, and validation
Health and Rehabilitation	
Actions	[Parents/Caregivers] Seek health/rehabilitation services
	[Parents/Caregivers] Seek early detection of developmental delays and intervention services
	[Parents/Caregivers] Seek routine medical care when necessary
	[Parents/Caregivers] Seek emergency medical care when necessary
	[Service Providers] Provide parents/caregivers with positive steps or encouragement about their child's future during a diagnosis of a developmental delay and/or disability
	[Service Providers] Provide parents/caregivers with appropriate referrals upon diagnoses or consultations
	[Lawmakers] Believe that the built environment is a barrier to participation rather than the disability itself

XIV. Annex IV: Ethical Approval from the Palestinian Health Research Council Helsinki Committee



المجلس الفلسطيني للبحوث الصحي Palestinian Health Research Council

تعزيز النظام الصحي الفلسطيني من خلال مأسسة استخدام المعلومات البحثية في صنع القرار

Developing the Palestinian health system through institutionalizing the use of information in decision making

Helsinki Committee For Ethical Approval

Date: 2019/02/04

Number: PHRC/HC/485/19

Name: Nader Said

الاسم:

We would like to inform you that the committee had discussed the proposal of your study about:

نفيدكم علماً بأن اللجنة قد ناقشت مقترح دراستكم حول:

Baseline Knowledge Attitudes and Practice (KAP) Study (with caregivers for children with developmental delays and disabilities in Palestine).

The committee has decided to approve the above mentioned research. Approval number PHRC/HC/485/19 in its meeting on 2019/02/04

و قد قررت الموافقة على البحث المذكور عليه بالرقم والتاريخ المذكوران عليه

Signature

Member

Member

Chairman

Genral Conditions:-

1. Valid for 2 years from the date of approval
2. It is necessary to notify the committee of any change in the approved study protocol.
3. The committee appreciates receiving a copy of your final research when completed.

Specific Conditions:-

E-Mail: pal.phrc@gmail.com

Gaza - Palestine

غزة - فلسطين
شارع النصر - مفترق العيون

XV. Annex V: Report on Pilot Study



24 March 2019

Baseline Knowledge Attitudes and Practice (KAP) Study, Participate in Development of Communication for Development (C4D) Strategy

Results of the Pilot Test of the Questionnaire

1. Introduction

AWRAD carried out (on March 20-21, 2019) the pilot test in the following locations and with the following care givers and disabilities:

Locality	Governorate	#	Caregiver	Type of disability
Al Samou'	Hebron (south)	4	Mother Mother (father present but not interested) Mother (with support from father) Aunt	Physical Intellectual/learning/memory (2) Visual
Balata refugee camp	Nablus	4	Mother (2) Sister Brother	Physical (2) Down syndrome (1) Intellectual/learning (1)
Jericho and Al Ouja	Jericho	4	Mother (2) Sister Father	Physical Visual Intellectual/learning Autism
Khan Younis Al Nuseirat camp Gaza city Jabalya camp	Gaza	8 (2 each)	Mother (5) Father (2) Sister (1)	Physical disability (2) Developmental delay - and Intellectual/learning, memory (4) ⁶ Down syndrome (1) Multiple - hearing and Intellectual/learning (1)

As expected, the majority of parents/caregivers were women (mothers mostly, sister, aunt). In some cases men (father, brother) were also involved. The small sample reflects the various disabilities (including mention of developmental delays which is viewed by most as

⁶ As labeled by the caregiver.

learning difficulty; psychological and emotional; inability of child to cope with same-age mates in their progression).

2. Overall reaction to study

The team reports great interest in the study among families. They reacted positively to the study. Many reiterated their pleasure that someone is interested in the conditions that they are going through. Most reported no one else had asked them about their child and their conditions resulting from having a child with disability/developmental delay. They were hoping that this would result in a positive change in the surrounding environment and how their child is treated; as well they hoped that the study would result in reliable services for them and their children.

