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Gratitude versus children’s rights: An exploration mothers’ attitudes towards disability and inclusive education in Palestine

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**Abstract**

The Palestinian National Authority has signed into law human rights protocols that promote, protect and ensure the rights of all children and the rights of persons with disabilities, including the right to an inclusive, equitable education. These protocols are supported by a series of laws and policies which seek to realise the aim of respecting all human rights entitlements. However, chronic occupation has devastated Palestine’s infrastructure, fractured the economy, and fragmented the integrity of the State, with the consequence that inclusive education is difficult to achieve. Shame, stigma, and prejudice about disability, and general ignorance about the rights of children are also significant barriers to inclusion. This research focuses on the inclusion of children and young adults with disabilities in educational and vocational training centres in Palestine. Two, semi-focused focus groups were conducted with mothers of children with disabilities to explore their attitudes to disability and whether their children were being provided with an education that met their needs as learners with disabilities. The data was analysed against the Convention on the Rights of People with Disabilities, and reveals that the mothers generally valued the children. However, low expectations and lack of respect for, or understanding about, children’s rights, mean that children with disabilities do not have equal opportunities to make the most of their talents and develop to their fullest potential. As a result, children will continue to face discrimination, segregation or exclusion, not only within educational settings but also within their communities.

1. Introduction

The World Health Organisation (WHO) (2011) understands disability as:

the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors). (p.4)

The Preamble to the Convention on the Rights of People with Disabilities (UNCRPD, 2006) explains that ‘disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others’ (p.1). Disability is, therefore, complex and diverse, resulting from the interactions between health, personal and environmental factors. It is affected by age, sex, socio-economic status, sexual orientation, culture, and political and social arrangements – laws, policies, and strategies. War, environmental disasters, or occupation also impact on disabled people.

Children with disabilities are one of the most marginalised and excluded groups in any society, but in Palestine they face a particularly dire situation because of the levels of cultural stigma, and the protracted Israeli-Palestinian conflict that has devastated Palestine’s infrastructure, fractured the economy, fragmented the integrity of the State of Palestine, and overwhelmed service providers (UNICEF, 2018). The conflict has contributed to many of the barriers preventing the rights of children to a quality education.

Around 600,000 Israeli settlers live on 60% of land that is recognised by the United Nations as belonging to Palestine, and Israeli security measures scatter Palestinians across their territories which makes access to education, health care and employment difficult (Amnesty International, 2019). Israeli movement restrictions also prevent rehabilitation workers from providing early intervention, leading to shortages in medical supplies and assistive devices, as well as scarcity of fuel and electricity needed to operate these devices (Swedish International Development Agency (SIDA), 2014).

The Ministry of Education and Higher Education (MoHE) (2014) reports that the education system is vulnerable to political, financial, physical constraints. The school infrastructure is poor and fragmented, there is a shortage of adequately trained teachers, and access to schools in marginalised areas is difficult. The capacity of schools to accommodate the education needs of students generally, and students with disabi-
ties specifically, is highly constrained. Despite policies and laws on the right to equitable education for all, the effective inclusion of students with disabilities requires urgent improvements in ‘physical accessibility, the training of teachers to better support students with disabilities in mainstream classes, and appropriate teaching aids’ (SIDA, 2014, p.3).

Data collected by the Population, Housing and Establishments Census, 2017 shows that the prevalence rate of disability in Palestine is 2.1% of the total population, but this is probably an underestimate as we will discuss later. Approximately one fifth of people with disabilities are children under the age of 18. The most common disability is mobility (50.7%), followed by visual impairment (31.2%) and hearing impairment (21.4%). Invisible disabilities are not recorded. Illiteracy rates amongst persons aged 10 years and over is 32%, and 46% of children with disabilities aged 6–17 years are not enrolled in formal education. The unemployment rate amongst persons with disabilities was about 37% (The Palestinian Central Bureau of Statistics, 2019).1

In April 2019, we undertook research on the assessment of children and young adults with disabilities and their inclusion in educational (6–13 years’ of age) and vocational training centres (for young people aged 13–18) in Palestine. Our aim was to promote understanding of current conceptualisations of disability advanced by disability groups in the UK and elsewhere that was evidence based and informed by the UNCRPD (2006) and the General Comment 4: Article 24 (Education) of the UNCRPD. For this article, we report on the research we undertook with mothers of children with disabilities who attended two of centres supervised by a charitable campaigning society in Palestine. The first group comprised seven mothers associated with an education centre for children with disabilities (henceforth ‘CCD’) and the second comprised five mothers from a centre for vocational training (henceforth, ‘CVT’).

The discussion is organised as follows: in Section 2 we discuss the Palestinian education system and some its key laws and policies on children’s with disabilities rights to inclusive education. In Section 3 we discuss the key features of the UNCRPD, General Comment 4, on what an inclusive, equitable education should look like. In Section 4, we present the Methodology and in Section 5 the Findings. Section 6 provides a discussion of the findings against the UNCRPD, and we conclude, in Section 7, by making brief recommendations on a rights informed curriculum and pedagogy.

