The Experiences of Institutionalized Persons with Disabilities in the West Bank, Occupied Palestinian Territory:

A Pilot Investigation

June 2024

Author
Shatha Abu Srour, Consultant, Institute of Community and Public Health, Birzeit University, Occupied Palestinian territory

Supervisor and Mentor: Suzan Al-Mitwalli, Academic Researcher, Institute of Community and Public Health, Birzeit University, Occupied Palestinian Territory and Rita Giacaman, Professor, Institute of Community and Public Health-Birzeit University, Occupied Palestinian Territory.

The De-institutionalisation Under Siege: A network for deinstitutionalisation of persons with disabilities in the Middle East is funded by the Arts and Humanities Research Council (AH/X009467/1)

Arts and Humanities Research Council

Table of Contents

INTRODUCTION

There are several ways and methodologies to address the causes and issues of underrepresented groups in Palestine, and which reflect the dominant culture as well as and the approaches and strategies that the west promotes through their donor agencies on the other hand. Institutionalization constitutes one of those strategies or methodologies, experienced by several persons with disabilities, including myself, a member of the team who prepared this report. Based on personal experience, I must say that institutionalization as an approach, constitutes a very important research topic because of its contradictions, attitudes and emotions on one hand, and the consequences it has on the individuals' identity and their relationships with their communities on the other hand.

Hence, this report constitutes an initial step towards exploring the experience of institutionalization as the persons with disabilities in Palestine experience, live and express it. This is an attempt to comprehend their attitudes, thoughts and feelings linked to this experience, the reasons for institutionalization, the common practices in residential institutions, and examine the attitudes and thoughts of persons with disabilities towards institutionalization.

RESEARCH OBJECTIVE

The objective of this research is to document the experiences of persons with disabilities who are institutionalized currently or were institutionalized in the past. Through this documentation, we seek to:

- Explore the nature of the practices of those institutions, the extent to which they enhance or limit the opportunities of inclusion of persons with disabilities in society and whether they conform to the general principles that establish their rights, such as respect for inherent dignity, self-determination, individual autonomy, full and effective participation and others.
- Monitor the level of understanding of the persons with disabilities of the inclusion or de-institutionalization approaches and examine the extent to which they believe it is applicable in Palestine, and how.

METHODOLOGY

This research followed a qualitative approach based on previous experience related to the research topic. A list of questions was developed to identify the general attributes of the experience of persons with disabilities at the institutions that provide education, rehabilitation and care in Palestine. The questions focused on the following topics: How and why do persons with disabilities live in institutions; did they have previous experiences with educational institutions that provided educational and other services at their place of residence; to what extent are the persons with disabilities involved in making the decision of being institutionalized. The questions also address communication with the teams that work with persons with disabilities to examine their compliance with the principles which form the basis for the rights of the persons with disabilities provided in the UN Convention on the Rights of persons with Disabilities (CRPD), and the main attitudes, emotions and thoughts. Moreover, the questions included whether the practices of the respective institutions encourage persons with disabilities to provide feedback that helps shape their relationships with the families and with other groups in society. They also included the main advantages and disadvantages of institutionalization from the perspective of the respondents, and their perceptions of the de-institutionalization approach and the extent to which it is realistic (to implement). It is worth noting that this research is not at all an evaluation of the work of those institutions.

It must be emphasized that the small size of the sample does not enable the generalization of the findings of this report in any way but provides the insights for developing a fuller research project focusing on the institutionalization of people with disabilities. In addition, the findings of this research only reflect the points of view of the persons with disabilities (and not parents, institutions or other establishments), since the main objective is to document their experiences, make their voices heard, and highlight their opinions and thoughts.

Interviews were conducted with ten persons with disabilities who are or were previously institutionalized. However, one interview was discarded because it did not fully meet the following criteria:

- All respondents lived or still live in institutions exclusively operating with and for persons with disabilities in Palestine.
- The sample, although small, must reflect views of both genders, and different types of disabilities and geographic distribution.
- The participants must have the desire to participate and ability to express and represent themselves.
- Participants should be 15 years or older.