3. The sample

As expected, the lists provided from the Ministry of Social Development (MoSD) were highly reliable in the West Bank, but not of much use in Gaza. The pilot cases in the West Bank were selected and approached based on the MoSD lists. In Gaza, the research team reported that they had to resort to community-based organizations and expert informants who work in the field of study to find cases for families with children with disability/developmental delays. To them, these organizations were very helpful, in addition a snow ball method as parents of CWD are familiar with other families who have the same conditions. In general, finding families with CWD was not as challenging as originally envisioned.

4. Knowledge of the terminology and issues

In general, the field team reported that parents are well-versed in the terms used and the issues raised in the questionnaire. This also was contingent on the level of education and interest among the parents (not all of them were of the same level). Very few terms (such as developmental delay, C4D, stigma) must be unified. AWRAD will draft the definitions based on the research protocol and UNICEF's training presentation and provide to the field team to make sure that they use them in case of need.

5. Sensitivity and emotional responses

In general, parents are comfortable in answering the questions as they were looking for someone to talk to about the any issues they face and are addressed in the questionnaire. Most families (with boys or girls) did not feel ashamed about having CWD. Many cited their acceptance of what God has given them (*it is His will and we accept it*). In a couple of case, mothers were emotional and needed comforting from the researcher as they talked about the conditions of their children and their own conditions as a family. AWRAD's field researchers have carried out many studies that involve emotional responses and their experience will be an added asset to the study. However, further emphasis on the need to address emotional responses will be provided in the training. The teams will also be provided with a list of institutions that provide psycho-social counselling in this field in the respective areas.

6. The questions

The vast majority of the questions are clear and any un-clarity stems from some of the Arabic phrasing. This will be rectified immediately by the AWRAD team based on the field team comments. In few cases, language use/questions and options were somewhat questioned:

As discussed in previous occasions, the questions on (treated differently) was contested; respondents wanted to know if (differently) mean positive or negative. The field team recommended that the questions/choices be changed to accommodate that.

The question (if the child lives with both parents, one parent) was sensitive and caused a bit of (bad taste) in the case of the families that were interviewed (as they all live in two-parent households). AWRAD does not recommend changing the question, but the field researchers will alerted to this sensitivity, and trained to ask the question in a more sensitive way such as who the child lives with?), and get their answer accordingly.

The term (stigma) in Arabic is very strong (Wasma الوصمة). Some parents did not like the use of the term in Arabic. We think that we should use in Arabic (negative views النظرة السلبية or discriminatory attitudes المواقف السلبية). This will not change the meaning of the question, but will be more culturally specific.

In the case of the following question:

According to your knowledge, what are some of the causes of disabilities in children?

- Illness or disease
- Abuse/violence
- Congenital, hereditary or birth defects
- The occupation and conflict
- Accident or Injury
- Other, specify _____
- I don't know

Three parents listed (lack of oxygen during birth) as the cause; we could add that as an option.

7. Duration of interview

The interviews took from 40 minutes to 75 minutes depending on the education/level of awareness of the parents. While the questionnaire was very long based on the parents' responses, they did not seem to mind the time spent on something that they consider as very important (the study and its potential benefits).

8. Additional comments and points

- Most of the mothers/women seemed very strong and resilient. They have much experience and are potential valued resources for any future interventions. While not all present fathers were interested, so were very interested and involved.
- The interviews were an opportunity to screen and select future participants in the FGDs and the participatory activities. When asked, many of the parents expressed willingness and desire to participate. This will help in the recruitment of participants in the future activities as our researchers are keeping log of parents who expressed interest.
- Many parents demanded better services and higher levels of participation for their children and themselves in all aspects of community life. There was also mention of the need for parents' support groups in each community.
- It was very difficult for parents to cite the names of organizations that provide services to their children or to families with CWD.
- There was no need to make any call backs (or appointments) as all the main caregiver was present; and families responded positively and were willing to give the time to be interviewed.
- In half of the cases, the team made phone calls prior to the visit while in the other half they did not. This did not make a difference in response. In both cases, parents were hospitable and receptive.
- The skips were logical.