2. Laws, policies on the education of people with disabilities

The education system in Palestine is divided into three sectors: the public sector which is governed by the Ministry of Education and Higher Education (MoEHE) across Palestine. The United Nations Relief and Works Agency (UNRWA) is located in the refugee camps in the West Bank and Gaza and provides free education to children up to 15 years’ old. Currently, nearly five million Palestine refugees are eligible for UNRWA services. Together with UNRWA, the MoEHE is responsible for providing inclusive schooling to children with disabilities; 80% of schools are run by the Ministry in the West Bank, and 8% by UNRWA. In Gaza, 49% of schools are run by the Ministry, 48% by UNRWA and 4% are supervised by the private sector (MoEHE, 2014, p.3).

Private schools are run by Nongovernmental organisations (NGOs), churches, and other local initiatives. Many students with disabilities are educated in special schools, usually in NGOs, or in privately run organisations that are funded through donations from other NGOs, internationally funded grants, and by in-kind donations by the community (furniture, toys, food). The centres we report on here belong to this sector. They are dependent on funds from NGOs and charge a small fee to attend (about £25/month), though these are waived if the parents cannot afford them.

The Palestinian National Authority (PNA) has developed a number of legislative and policy initiatives that demonstrate its commitment to advancing the rights of persons with disabilities. Since being recognised as a non-member state with observer status in the United Nations’ General Assembly in 2012,2 the PNA has signed and ratified a number of international conventions, including the United Nations Convention on the Rights of the Child (UNCRC) in 2014, and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) also in 2014. The PNA’s 2003 Basic Law recognises the right of all Palestinians to equality before the law and judiciary ‘without distinction based on race, sex, colour, religion, political views, or disability’ (Article 9). Article 22 commits the PNA to providing education services, health and social insurance to ‘the families of martyrs, prisoners of war, the injured and the disabled’; and Article 23 guarantees that ‘Every citizen shall have the right to education’.3

The MoEHE Development Strategy Plan for 2014 to 2019: A Learning Nation, restates the government’s commitment to inclusive education, which has been the general policy of the education sector since 1997. The Strategy Plan, which includes specific goals relating to students with special education needs, identifies the need for a more detailed and comprehensive policy pertaining to inclusive education for children with disabilities.

The majority of children with disabilities who access the formal public education system are those with physical, rather than cognitive, disabilities. In reality, this means that only those children with mild to moderate physical disabilities attend mainstream schools (PCBS, 2015). In 2012/13, only 0.83% of students with special needs and disabilities were included in secondary schools (MoEHE, 2014, p.107). The target for 2017/18 was 1.08%. Only five categories of disability are represented in the Ministry’s 2014–19 Development Strategy Plan: visual, hearing, mobility, speech and ‘mild mental’ (whether cognitive or psychiatric is not specified). In 2013/14, 5702 students with disabilities were in public schools, approximately 0.96% of the total number of students in public schools in the West Bank (p.76).

The Ministry also reported that the school environment is largely unsuited to most children with disabilities, except for those with mobility difficulties as the majority of schools (1013) have ramp access in the West Bank. For example, 492 schools do not have ramps, while 64 schools cannot be modified (2014, p.75). The Ministry has also sought to provide educational methods and supportive tools for individuals with ‘obvious’ disabilities (hearing aids and wheelchairs, for example), but acknowledges that there is a shortage of equipment for students with less obvious disabilities. In addition, the lack of diagnostic tools to accurately identify the specific disability, such as moderate and ‘severe mental difficulties’ and Autism, mean that teachers use criteria that do not consider individual differences and capacities. While secondary school tests for students with disabilities have been designed, they are limited to visual, hearing, and mobility disabilities (MoEHE, 2014, p.77).

The following challenges were recorded in the MoEHE’s Education Strategy Plan. First, that the actual disability rate exceeds the official figures for the following reasons:

- Unreported disabilities, particularly for women, since some families do not register siblings with disabilities. Pervasive shame, stigma, and prejudice can force families to keep their disabled children hidden;
- Lack of a unified definition of disability or strategies to support individuals with disabilities;

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2 UN General Assembly Resolution 67/19, adopted on 29 November, 2012. The resolution implicitly recognises the sovereignty of Palestine. For further information see http://palestineun.org/status-of-palestine-at-the-united-nations/

• The dire economic situation which pushes families to provide inaccurate data in order to obtain disability support and assistance from the Ministry.

Second, that the lack of a coherent and integrated policy across all institutions has led to a number of weaknesses, including:
• Lack of equity with respect to the distribution of funding and services across the country;
• Services are limited to individuals with mild disability, while few services are available to those with intellectual disabilities or who are autistic;
• Lack of safe and adequate transportation, as well as financial support, which contribute to school dropouts. (p.79)

In 2016, the Ministry of Education launched an Education for All programme with nine UN agencies,4 that focuses on inclusive and child-friendly education to ensure the right to a quality education for all Palestinian children (MoEHE, 2017). The package aims to improve teacher education and learning, and all new schools must now be built to accommodate children with disabilities.