The snowball approach was adopted in the selection of respondents, drawing on acquaintances and their acquaintances (who have had the experience of being institutionalized), i.e. an informal selection process, except for one respondent, who had a developmental disability, hence we communicated with the administration of the institution in which she stayed for the purpose of interviewing her. The interviews were held in person in May 2024, except for one interview which was conducted by phone due to the lack of time and difficulties on the roads.

The research team ensured the following while conducting the interviews:

- The respondents were informed and aware that the research team respects their privacy and confidentiality, i.e. they would neither share their personal data with any other party, nor disclose their names or any of the information that may identify them, and that they are informed of their personal right to refrain from responding to any of the questions.
- Conducting interviews in appropriate locations that are accessible.
- Providing the necessary arrangements, such as sign language interpretation by an interpreter they select or approve of.
- Ensuring that the respondents clearly understand the subject and goals of the research, and obtaining their consent to complete the interview.
- Obtaining the respondents' consent for recording the details of the interview by typing directly on computer during the interview.

Information about the sample

As mentioned earlier, ten persons with disabilities were interviewed, of whom nine were used for this report, and one was discarded because the institution in which the person attended was not exclusively for persons with disabilities.

Age groups: Five of the respondents are 17-25 years old, while four are 26-44 years old.

Gender and social status: all the respondents are single, three are males and six are females.

Type of disability/difficulty: Two respondents have partial visual disability, one has full visual disability; Four have hearing disability, three with partial disability and one with full hearing disability. One respondent described the difficulty as learning difficulty in school, and is institutionalized at an institution for persons with developmental disabilities. One respondent said that he has motor difficulties that aggravate when he is outside the environment where he lived.

Place of residence: Six respondents are from Ramallah governorate, one of them has been living since 32 years at an institution in the Bethlehem governorate; two are from Hebron, and one is from the Nablus governorate.

Regarding the **geographic distribution** of the institutions, two institutions in which the respondents live are in Ramallah, one is in Bethlehem, one is in Jerusalem and one is in Jenin.

Regarding the educational level and work, three respondents have Bachelor degrees, two are either university or college students, two are still in school and two did not complete basic education. Most respondents do not work except one, and another held several jobs until October 2023.

Regarding **the period of institutionalization of the respondents**, it ranges between two and a half years to 32 years as follows: one respondent has been institutionalized for 32 years and still is, four spent 10-12 years, one spent seven years and two spent 2-5 years at institutions. One respondent said that he could not remember, but feels that he spent a long time (years) there. The year in which the respondents left the institutions ranged between 1995 and 2023. Three respondents are still institutionalized.

FINDINGS

Since the sample is small, it should be noted that the findings below are not representative and cannot be generalized. The findings aim to guide and shed light on the main issues to be considered when planning and designing future research on this topic. Please take note that the names of persons or institutions mentioned in quotations were replaced by symbols.

How and why the respondents were institutionalized

Three respondents of those who have visual disability expressly stated that institutionalization was not their decision and did not reflect their wishes, but was the decision and wish of the parents. They attributed that decision to the (difficulty of) their disability. It is worth noting that some tried to enroll at regular schools in their places of residence, but they were either rejected or faced bullying by students, which made the school administration push the parents to transfer them to special schools for the deaf.

A respondent said, “I said I don’t want, I don’t want, then it became fine. First I had no friends, then when I had friends and got used to the situation”.

(A young man with hearing disability, 17 years old).

In response to the question (of how and why respondents were institutionalized), a respondent said she could not remember:

“I don’t remember, I was young, I was at a nursery school for persons who can hear. Then the teachers decided that it is hard for me to stay, and told my parents and … it was expensive, and the place was far, and some people told my parents that the institution has a boarding section, so they decided that it would be easier and less costly in terms of transport and such”.

(A young woman with hearing disability, 22 years old).