XVI. Annex VI: FGDs and KIIs Conducted

Table 25: FGDs Conducted - Gaza

Governate/Location	Target Group	Total Number of Participants	Number of Females	Number of Males
Gaza City	Primary parents/caregivers and community members	14	14	-
Gaza City	Extended family and community members	21	14	7
Khan Younis (Khuza'a- border area)	Extended family and community members from confrontation border areas)	16	16	-
Khan Younis	Primary parents/caregivers (parents)	11	9	2
Deir el-Balah	Primary parents/caregivers (parents)	18	14	4
North Gaza	Extended family and community members	12	6	6
North Gaza	Primary parents/caregivers (parents)	13	13	-
Overall/central	DPOs	8	3	5
Overall/central	Social workers and service provider	11	9	2
Total Number of Participants		124	98	26

Table 26: FGDs Conducted – West Bank

Governate/Location	Target Group	Total Number of Participants	Number of Females	Number of Males
Hebron Region	DPOs and social workers	22	11	11
Hebron City	Extended family and community members	13	11	2
Hebron (Yatta)	Primary parents/caregivers	8	8	-
Jericho & Jordan Valley	Extended family and community members	8	2	6
Jericho & Jordan Valley	Primary parents/caregivers	10	7	3
Nablus (Beita and surrounding villages east of Nablus)	Extended family and community members	10	6	4
Nablus City	Primary parents/caregivers	8	7	1
Nablus Region	Social workers and service providers	12	9	3
Total Number of Participants		91	61	30

Table 27: KIIs Conducted - Gaza

Location	Organization	Designation
Gaza City	People with A Disability Association	Community Leader/Service Provider
Gaza City	Atfaluna Society for Deaf Children	Policy Influencer/Service Provider
Gaza City	The Association for the Training and Rehabilitation of Persons with Disabilities	Service Provider
Khan Younis	Palestinian Red Crescent Society	Service Provider/Influencer
North Gaza	Mayor's Office in Jabalia	Community Leader
Gaza (central)	YMCA - Gaza	Community Leader/Service provider
Gaza (central)	MoSD	Decision/ Policy maker
Gaza (central)	1) General Union of People with Disabilities 2) Knight Club of Palestinian for Women with Disabilities	Policy/Decision Maker
Gaza (central)	Ministry of Health	Policy/Decision Maker
Gaza (central)	Ministry of Education and Higher Education	Service Provider
Rafah	National United Association	Community Leader
Rafah	Alasdiqaa Association for People of Special Needs	Community Leader/Service provider

Table 28: KIIs Conducted - West Bank

Location	Organization	Designation
Hebron	Palestinian Children's Relief Fund	Service Provider
Hebron	Yatta Community Centre	Service Provider
Hebron	General Union of People with Disabilities	Service Provider
Jericho	Jericho Municipal Community Centre	Service Provider
Jericho	UNWRA/Aqbat Jabr Camp	Service Provider
Nablus	YMCA - Salfeit	Service Provider
Ramallah	Palestinian Medical Relief Society	Service Provider
Nablus	Community Service and Continuing Education Centre – An – Najah National University	Community Leader
Jericho	MoSD Regional Directorate	Decision/Policy Maker

Nablus	Directorate of Social Development	Decision/Policy Maker
Ramallah	Ministry of Social Development	Decision/Policy Maker
Ramallah	Ministry of Education	Decision/Policy Maker

XVII. Annex VII: Original Terms of Reference

UNICEF State of Palestine TERMS OF REFERENCE FOR INDIVIDUAL CONSULTANTS AND CONTRACTORS

International Consultant for leading the baseline Knowledge Attitudes and Practice (KAP) study, and development of communication for development (C4D) Strategy Lead a baseline KAP study on the societal factors influencing nurturing care and positive parenting practices, and for families to demand services for children with developmental delays and disabilities, and engage the national research institute or academia in continuing research on KAP and development of the C4D strategy with theory of change to reduce stigma and discrimination towards children with disabilities.