The Education Sector Strategic Plan (ESSP) 2017–2022 was produced in response to the United Nations’ 2030 Sustainable Development Goals (SDGs), particularly SDG 4, A Quality Education. The Sector Plan is premised on a vision of a ‘Palestinian society that possesses values, knowledge, science and technology and is able to employ that knowledge for liberation as well as development’ (MoEHE, 2017, p.7). Target 4.5 of SDG 4 seeks to ensure equal access by 2030 to all levels of education and vocational training for marginalised and vulnerable groups, including disabled people. The ESSP also adopted three sectoral goals:

Sector Goal 1: Ensuring safe, inclusive, and equitable access to quality education at all levels of the system, particularly for disabled people.

Sector Goal 2: Developing a student-centred teaching and learning pedagogy and environment.

Sector Goal 3: Enhancing Accountability and Results-Based Leadership, Governance and Management.

It is clear that Palestine takes seriously the right to inclusive, quality and equitable education. Human rights protocols inform and underpin the PNA’s educational policies and laws, recognising that inclusion in regular schools is essential to human dignity and a fundamental human rights entitlement. The inclusion of disabled people is regarded as key to achieving the right to education for all, and is regarded as being essential ‘for the development of inclusive, peaceful and fair societies’ (UNCPRD, 2016). However, despite these aspirations, the education sector is severely hampered in realising the goals of an inclusive, equitable education for all because of the effects of occupation, inadequate resources and poor infrastructure, as we will discuss below. First, we present an overview of the UNCRPD, General Comment 4, against which we assess the findings of this research.

3. UN convention on the rights of people with disabilities, general comment no. 4: the right to an inclusive education

The Preamble to the UN Convention on the Rights of Persons with Disabilities (UNCPRD) (2006) states that education is a fundamental right, and is set out in Article 24: Education, the first legally binding treaty to define the concept of inclusive, quality and equitable education. In 2016, the Committee on Rights of People with Disabilities (CRPD) published General Comment, No. 4: Right to inclusive education. Once regarded as ‘welfare recipients’, the Committee observed that persons with disabilities are now recognised under international law as ‘right-holders, with a claim to the right to education without discrimination and on the basis of equal opportunities’ (p.1). However, despite the progress that has been made since the near universal adoption of landmark human rights protocols such as the CRPD, ‘profound challenges persist’. Persons with disabilities continue to be denied a right to education, and many are educated ‘in settings where they are isolated from their peers and receive an inferior quality of provision’ (p.2).

The Committee enjoins States Parties to ‘ensure the realisation of the right of persons with disabilities to education through an inclusive education system at all levels’ (p.2), from preschool to tertiary education, including vocational training and lifelong learning, extracurricular and social activities. It states very clearly that all students, without exception, are entitled to this right and on an ‘equal basis with others’ (p.2). Children should not be discriminated on grounds of disability, gender, race, language, religion, legal status, age, sexual orientation, social origin, or because of their association with their parents, siblings, or relatives.

The barriers to inclusion are many, and are directly relevant to Palestine. For example:

(a) The failure to understand or implement the human rights model of disability, according to which barriers within the community and society, rather than personal impairments, exclude persons with disabilities;
(b) Persistent discrimination against persons with disabilities ... low expectations about those in mainstream settings, allowing prejudices and fear to escalate and remain unchallenged;
(c) Lack of knowledge about the nature and advantages of inclusive and quality education and diversity ... leading to misplaced fears and stereotypes that inclusion will cause a deterioration in the quality of education or otherwise have a negative impact on others. (p.2).

General Comment 4 is also the first treaty to give an explicit definition of inclusion. Inclusion is: a) a fundamental human right of all learners, and of the individual learner in particular. It is b) a ‘principle’ that values learners’ wellbeing, respects their inherent dignity and autonomy, and who can be effectively included in, and contribute to, society. It is c) ‘a means’ of realising other rights. Finally, inclusion is d) ‘the result of a process of continuing and proactive commitment to eliminating barriers impeding the right to education’, that includes changes to the ‘culture, policy and practice of regular schools’ (UNCRPD, 2016, p.3). The Committee also distinguishes between exclusion, segregation, integration and inclusion. Exclusion occurs when ‘students are directly or indirectly prevented from or denied access to education in any form’. Segregation occurs when education is provided in ‘separate environments designed or used to respond to a particular impairment or to various impairments, in isolation from students without disabilities’ (p.3). Segregation and isolation are barriers to inclusion, and both undermine the status of disabled people as persons worthy of equal respect. Integration is defined as the process of placing disabled people in mainstream educational settings on the assumption that they can ‘adjust to the standardized requirements of such institutions’ (p.3).