While the parents of a respondent have always wanted him to be institutionalized, he did not want that for himself. However he made the decision unconsciously, following a call he received from a teacher at that institution. He himself does not know how he agreed, maybe out of embarrassment. He explains:

“Education… to have braille skills and get away from certain people who surrounded me, with no participation in the community or something like that”.

(A young man with visual disability, 23 years old).

A respondent who was institutionalized at the age of ten said that she took the decision by herself, after she accepted the fact that she had a visual disability. At the same time, a teacher at the regular school told her that she must go to a special school for the blind, and this may be the reason. At the same time, her sister was at the special school, and the school itself was promoting its services through home visits. As she put it, it was both her parents and her own willingness. Describing the reason for institutionalization she said:

“I always knew the answer, simply because I have a disability. If I do not go there, there would be no other place, either staying ignorant or living in such a place”.

(A woman with visual disability, 42 years old).

The response of one participant revealed that the decision of institutionalization was neither wished for by her or by her parents, but the only option given the fact that regular schools at the time rejected students with disabilities. She explained:

“That they consulted me to see whether I agree or not, no, but they notified me, otherwise I would not have spent two years crying and upset. The problem is that my parents were forced to opt for this choice, because the schools in our community rejected me, the principal rejected me. I knew that as my father refused to let me go and he was crying when they took me. My mother convinced him until he agreed. This is what I heard later. Neither my parents nor I consented as far as I know. I remember well that both my mother and I were weeping. She wept in silence, and I felt her shaking because she was hugging me. My sister told me that my mother cried day and night throughout all the time that I spent there. I knew this recently, only few months or one year ago”.

(A woman with visual disability, 40 years old).

A respondent pointed out that the information on the institution and staying there was presented to his mother, not to him. He said that the reason for that and for not participating in taking the decision was that he was young then. As for the reason for being institutionalized, he said:

“Because of the disability I have, the disability I have; they told my parents, send him there so that he would get better and receive treatment. When I am young, everything is easy”.

(A young man with motor disability, 31 years old).

A respondent said that the death of her mother was the reason for institutionalization. She said, “My brother brought me here, got married and left the country; my mother had died”.

(A woman with developmental disability, 40 years).

Since receiving services is one of the main reasons that push the parents to opt for institutionalization, we monitored the services that some received, or still receive at those institutions. The respondents who have visual disability indicated that these services are: educational and accommodation services, training courses in technology and developmental services such as memorizing the Quran. A respondent said that the institution sometimes provided clothing, while another said that she learned swimming. In addition to educational services, the respondents with hearing disability said that they had speech therapy sessions, especially in the past, in addition to life skills, though limited according to a respondent. Some added receiving recreational services, while others mentioned other services such as physiotherapy and play. It is noted that the respondents do not perceive institutionalization as a service, as they do not mention it, except for two respondents.

Regarding the services that strengthen self-reliance and autonomy, most respondents said that there were no services at the institutions that specifically taught such skills, but some said that they learned them on their own. One respondent said that the lifestyle at the institutions pushes them to learn and acquire such skills. Another respondent said that she did not have to learn and practice skills such as cleaning pots, tidying up, caring for others and similar skills at an early age. Two respondents said that they learned using the white cane, and one said that she received two lessons only.

Regarding the question on extra-curricular activities at the institutions that enable meeting persons from outside, the responses revealed that there were some attempts to visit other schools or to enable meeting other students during such visits, however, the respondents said that those visits did not constitute opportunities for getting to know others. Some added that there were some extra-curricular activities, but were insufficient. Respondents almost unanimously agreed that they would have preferred to have athletic activities, games and visits to clubs, parks restaurants and others.

Regarding the availability of services in the respondents’ places of residence, there was full agreement that educational services were available in their places of residence, but that they lacked the necessary services that respond to individual differences among students. Such services include sign language, the braille system, and other services that must be available to provide opportunities of quality education to the students with disabilities. In this regard, a respondent said:

“Education is available, but a person with visual disability faces extreme difficulty to obtain it. There is a difference between availability of service and accessibility to the service”.