Homebased with two travels to Country Office
Chief, Health and Nutrition, UNICEF SOP
147 working days over the period from 20 August 2018- 20 March 2019 20 August 2018 (revised to September, 2019)

11. PART ONE - External

1. Background

Children who do not receive adequate health, nutrition, early stimulation, learning opportunities, care and protection, all identified as elements of 'nurturing care', tend to have lowered cognitive, language and psychosocial outcomes as well as executive functioning, which translates to lowered academic achievement in primary school and, ultimately, dropping out of school.

It is estimated that 11 to 17 per cent of children are at risk of or have disabilities. At the present time, reliable data regarding the incidence of children with developmental delays are not available. It is known that any such children are "hidden from view" and some are only identified when they enter primary school. Others are simply kept at home without any developmental services.

Some disabilities and developmental delays among children result from consanguine and early marriages. In 2011, the National Survey on People Living with Disabilities (PWD) found that approximately 2.7 per cent (113,000: 75,000 in the West Bank and 38,000 in Gaza) of the population have a disability. These are all low proportions by international norms, but are based on a restricted 'narrow' definition of disability: 'a person with disability suffers from a lot of difficulties or cannot at all' perform a function/action. Using a wider definition including 'some difficulty' the proportion increased to 6.9 per cent. The most common forms of childhood disability were related to speech (24 per cent) and mobility (19 per cent). The main causes of childhood disability amongst children were found to be congenital (30 per cent), illness (24 per cent), birth- injury related (15 per cent) or hereditary reasons (12 per cent). Less common causes are accidents (6 per cent), physical or psychological abuse (1.4 per cent) or post-traumatic stress (0.4 per cent).

To look into the issue of disability in SoP in more details, UNICEF, commissioned a study on the needs and perspectives of children living with disabilities in the State of Palestine (Every child counts: Understanding the Needs and Perspectives of Children living with Disabilities in the State of Palestine". The analysis found that 42 per cent of children living with disabilities had multiple disabilities, and that among households of children with a disability, 41 per cent had at least one other person living with a disability. There were high levels of poverty among families of children living with a disability; almost four in ten households had monthly incomes that were far below the threshold of extreme poverty, and more than half of households in the Gaza Strip. The study also revealed that children living with disabilities and their parents/caregivers experienced significant barriers in accessing basic services: 37.6 per cent of children living with disabilities

1 Ibid. Also see Pia R. Britto, et al., 'Nurturing Care: Promoting early childhood development', The Lancet, vol. 389, no. 10064, January 2017, pp. 91-102. <http://www.sciencedirect.com/science/article/pii/S0140673616313903>

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are out of school and less than 44.7 per cent are enrolled in regular education (17 per cent are enrolled in special education and less than 1 per cent in vocational education).

The prevalence of social stigma related to disability remains high, and more than one-third of children surveyed said they avoided participating in community life because of the discriminatory community attitudes. Some families struggled to accept that their child has a disability while others have not been able to obtain an accurate diagnosis or intervention. Almost half of families surveyed were unaware that they were eligible for community-based rehabilitation. Girls with disability, sisters of children with disabilities and mothers of children with disabilities often face gender-specific vulnerabilities. Adolescent girls with disabilities are especially unlikely to attend school or be allowed to socialize. Those same girls-and their mothers-are at high risk of intra-familial violence.

Communication for Development is an essential cross-cutting strategy for UNICEF as the majority of the key development results to which UNICEF contributes are dependent on the kinds of behavioral and social changes which C4D promotes in terms of impact, scale and sustainability.

Through use of a comprehensive communication for development approach (C4D) designed based on KAP data, UNICEF plans to collaborate with partners to ensure positive change in social attitudes and practices that harm girls and boys, especially where these render particular groups of families with children with developmental delays and disabilities.

An information baseline on prevalence, root causes and drivers of stigma and discriminatory attitudes towards disability in the society as well as the level of societal factors influencing on nurturing care, positive parenting among parents, practitioners, and demand for services for children with developmental delays and disabilities will enable future programming and monitoring at outcome level as well. Generation of baseline information through KAP surveys and focus groups with the targeted populations, combined with mapping and synthesis of existing information, will inform development and rollout of the C4D strategy in ECD.