By contrast, inclusion is a process of:

systemic reform embodying changes and modifications in content, teaching methods, approaches, structures and strategies in education to overcome barriers with a vision serving to provide all students of the relevant age range with an equitable and participatory learning experience and the environment that best corresponds to their requirements and preferences. (p.3)

Inclusion cannot occur without a ‘whole educational environment’ in which the leadership of educational institutions must introduce and embed ‘the culture, policies and practices needed to achieve inclusive education at all levels and in all areas, including in classroom teaching and relationships’ (p.4). Further, schools need to adopt a ‘whole per-

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4 Food and Agriculture Organization; United Nations Development Programme; United Nations Population Fund; United Nations Children’s Fund (UNICEF); UNRWA, United Nations Educational, Scientific, and Cultural Organization (UNESCO); World Food Programme; and World Health Organization (WHO) - coordinated by UNESCO.
son’ approach so that the ‘capacity of every person to learn, and high expectations are established for all learners, including learners with disabilities’ (p.4). Schools should offer flexible curricula, and teaching and learning methods that are adapted to different strengths, requirements and learning styles; teachers should focus on learners’ capacities and aspirations rather than on content when planning teaching activities; and schools should provide accessible learning environments with appropriate supports (p.4).

Inclusive education is a fundamental human right. It is a principle that values all students equally, is a means of realising other rights, and is a process of eliminating barriers to the right to education. Inclusive educational practices develop the confidence, skills and capacities of all children, and honour the dignity of the child.

4. Methodology

The research we report on here was part of a larger project on stakeholders’ (children, parents and teachers) views and experiences of inclusion of children with disabilities, disability assessment and follow-up support, supervised by a non-governmental society in Palestine. The society supervises eight community day-care centres (six special education and two vocational training centres) in cooperation with the local committees and municipal councils in the villages and refugee camps in the Bethlehem and Hebron districts of Palestine. The education centres focus primarily on educating and rehabilitating children and young people with disabilities who are unable to access mainstream education. We visited the centres over a 10-day period. For this article, we focus on the views and attitudes of mothers (n = 12) whose children attended two of these centres.

4.1. Recruitment and participants

We held two focus groups with mothers5 of children and young adults who attend a special needs centre and a vocational centre for young adults with disabilities. A purposive and opportunate sample, the mothers were members of an established and active support network who liaise closely with the centres. An employee of the society who worked closely with the centres assisted with the recruitment of the participants. He contacted the centre Directors who agreed to pass on information letters. The employee was also our interviewer and interpreter, and was very familiar with the research aims and design, including the interview questions. A Palestinian researcher, he also advised us on Palestinian politics, the effects of occupation, the socio-economic situation, and the country’s cultural norms and values.

We conducted a focus group with seven mothers associated with an education centre for children with disabilities (henceforth CCD), and five mothers connected to a vocational training centre (henceforth, CVT). Young people in the vocational centres were taught skills such as paper making, and were engaged in making gifts for the tourist trade and laundry cleaning for the local hotels and restaurants, for which they received a very small remittance. The CCD was based in a rural location, and the CVT was located in an urban setting. The focus group sessions lasted approximately one hour and took place after school hours. The age range of the young people discussed in the CVT was between 19 and 38; and in the CCD the age range was between 6 and 16. The disabilities of the children and young adults ranged from Down Syndrome, Autism Spectrum Condition (ASC), to hearing and visual impairment and a variety of learning disabilities.

We sought responses to four specific questions:

Why did you send your child to this centre?
What benefits did the centre bring you and your child?
How could the centres be improved?
Do you and your child feel included and informed about your child’s progress?

The semi-structured design of the focus group meant that the mothers often strayed away from the direct questions, and this was particularly evident with the mothers of children in the CCD who were very keen to talk about the difficulties associated with their children’s needs. We asked the interpreter to adopt an active style of interpretation in order to ask follow-up questions, seek clarity and obtain longer, in-depth answers (Plumridge et al., 2012). While the focus groups were conducted in Arabic, the interpreter provided on-going summaries of what the participants said. The focus groups were audio-recorded on three devices (Dictaphone and two mobile phones), and translated into English by a professional translator, who was also Palestinian.

4.2. Data analysis

The data was organised using Braun’s and Clarke’s (2006) six stages of thematic analysis.6 Thematic analysis is a basic method that works flexibly with a diverse range of research questions and for minimally ‘identifying, analysing and reporting patterns, or themes, within data’ (p.77). The data collection focused on the extent to which mothers felt their children were being provided with an inclusive, equitable education that met their needs as learners with disabilities. In compliance with our research brief, our questions necessarily sought information on this theme and we thus coded the data to the specific aforementioned questions. We began the analysis by adopting a semantic approach meaning that we confined ourselves to the ‘surface meanings’ (p.83) of the data, and did not look for meaning beyond what a participant had said (stages 1–3 of thematic analysis). We then progressed to ‘latent analysis’ (p.84) to examine how the data revealed the mothers’ attitudes to, and beliefs and feelings about inclusion and the importance of the centres to them and their children (stages 4–6).

4.3. Privacy and confidentiality

The privacy of the mothers was protected through a series of confidentiality measures: the interview took place in a private room with a closed door with the researchers and interpreter; a confidentiality agreement was signed by the interpreter, participants and translator; audio recordings were transcribed and anonymised; the transcriptions had all identifying information removed and were deleted following data analysis. Only the researchers and interpreter had access to the transcriptions and audio. The research was approved by Queen’s University, Belfast, (UK) and adhered General Data Protection Regulations (GDPR).