(A woman with visual disability, 42 years old).

Another respondent added:

“Because they expelled me and I often ran away; they also told me that deaf persons are not allowed to stay with those who can hear. The school administration said it is difficult for them to stay together, and asked my parents to transfer me”.

(A young man with hearing disability, 17 years old).

Regarding the weekly schedule of students with disabilities at the institutions, five respondents said that they used to go home to their families on Thursdays and back to school on Sunday morning. One respondent said:

“I visit my sister when she wants me to, but now I do not visit her because the roads to Ramallah are closed”.

(A woman with developmental disability, 44 years old).

Another woman pointed out that at first she went home regularly every one or two weeks. She remembered that once she could not go home because of the Ibrahimi Mosque Massacre. She added:

“Yes, we always met except during the Ibrahimi Mosque Massacre because there was a complete curfew, no one was allowed to move. During that period my parents used to call and try to talk to me all the time, but the school did not let them reach me telling them that I was in class. They did not tell me that my parents called, for three months. During all that period, I thought that my father was angry with me and did not want to come and pick me up”.

(A woman with visual disability, 40 years old).

Responding to the question on communicating with parents during their stay at the institutions, the respondents almost unanimously agreed that communication were allowed only in cases of necessity. Some respondents who either left the institutions during the past years or are still there pointed out that they have to hand over their cellular phones once they enter the institutions and get them back on their way home. Only two respondents said that they could communicate with their families whenever they pleased, and only had to notify the staff of their wish. One respondent said that they had no means of communication, and that her parents did not seek to contact her, unlike the parents of other students.

Responses to the question, “How did/do you spend your time at home?” included spending routine time with the family and cousins, playing with friends, eating favorite foods including sweets, spending the longest possible time outdoors, and some interesting responses such as:

“When I was younger I liked going back home more. Then after (I reached) class five or six, I started to prefer staying at school, because of my friends and sports, and because we the deaf stay together. At home, they all speak quickly and I do not understand them. When my father used to give me something, he would speak for a long time, but the interpretation of my father’s talk would be short”.

(A young woman with hearing disability, 22 years old).

Respondent descriptions of their experiences in institutions (thoughts, attitudes and emotions they live or remember)

It would not be possible to say that responses to this question were easy to digest. This is because each line or paragraph describes the experiences of persons with disabilities at institutions is unique and does not apply to all. Although there are only nine respondents, however, every word or statement constitutes a subject worth exploring and researching, whether we link those responses to a specific context or consider them in different contexts. Nevertheless, some thoughts and emotions were relatively common among respondents, such as dislike of the strict system, fear, especially at early stages, feelings of deprivation, and comparison between the faculty and the supervisors at the boarding sections. Some said that teachers treated them better, while others complained about the unjustified cruelty of teachers. A respondent said:

“In the afternoon, at the boarding section, the treatment of the supervisors was not acceptable at all. It was extremely bad. (Except that) one older supervisor was compassionate with the students and helped them. They yelled at us all the time, and some students were beaten, not for discipline, they were beaten very violently. Sometimes they deprived us from specific things, such as certain activities; sometimes students were deprived from food. I was always determined to leave this school, I cannot stand this place, Some students, including myself, were upset with some supervisors because there was discrimination among students”.

(A young man with visual disability, 23 years old).

Another respondent said:

“There are two stages: At an earlier stage, when I first joined as a child, things were normal, there were no difficulties or problems. I did not feel any psychological pressure or problems. Later, I started feeling difficulties, I started to understand things. I remember that food did not taste good. I did not like fish, but if I did not eat fish, there was no alternative”.

(A young woman with hearing disability, 25 years).

Describing the fear, agitation and confusion, a respondent said:

“During the first week I did not understand anything; the teacher yelled at me … write, and I could not understand what is required of me, I was scared. Then when I stayed with my sister I was relieved. The teacher yelled and the students looked at me because I was new”.