The overall objectives of the baseline KAP survey are:

- o Provide an understanding of societal factors influencing nurturing care and positive parenting practices and for families to demand services for children with developmental delays and disabilities,
- o Provide evidence for developing a communication for development strategy to reduce stigma and discriminatory attitudes towards disability and to provide a supportive environment for positive parenting practices and for families to demand services specially for children with developmental delays and disabilities,

Survey will be designed to determine the following:

- Level of awareness among key parents/caregivers and service providers on importance of nurturing care, positive parenting and ECD and ECI services for children below the age of 8 with focus on children with developmental delays and disabilities
- The attitude and feelings of the parents/caregivers and service providers towards these issues.
- The practice or ways in which the parents/caregivers and service providers demonstrate their knowledge and attitudes through their actions and behaviors
- Barriers to and drivers of improving good practices and behaviors

Proposed Research Questions

- Who are the influencers of the behaviours of ECD practitioners, health workers, social workers? Reference networks are expected to be defined.
- What are the social and cultural norms that influence the behaviours of ECD practitioners, health workers, social workers with regard to children 0-6, particularly 0-3?
- What are the current levels of knowledge, attitudes and beliefs of parents/caregivers on nurturing care and positive early stimulation and their benefits?
- What are the social, cultural and gender norms that influence the behaviour of parents/caregivers, particularly fathers, as well as ECD practitioners with regard to children with disabilities 0-6? Similarly, to above, the main defining elements of these norms should be characterized.
- Are there any interventions for children 0-6 that parents/caregivers are aware of? If so what do, they think are their benefits and how can they be improved? Have they or anyone stimulated family and peer dialogue on care and development of children 0-6? Do those parents/caregivers who have participated in training/capacity building sessions on caring for young children feel more confident and capable to engage in caregiving and interaction with young children? Are they able to practice them? If not what are the barriers that prevent them from doing so? Does stress/fatigue play a role?
- Who are the influencers of the main child-rearing behaviours / categories of behaviours of parents/caregivers of children 0-8 at the family and community level? What are ways in which they influence the caring and nurturing behaviours of parents/caregivers towards their children? Who are the main trusted sources of advice? Whose perceptions of their actions do parents care about? This should

lead to defining the reference networks for parents/caregivers, broken down by practices / categories of practices if needed.

- How do people in the community perceive / would qualify a parent practicing certain behaviours? E.g. a father bathing a child, a father slapping a misbehaving kid in public, etc.? How do the religious beliefs influence the behaviours? Which practices are justified by parents on religious grounds?
- What is the role of gender, social and cultural norms which act as barriers to the greater involvement and engagement of fathers in nurturing care and stimulation of their children? Do parents/caregivers expect fathers to be involved in caregiving of young children? Why/why not? Who are the people in the community that enforce these norms and are there social sanctions for people who don't follow them? What are these?
- What are the decision-making patterns within the family when it comes to child rearing? How are spousal and family communication around these topics? What are the disagreement/ conflict solving habits?

2. Purpose of the Assignment

- Conducting a baseline KAP study
- Developing C4D strategy and implementation plan including the Theory of Change to reduce stigma and discrimination towards children with disabilities

International consultant is sought to develop a KAP survey methodology, analyze data collected by the academia or national research institution, and prepare findings report and recommendations of the key elements. The second step would be development of the C4D strategy to reduce stigma and discrimination towards children with disabilities based on the KAP findings and recommendations.

International consultant is encouraged to engage with the academia or national research institution which will be contracted by UNICEF for this assignment, and to build and strengthen their capacity on continued research, but also to forge alliances for repeated or follow on studies and implementation of the C4D strategy.

The assignment will have several distinct phases for which international individual consultant and national research institute or academia are being sought. The international consultant will be responsible for strengthening capacities of the national research institute or academia on the KAP research methodology through mentoring and supervising from a distance particularly during the data collection and entering.