5. Presentation of the findings

5.1. The value of the centres to the mothers

The mothers chose the centres because of convenience, cost, the opportunity for their children to socialise, and because there were few local facilities. The mothers of the young people who attended the vocational centre (CVT) were particularly enthusiastic about the quality of the services offered here:

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5 Palestine is a predominantly traditional and patriarchal society, which means that women have fewer rights than men in a region where rights are routinely violated. Palestinians’ rights to political participation, housing, freedom of movement, economic development, education and health are often restricted by the practices of the Israeli military. Women’s restricted access to these freedoms are exacerbated by the ‘culture of control’ which is, according to Shalhoub-Kervorkian and Daher-Nashif, 2013, ‘the localized manifestations of patriarchal and masculine logics that are empowered by the politics of exclusion’ (2013, p.168). The care of children is the responsibility of women.

6 The six themes are: 1. Familiarising yourself with the data; 2. Generating codes; 3. Searching for themes; 4. Reviewing themes; 5. Defining and naming themes; 6. Producing the report. p86.
K was at the (name) centre, but when he got older, we sent him to (name of the centre) for a year, and when he grew older there was no place for him to go, so he stayed at home and his psychological condition became much worse … When this centre opened, we registered him in it and … he began to improve. He started communicating with children and they began to understand him. (CVT)

My daughter was a recluse … she would never see anyone and would remain in her room, but since she started at the centre, she takes part in the community and interacts with people and reacts to them. She interacts with teachers and students and she has improved very, very much because of the centre. (CVT)

A mother of a teenager with Down Syndrome valued the fact that her son was given the opportunity to socialise and to feel ‘normal’:

He feels normal. When he stays at home on Thursday and Friday or Friday and Saturday, he gets very cranky and starts doing things like pouring water on the ground to clean it. He gets cranky because he is at home … and he always wants to go out. (CCD)

The vocational centres allowed the mothers to form a strong group, with whom they could communicate their concerns and raise awareness of disability:

First of all, it has benefited our children; second, it has benefited us. Now we work together and know people that we didn’t before … We’ve got to know people, including respectable mothers, and we’ve got to know you [the interpreter] … Thank God, both we and our children have benefited. (CVT)

We are now famous on Facebook, where they posted our pictures, and they take the children on field trips to have a change of scenery. This is important and better than remaining at home. Of course we benefited. (CVT)

The mothers also feel included by the centre and that the centre provides valuable life skills:

Yes, when there is something done in her or the centre’s name, she [the Director] invites us to give moral support to the children. When it comes to [name of the child] he is good, he started helping at home, and he has come a long way. It is excellent. He benefits us at home and benefits himself. It is no longer like before when he would rely on me or my mother. He now relies on himself in personal things. (CVT)

In the CCD, the mothers likewise valued the centre for reasons of cost and convenience, but felt the centre could do more to educate their children, particularly with respect to vocational skills:

… due to the financial situation we decided to move him from there [centre the child had previously attended] to here because it cost 800 shekels … but here it is less costly because the only cost is the taxi … and thanks be to God the boy is becoming more and more open … At first he rejected this centre because they wanted to teach him what they had already taught him at another centre … I wish they could find skills to teach the boys. (CCD)

A mother of a child with Down Syndrome could not see the value in her child learning to read and write, primarily because she did not believe he could or that it would be useful to him since no-one would ever give him a job (and later asked if there was a cure for Down Syndrome).

You know, reading and writing is the last thing I care about. To read and write and spell; they should have nothing to do with reading and writing. (CCD)

It was more important that her child learned good behaviour so that he did not ‘create trouble for her’. When asked if the centres help their children learn skills, the mothers of the CCD responses were mixed:

Honestly, the education is not that great. It’s not that they [teachers] are bad, God forbid, but they don’t learn much.

My son has been here for four months and has not benefited at all, and they (the centres) are all the same. He goes and comes back, but nothing changes.

Interviewer: You have not seen any improvement in your son after four months?

He is calmer. He became calmer. I do not know if my child is too young to attend the centre. (CCD)

Thank God, it’s good. We don’t want to say excellent. It helps them get a change of scenery. It’s not good to stay at home all the time. (CCD)

Honestly, the centre is good. As a mother of a young child, I think the centre is good, frankly. When he comes home, I ask him what the teacher has taught him, and he will start making facial expressions or he stands and starts reciting. (CCD)

5.2. Communicating education goals and objectives

There was a mixed response as to whether the CVT set clear goals and objectives. One mother insisted that as a group they could ask about progress and that there was an opportunity to do so at the monthly meetings. It is also clear that because they act like a support network, they can get the information they need from the centre. Parents were also informed if their children had made progress. In terms of setting goals, this naturally varied from person to person, depending on the level and nature of the disability. One mother stated that the goals were not clear: ‘Our children are the ones who tell us we did this and we did that’; another insisted that the monthly meetings provided an opportunity to learn about their children and to ask questions:

… we have monthly meetings where we share our point of view and they give us an assessment of each child. In the monthly meetings, they share the assessment of everybody. (CVT)

When it comes to [name of the young person] they assign her a paper to write about, for example, the benefits and harms of cold coffee. She gets the information from the internet and then reads it out to students in the class, [name of the young person] likes cold coffee, so they asked her to bring a report about it so she can know its benefits and harms. (CVT)

[Name of the young person] situation is difficult. He has not improved mentally to benefit from the centre because he is mentally retarded. For example, [name of another child] improved and started working with things, but [name of her son] is still not improving. (CVT)

5.3. The quality of services in the centres

When the mothers were asked whether their children could learn new skills if the quality of education at the centre improved, the mothers in the CCD replied that they could, and suggested that cooperation between families would be beneficial. They also believed that teachers should focus on writing, homework and better communication with the parents:

Writing … they should have a notebook and have homework to write at home because I cannot come to the centre every day. I come every two or three weeks to ask about my son, but he should have a notebook to write on each day, for example, one, so I can know what he learned. (CCD)

It also seems that the CCD does not communicate with parents about targets or what the child should concentrate on with respect to skills.
Some parents were told of progress in the first semester but that it had now stopped:

No one told us anything or called for a meeting. I used to have my daughter [contact them] because I didn’t know what to ask. (CCD)

Unsurprisingly, the mothers would like more therapeutic services:

All this should be available, speech therapy, physiotherapy, all of it. There should be more than two teachers, although the teachers are great, but there are things that they cannot deal with like special needs, for example.

Given that the centre was established for the purposes of educating disabled children, it is disheartening to learn that some mothers do not expect teachers to be able to deal with special educational needs. They would also like teachers to help their children acquire vocational skills in order to be independent, and agreed that the centre needed many more resources (books, assistive devices and technology) and services. The following exchange between the interviewer and one mother is instructive:

Mother: My husband knows someone in America whose condition is like my daughter’s [autism]. She’s three years old and she speaks and walks and has abilities. Why is that?

Interviewer: Why do you think she can speak and walk?

Mother: Because of the development resources they have? The skills of the teachers? Of course, they’re not like us at all. She used to send us videos of her daughter.

Interviewer: I will give you an example of two people with no disabilities at all. You send one to school and keep the other at home. Who would be, let’s say, smarter and know more?

Mother: They have resources and have everything. They love children as well.

Interviewer: It’s not just that. The more opportunities you have, the more capabilities you get. (CCD)

The mothers acknowledged that children can learn and develop given the right resources, interventions, and teachers with the right qualifications and attitudes.

The mothers were more positive about education in the CVT. Young people with disabilities are taught ‘general knowledge’, the difference between ‘right and wrong’, how to ‘distinguish colours’, and about their rights: in essence, life and social skills:

They learn things. Now, when he walks in and I’m at home he greets me and calls out to me. Now they know things that they did not before. Before, he wasn’t like that. He comes home happy and says “Mom, how are you?” Now, there are more things that they know, such as Mother’s Day, when he wished me Happy Mother’s Day.

Yes. For example, they make them distinguish between what is right and what is wrong, and make them distinguish between colours. They also give them educational and recreational games. Their activities are excellent for children like them.

They teach children about their rights, and tell them how to deal with sexual threats, for example. They make them aware of what is right and wrong.

However, positive though the mothers were about the CVT, they recognised the importance of qualified teachers and of ensuring that other disabled children and young people attend the centre, as this mother explained:

These people should be qualified and not just bring people in who cannot do anything. Also, I would like them to go to parents of other children with disabilities and make them aware that this child is like their children, especially youths and young people who need the centre itself to give them seminars to educate them.

5.4. Mothers’ attitudes to disability

While the mothers cherish their children and do all they can to safeguard and educate them, it is clear that they regard disability as a medical and in-child problem (deficit), and fear for their futures. This is hardly surprising when the communities in which they live still regard disability in deficit and ableist terms, and as a burden and a stigma. It is for reasons such as these that they could regard their children as ‘not normal’:

Let me tell you, at first I was devastated for having a child like that (Down Syndrome) but now you start to believe in fate and pay attention to him, not ignore him. On the contrary, we pay more attention to them [children with disabilities], and love them more. (CCD)

They also tended to excuse the centre’s poor teaching because of their own child’s disability:

The condition of my son does not help; he’s in a bad condition. But it’s better, there is slight improvement. It is better than staying asleep at home. (CCD)

The child of one mother was kept in his wheelchair which was tied to the wall in the centre, even though he could walk. From our observations, and from speaking to staff, this was done for his ‘own safety’ and for the safety of the other children. This child, who was also non-verbal, liked banging cupboard doors and generally making loud sounds. We asked if the child could be released from his chair and this is exactly what he did; he also moved energetically around the class and in the playground. It seemed clear to us that the child was under-stimulated and under-exercised – and largely ignored. The noise seemed to be therapeutic. The mother excused the school from tying him up:

At home, I don’t mind him moving even if he breaks everything. At school they have other children and cannot keep chasing after my son. (CCD)