(A young woman with hearing disability, 22 years old).

Another respondent said:

“Those places remind me of deception. They may look nice from the outside, and convey to people messages of values. However, within the walls, there are many scary things, such as control and domination. Those things used to upset me”.

(A woman with visual disability, 42 years old).

However, the respondent herself asserted that the experience in general was useful, and just like any other experiences, has its advantages and disadvantages.

Another respondent with visual disability too, who had left the institution in 1995 after spending four and the half years there, described details of her first day there. She mentioned crying heavily and feelings of disappointment because the teachers lied to her and told her that her parents had left the premises, but she discovered later that they had not left. She also said that she felt lonely because she stayed at a section with older students.

One respondent who was institutionalized in Jerusalem while he is from Ramallah, remembers a situation he has not been able to free himself from:

“The conditions were very bad, checkpoints and army; once the soldier was about to shoot me, I remember this until now. We did not have a permit, and the soldier told my mother: go away or else I will shoot him. However, the experience at the institution itself was very nice”.

(A young man with motor disability, 31 years old).

On the other hand, the majority focused on having a community of friends at the institution, with whom they shared feelings, experiences and means of communication they lacked with their own families and communities. Hence, some preferred the institutions despite the other conditions that they disliked. This became evident in the subsequent sections of the report. Two respondents clearly confirmed that the institutionalization experience was very good in terms of receiving the services they needed, and the treatment of the staff, one with motor disability and another with developmental disability. It is noted that both used words like “happy” to express their feelings.

Respondent descriptions of the treatment and communication of staff at the institutions

Questions were asked about the treatment and communications of the staff at the institutions, their conduct in general, reactions to inquiries and comments, responses to comments, opinions about the reasons for such treatment and communications, whether they believe that they changed with time.

The majority of respondents indicated that the most prominent practices were violent, discriminatory, controlling, dominating, and included ignoring the comments and remarks of people with disability. Seven respondents with hearing and visual disabilities said so explicitly and implicitly.

A respondent described violence and discrimination as follows:

“They used beating, deprivation and intimidation; they often tried to discriminate among students and used methods that encouraged subversion and compelled us to talk more than we should, and say things we should or should not say. They used a mix consisting of kerosene, oil and vinegar for our hair, claiming that it is for hygiene. This mix was very harmful and caused burns in my neck and scalp, not mild burns. Add to this all forms of beating, with sticks and shoes that I used to suffer from or watch others suffer”.

Upon explaining discrimination she said, “Sometimes, we saw them discriminate in favor of a specific student in class, whatever she did she would not be beaten or yelled at, while other students would do nothing, but would be beaten. You would never know the reason, they used to beat us for no reason or for small things. This created rivalries among students, and favorite students would be pampered, unlike other students”.

(A woman with visual disability, 40 years).

No one told her anything about the person to whom she should submit her comments she pointed out that the social worker was not the best option. She also said that the only way that her mother knew that she was suffering from violence was when she noticed the bruises on her body. This could not be linked to a specific period, however the respondent left the institution in 1995. One respondent who left the institution in 2016 described the violence and the discrimination as follows:

“For example some teachers were violent; one teacher used to hit any student she did not like, or who made any mistake; she would immediately hit him for reading mistakes, even if he only read “a” instead of “o”. My classmate made a mistake in reading, so she held his head and hit it on the desk. This happened for the simplest mistakes. A teacher taught small children in the first and second grades; when they made mistakes, he hit them with a hose and hurt them."

He added, "The most violent persons were the supervisors. They used their hands to hit, they were tense; they cursed and said bad words. Violence was not only physical, but also psychological and verbal violence and have a grave impact. Sometimes when they merely see someone they do not like, they hit him immediately, regardless of the type of beating. This person would be humiliated in an inappropriate manner. Even if it was cold, the supervisor did not care; she would let him stay outside in the cold, and would not allow him to move for at least one or two hours. I used to go to school on Sundays, and on my way to school, I literally felt that I was going to jail".