The table below describes types of expected involvement of the international consultant in various phases during the assignment:

Major phases	Lead Responsibility	Inputs/Collaboration
1.Desk review of existing information sources to understand gaps/identify key domains and develop the external KAP survey plan	National research institute or academia (<i>under separate contract with UNICEF</i>)	International consultant
2.Develop an KAP survey design and protocol, the research instruments and sampling framework, interview and focus group questions and analysis plan, and outline of the final KAP report, based on the survey questions	International consultant	National research institute or academia
3.Conduct initial workshop with UNICEF staff and national research institute or academia, as well as relevant partners, to discuss and agree on the KAP methodologies	National research institute or academia	International Consultant
4. KAP field work, data collection and entering; (Contracted national research company or academia will be contracted)	National research institute or academia	International consultant
5. Analyze the data collected	International consultant	National research institute or academia
6. Presentation to National ECD committee on preliminary findings.	National research institute or academia	International consultant
7. Develop draft survey report	International consultant	National research institute or academia
8. Prepare for an end-of-KAP survey validation workshop with stakeholders to present the preliminary findings and recommendation in order to obtain feedback and verification of overall findings.	International consultant	National research institute or academia
9. Finalize the survey report including recommendations; Submit it to UNICEF on time	International consultant	National research institute or academia
10.Draft C4D strategy with Theory of Change and verify document in consultation with national research institute or academia and UNICEF	International consultant	National research institute or academia
11. Finalize the C4D strategy with Theory of Change and submit it to UNICEF on time	International consultant	National research institute or academia
12.Prepare presentation and conduct an advocacy event with key policy makers UNICEF and relevant national stakeholders	International consultant	National research institute or academia
13. Publish paper on the evaluation results in academic publications	International consultant	National research institute or academia

3. Major Tasks to be accomplished:

- Engage with the national research institute or academia and establish working arrangement/communication
- Lead the KAP survey and provide technical inputs into design the external KAP survey plan including the following, among others
 - *Survey timelines and activities*
 - *Methodology including a matrix with a row for each question and columns for criteria, how judgement will be formed and methodology per question.*

- *Data collection instruments (qualitative and quantitative)*
 - *Data entering programme*
 - *Ethical protocols aligned with principles outlined in ethical issues below Interview and focus group plan and protocol*
 - *Plans for data analysis (quantitative and qualitative), report preparation and dissemination*
- Mentoring and supervision to the national research institute or academia from distance
 - Analyze data collected through national research institute or academia, prepare draft report and seek review from UNICEF
 - Write final report that includes baseline data and recommendations for the C4D strategy

The report shall be structured as per the UNICEF Report Standards:

1. Executive summary
 2. Object of evaluation
 3. Evaluation purpose, objectives and scope
 4. Evaluation methodology
 5. Findings
 6. Conclusions and lessons learned
 7. Recommendations
- Prepare a short powerpoint presentation of results and present to UNICEF and relevant national stakeholders
 - Develop draft C4D strategy with Theory of Change following the KAP baseline data and recommendations
 - Present the C4D strategy with Theory of Change to UNICEF and relevant national stakeholders,
 - Finalize the C4D strategy based on comments and feedback received from UNICEF and partners
 - Published paper on the KAP survey results in academic publications

The incumbent's duties and timeframe are outlined below and are to be undertaken in line with UNICEF rules and regulations.

Specific tasks include:

The contractor will be engaged to perform tasks and duties on full time basis.

The contractor will not be based at the UNICEF office.