One of the ways in which the mothers seek to protect their children is to keep them locked in the house and to control where they go and with whom they can associate:

I do not let him out because we live on a street and I fear for him. If he wants to go out, I go out with him. You know? I work until one o’clock, then I go home, lock the door and hide the key. I cannot let him out at all. (CCD)

One mother kept her child indoors, not because she cared about what people said, but because she wanted to protect him. When she was advised that it might be better to let him play outside to see a different life and be a normal person, she replied:

He cannot live like any other person... He is not a normal person ... We’re deceiving ourselves if we say this ... He’s not a normal person. (CCD)

The mother who had advised this mother to let her son play outside agreed with her assessment: ‘He’s not a normal person, I agree with you, I understand that’. (CCD)

Fear of what others would do was also motivating reason to restrict the child’s movements:

I treat him like his brothers. I have a brother who adores him and takes him along. I’m only comfortable when there’s an adult with him. Would I let him go with someone young? No, I wouldn’t, not

\footnote{Before we met the mothers, we spent the day observing teacher-children interactions. The researchers are both qualified secondary school teachers, and one worked in a special needs school in the UK.}
because those around me are bad, but because I want to protect my son. I fear for my child. (CCD)

When I take a nap during the day, I place the key under my head so he can’t take it. (CCD)

Sometimes the, arguably, prejudicial attitudes of the medical profession emerged in the advice given to the mothers:

I want him to walk well and stop making noise because this is exhausting for me. The doctor told me last time that “dogs and donkeys were taught to use the toilet. Why can’t your son be taught so he can get used to it”?

5.5. The possibility of inclusion

When the mothers of the CCD were asked if inclusion was possible the answer was overwhelmingly ‘no’.

Even at the kindergarten level, when I used to take him with me, the children were scared of him. They’d start screaming at my son and he’s never hurt anyone. I teach at a kindergarten and took him with me to a party once and the children started screaming. Some people tell them who he is, and they pick him out, although he is not very scary.

Another parent was advised that it would be ‘unjust’ to send her son to a mainstream school:

Dr M told me to register him in a school next year but Ms N [teacher] told me, “no, that it would be unjust to send him to a school now while there is still much more work to be done with him”. (CCD)

In our school even children without issues are trampled on if they don’t have a strong character. If the child has issues, they will be brutalised. It’s not fair to send them to a normal school. (CCD)

They don’t know how to deal with them at regular schools. There were no centres in [name of the town] and we had no centre close to us, so I registered my son in a regular school, and I swear to God they paid no attention to him at all.

Not at all, even teachers here don’t take care of the child…I know that some people [with special needs] who are adults are treated disrespectfully. (CCD)

We don’t want them to take care of them, we want them to defend them if, for example, another child does something to them. (CCD)

However, because the children do attend the centre, they are visible, and it sends a signal to the community that the children can be educated:

Honestly, now people accept them.

When I see anything they’ve done I publish it on Facebook. They do nice things and I publish them. (CCD)

The view of mothers whose children attend the CVT was much more optimistic. Many felt that their children’s inclusion in the centre was excellent but that awareness in the community was not high:

It is for them in the community, but the community is not good to them … his inclusion is excellent because he likes youths and comes and goes with them. But to me the issue is not that we should raise parents’ awareness of students with disabilities, but should raise the awareness in the community … We want the community to rise up; we have risen up and understand. He interacts with the community, but the community does not accept him.

It seems clear from the discussions that the principle of inclusion as a fundamental human right of all learners, that values learners’ well-being, respects their inherent dignity and autonomy, and that is the result of a continuing and proactive commitment to eliminating barriers to education does not exist at a whole school or whole person level.

6. Discussion

Despite the mothers’ support for the centres, what came across was a sense of gratitude that the centres existed and that their child had somewhere to go. If there were problems with educational and therapeutic provision, they regarded these issues as the fault of their child’s disabilities, and the challenges they posed to their teachers. These mothers also live in a society which is saturated with beliefs about ableism and the able-bodied (a form of prejudicial discrimination that is to be found everywhere). One 16-year-old boy was being educated with children as young as six, and the activities being offered did not seem designed to improve his communication, socialisation, or basic literacy and numeracy skills. This young person also seemed to be angry and frustrated, and was used to discipline other children, which he often did aggressively. He did not appear to be receiving the kind of education that stimulated his imagination, senses or thought, and which enable to him to be included in or contribute to his community. A capable boy who, his mother informed us, enjoyed helping his father and brothers, was being contained in this centre. His-mother was grateful he had somewhere to go.

Of further concern was that the teachers of the CCD did not seem to plan their lessons or to know how to effectively include these children. The lessons seemed haphazard, lacking coherence, structure or purpose. They were also focused on one child at a time, while the others were left to their own devices – banging cupboards, playing with elastic bands, randomly looking at books, or playing with the resources that we had brought along. There were two autistic children, both of whom were constantly stirring, a sign that they were lacking in stimulation or were over stimulated by noise and lack of order. One child took apart the tactile ball made of elastic bands and scattered these in the class and in the playground. It seemed clear to us that this child needed tactile stimulation.