(A young man with visual disability, 23 years old).

This young man confirmed that a social worker used to listen to them and asserted that she would look into their complaints. He added that that social worker played a role in adding motor education service, i.e. the use of the white cane. However, violence did not stop until the last day of school, as he said, although the social worker always promised that she would look into the matter.

One respondent pointed out the differences between the teachers and the supervisors at the boarding section. She said that the quality of education was good, and commended the way the teachers treated the students. On the other hand, the supervisors practiced control, domination, humiliation and blackmail:

"In the boarding section, we did not eat like we ate at home. They would shame us and tell us we provide for you, your parents abandoned you".

(A woman with visual disability, 42 years old).

A respondent with hearing disability described the violence and neglect as follows:

"Teaching always involved beating, all the time, since a long time until now, day, night and noon, all the time apprehension". She stressed that there was no specific person assigned by the school to whom she could talk and say her comments. However, she would tell the students, the school principal or her brother who in turn would tell her parents. She added, "I would tell the supervisor, and she would ignore me, then I would tell the principal, then she makes a program for cleaning, dishwashing and mopping. We clean at the boarding section. I tell the principal when the supervisor hits the children, (but she responds that) a light beating is ok, but not much".

(A young woman with hearing disability, 17 years old).

Another respondent at the same institution and of the same age group confirmed maltreatment (violence and neglect/lack of attention), adding injustice. He described the situation as follows:

“During teaching the punishment is harsher on students (these days). Before they used to hit the hand, but now there is a lot of beating, yelling, tension and calling parents”.

(A young man with hearing disability, 17 years old).

A respondent with developmental disability asserted that she was treated well, and emphasizing this by insisting on using words such as (I love them and they love me). She asserted that she knew to whom she could go if she had any inquiry or problem. Another respondent with motor disability also noted that he was treated well, and that he left the institution because he felt that his presence bothered the mothers of his female colleagues. He added that if he had the opportunity, he would go back there immediately.

In an attempt to explain the causes of such violent practices, respondents gave three major underlying factors that require research. The first factor is the lack of accountability and follow up from any party, including parents, either because of a lack of interest or a lack of awareness towards such practices. A respondent described the situation as follows:

“Often parents are ignorant of what happens inside the institution or school, either because they do not care, or are indifferent, or because they do not know. Sometimes, the reason is the students themselves. My mother said I always asked you but you never told me. The lack of accountability by the parents or by official parties enabled them to do as they please. However, many students stayed at the institution throughout the year, and did not go home at all. Those were probably the most vulnerable and susceptible to violence and abuse because no one cared for them. However, this is not necessarily the case, because we used to go back home all the time, but we did not speak up”.

(A woman with visual disability, 40 years old).

The second factor is the lack of selection criteria (in choosing) the staff at institutions, particularly the staff of the boarding section. One respondent said that the supervisors at the boarding section mostly come from difficult socio-economic backgrounds. The third factor is poor accountability, control and internal evaluation systems at those institutions, which raises several questions on how the staff perceive themselves and their roles and responsibilities, their perceptions of persons with disabilities, the compliance of those institutions with the principle of respect for the inherent dignity of students and beneficiaries, and more. This factor stems from the comments of some respondents, such as:

“Because they do not treat their students as if they are under their custody, guardianship and care , or as family members, spending a long time with each other eating and drinking together. They think they are here to control others, not to give a feeling of family and kinship”.

(A young man with visual disability, 23 years old)

“Because they think that we do not like to learn and we only want to play. When we told the principal about a teacher who slapped us or beat us with a cane or a hose, she would beat us more severely when the principal left, and when we remained silent, she would tell us we are clever”.

(A young woman with hearing disability, 22 years old).

Responses to the question comparing the current and previous conditions at the institutions varied. While a respondent said that things remained the same, because the reasons for the practices, such as lack of control and accountability, persisted, another respondent said that things improved, because the educational counseling directives have been disseminated (and therefore used by staff). A third respondent mentioned what she heard from her friends who are still institutionalized, and who say that things got worse. Another respondent said that he did not know and he did not want to know anything about those institutions.