4. Deliverables and timeline(s) for submission:

Deliverables:

1. The external KAP survey plan
 - *Survey timelines and activities*
 - *Methodology including a matrix with a row for each question and columns for criteria, how judgement will be formed and methodology per question.*
 - *Data collection instruments (qualitative and quantitative)*
 - *Data entering programme*
 - *Ethical protocols aligned with principles outlined in ethical issues below Interview and focus group plan and protocol*
 - *Plans for data analysis (quantitative and qualitative), report preparation and dissemination*
2. Technical assistance to the national research institute and academia during the data collection
3. **Draft report** integrating all data collected
4. **Final report** that captures data collection methodology baseline data and analysis of findings; powerpoint presentation with the findings and data files (both quantitative and qualitative) to UNICEF at the end of the research. Revisions to final materials may be necessary following the stakeholder review.
5. **Draft Communication for development Strategy including Theory of Change**
6. **Final Communication for development Strategy** to reduce stigma and discriminatory attitudes towards disability. Revisions of the final C4D strategy may be necessary following the stakeholder review.
7. The paper on the KAP survey results published in academic publications

Ethical Issues

UNICEF directive on Ethical Standards will be shared with the contractor and should be strictly followed.

All interviewees, including children, should be informed about the objectives of the evaluation and how findings will be used; they also should be informed that collected data and any statement about the programme will be kept confidential and respondents will not be named or identified in the reports with regard to their statements.

All interviewees should agree without coercion to take part in the evaluation and be given the option to withdraw or not to participate at any time during the process. Interviews shall be carried out in line with interagency evaluation project interview good practice guidelines.

All gathered data should be confidential and names of individuals deleted from the data and replaced by codes in the evaluation notes.

Ownership of all data/information/findings gathered, databases and analysis prepared for the evaluation lies with UNICEF. The use of the data/information/findings for publication or any other presentation or sharing can only be made after agreement with UNICEF.

XVIII. Annex VIII: Informed Consent Request

Informed Consent Form

Children with Developmental Delays and Disabilities KAP (Knowledge, Attitudes, Beliefs, and Practices), Palestine

Investigator: _____

You are being invited to participate in a research study to look at Knowledge Attitudes and Practice (KAP) related to children with developmental delays and disabilities, and which will lead to the development of a Communication for Development strategy in Palestine. This research project is being conducted by AWRAD, an independent consulting agency. AWRAD is contracted by, and funded by UNICEF. In this research study, we seek to generate and document evidence on knowledge, attitudes, and practices around children with developmental delays and disabilities. Through conducting a KAP survey and follow-up focus groups with parents and caregivers of children with developmental delays and disabilities, persons with disabilities, and members of the community we will gain a better understanding of their treatment, de-stigmatization, positive/negative caregiving and prevention among other issues.

The research will also investigate the things that influence the behaviour of parents/caregivers of CWDs 0-3 and 4-8 years old, as well as trusted sources of information related to providing caring for children with developmental delays or disability. The study will in addition investigate caregivers' perceptions of the sources of negative attitudes, their reactions to stigmatization of their child, and the barriers to their child's full participation in education, social life, and health and rehabilitation services.

There are no known risks if you decide to participate in this research study, nor are there any costs for participating in the study. The information you provide will help understand early childhood development and importance of early detection of developmental delays in Palestine better. The information collected may not benefit you directly, but what is learned from this study should contribute to improved early childhood programs and institutions.

This survey is confidential. If you choose to participate, your name will not be written on the questionnaire. No one will be able to identify you. No one except for the research team will know whether you participated in this study. Nothing you say on the questionnaire will in any way influence any relationship you may have with a center of early childhood learning, service providers, health care professionals, or other organizations or individuals who may provide services to you or your children. Taking part in this study is completely voluntary. If you choose to be in the study you can withdraw at any time without consequences of any kind. You may choose to skip any question that you do not wish to answer. Participating in this study does not mean that you are giving up any of your legal rights. The records of this study will be kept private and will not be seen by anyone outside the research team. The questionnaire will be destroyed after data entry. Any report of this research that is made available to the public will not include your name or any other individual information by which you could be identified.

If you have any questions or concerns about completing the questionnaire or about being in this study, you may contact Nader Said – AWRAD CEO at 0599204527 or email at nader@awrad.org.

If you consent to participate in the study, please sign your name below or give the interviewer your oral consent.

Optional Participant Signature: _____

OR VERBAL CONSENT GIVEN; MARK []

Interviewer Signature: _____