What we observed differed radically from what the mothers believed the centre was doing for their children. They were grateful that the centre exists at all and regarded disability as a deficit and within-child problem, which might help explain the discrepancy between what was actually happening and the mothers’ views. This particular centre’s practices (CCD) were disabling and were not equipped to effectively teach or include the children, either in terms of resources or teachers’ qualifications, skills and attitudes. Such low expectations breach Article 29(1) of the Convention on the Rights of the Child (UNICEF, 1989) with respect to the goals of education: the ‘development of the child’s personality, talents and mental and physical abilities to their fullest potential’. Low expectations also impede inclusion. There was a lack of knowledge about the ‘nature and advantages of inclusive and quality education and diversity’ (UNCRPD, 2016, p.2), and evidence that inclusion of children with diverse needs hampered teachers’ ability to provide good quality of education. The absence of a “whole system”, “whole environment”, and “whole person approach” was evident from the findings of the mothers.

In the CVT, by contrast, the young people were purposively engaged in their activities, and seemed to enjoy what they were doing. The staff were caring and empathetic, and had many years of experience working in the centre. The mothers felt included, informed, and valued, and felt strengthened by their mutually supportive network. The mothers of the CCD also gained strength from their support network, but unlike the mothers of the CVT, did not talk about Facebook, raising awareness in the community, or that inclusion was possible for their children. We also became aware that these mothers would benefit from understanding more about disability and their ‘causes’ – that disabilities and impairments are aggravated when the social environment effectively bars them from being included so marginalising them even further. To speak of curing for Down Syndrome and ASC, or that children with disabilities
are not educable save by small degrees, is unfortunate and uninformed – but such views are common and are largely unchallenged.

7. Conclusion

Human diversity is a pervasive and ineradicable aspect of human lives, and are central the tenets of equality and justice (Sen, 1992). We are diverse in three fundamental ways. First, we are different with respect to personal characteristics such as physical and mental abilities, talents and skills. We are, second, different with respect to external circumstances such the political, social and cultural arrangements into which we are born. Third, we are different in terms of our ability to convert resources into valued ‘functionings’ – or what we can do and to be – being a musician, for example, or being able to read and write (Sen, 1992, p.xi). These differences are sources of inequality and injustice, conferring advantages or disadvantages depending on our gender, our socio-economic status, or whether we live in a society which enables young people to reach their potential in safe, secure, and respectful environments. Impairment and disability are aspects of human diversity, which too often confer disadvantages, primarily because they are seen as deficits and limitations, conditions to be fixed or cured, and, perversely, as a burden on the State, community or family. This kind of diversity means that distributive patterns of resources or respect for human rights are unjust and unequal, patterns that we observed in the centres and which were revealed in the mothers’ data.

The highly aspirational goal of education that is effective and equitable, and which provides quality education for all children, is far from being realised. Inclusion, as defined by the UNCRPD (2016) does not yet exist. There are a number of reasons for this: the centres lack adequate funding, educational resources, facilities, teacher training and qualifications, ongoing professional development and training, and an understanding of current understandings of disability that is informed by social models of disability. These problems are compounded and aggravated by the ongoing impact of the Occupation which pervades almost every aspect of Palestinian life in highly adverse ways as a result of checkpoints, detention and mistreatment of children by the Israeli army, attacks on schools resulting in damage to the buildings and disruption of schooling, and military use of premises, settlers related violence and/or vandalism, and military demolition (or threat of demolition) of schools in the West Bank (CCIA, 2013), all of which cause fear and anxiety which inhibits learning. The relentless appropriation and annexation of Palestinian land and property are further and profound aggravations. The ‘process of continuing and proactive commitment to eliminating barriers’ (UNCRPD, 2016, p.3) that impede the right to education is extremely difficult in such circumstances.

We can develop an inclusive, equitable education only if developing an attitude that children and young people with disabilities can learn if creative approaches to teaching and learning are adopted. This can be achieved by adopting flexible curricula and teaching and learning methods that are adapted to different strengths, requirements and learning styles, that is focused on learners’ actual capacities and aspirations, rather than on content. There is an urgent need to make accessible learning environments with appropriate supports and design – lighting, noise, visual design, tactile and therapeutic objects more widely available. The provision of support, reasonable accommodation and early intervention so that all learners are able to fulfil their potential, is critical.

Restricting opportunities to a meaningful education, a narrow or limited curriculum that does not expose children and young people with disabilities to skills, other worlds, lifestyles, or ways of thinking, means that they cannot fully realise their potential to conceive of a life that they might want to follow. If the child has complex educational needs, there is a danger that she or he will be stereotyped as incompetent, with the result that teachers will have fewer positive attitudes, and, accordingly, lower expectations for students with disabilities. If children are constructed as incompetent they may not be encouraged to develop goals, plans, interests that accord with their interests and personality, and so conform to the stereotype that children with disabilities can do and be only with benevolent interventions. This is neither just nor fair.

Declaration of Competing Interest

There are no conflicts of interest.

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