Responding to the question on whether they would have chosen those institutions if the decision was theirs, six out of nine said “no”. Explanations of their responses included issues such as violence and the fear of violence, refusing the approach of isolating persons with disabilities, and preferring the approach that enables their inclusion in society and staying with their families. One respondent said:

“It is impossible for me to sleep in an institution which I chose. Once the religion teacher hit me with a silicone dispenser on my hand and it was very hot. I was devastated; beating and burning at the same time. It is impossible for me to choose such a school. They must fire them and hire a new team that knows how to treat the students, both the boarding team and the school team alike. True we may make mistakes, but the method of punishment is not right. There are things that cannot be erased off the body, such as burns. She beat me with metal, there was a teacher whose name I still remember (S), who beat us the most. Even when we told the school principal she would tell us it is your fault. When she beat us, we would run away, go to bed or anywhere. We would stop breathing, although they should have taken us to hospital”.

(A young woman with hearing disability, 25 years old).

Another respondent said:

“After trying both ways, frankly during my childhood, I did not know. But now I think definitely not. The feeling I had, violence and other feelings, it was like a prison. I believe that every human has the right to be raised, live and grow with their parents. Those schools are part of a system and of policies of exclusion and isolation. They leave very negative consequences on the persons, who themselves become violent; if they are (not) conscious of the situation and make effort, they will have a very negative impact as the person will be violent and have a weak personality. Many people whose stories we heard at those institutions say that they grew up with distorted personalities, they were shy even to say their names, they would say their names in very low voices, not heard at all. They also cause isolation, exclusion and create a gap between the person and the surrounding community. The persons need a long time until they can accept their original communities".

(A woman with visual disability, 40 years old).

Another respondent said, "Not at all, because there is a lot of punishment. When I quit and get out, I do not consider visiting the school. This is the reality".

(A young man with hearing disability, 17 years old).

Responding to the same question, three respondents said that they would choose the institutions, either because they could receive services that meet their needs, or as one respondent put it:

"Yes, I would choose to be here, why would I stay at home alone?"

(A woman with developmental disability, 44 years old).

Asking whether the respondents would select boarding or day schooling, six of them said that they would not select it at all even if it was a day school, three respondents said that it would not be their option for their sons or daughters if they needed different forms of learning, while two said that they preferred if it was a day school. One respondent said:

"Yes, I swear to God, yes, I would prefer it as such. I was young and I wanted to play with someone. I wanted to see people. I thought and said that I wished it (the school) were close. What can we do, but those are memories that I can't forget until today".

(A young man with motor disability, 31 years old).

Another respondent added:

"Certainly, my nightmare was accommodation, not more. The institution itself provided good academic services).

(A woman with visual disability, 42 years old).

A respondent with developmental disability does not prefer to be at day school, because:

"My room is here, and everything I have is here".

(A woman with developmental disability, 44 years old).

It is worth noting that a respondent who said that the institution would not be his option if it were his decision, said in response to this question:

“Boarding is better, we have fun together, now I am at home alone. I am isolated with the people who can hear around me. Most of them make fun of the deaf, especially young people, I want to be with the deaf, but they are far away; each one is in a different town; transportation has a cost; if they ask me to go today and sleep over, I will go, but in two sections, one for boys and another for girls, so that everyone feels at ease”.

(A young man with hearing disability, 17 years old).

When respondents addressed the advantages of institutionalization, they unanimously agreed that education in these institutions is better. In addition, some mentioned play and music. Most respondents said that those institutions constitute an environment that enables building friendships that with time become like family. As for disadvantages, the respondents reiterated previously mentioned issues, such as violence, discrimination and isolation.

Respondent reactions to suggestions for making institutions more comfortable and satisfying

It is worth noting that the respondents found this question hard, possibly because some do not believe in institutionalization, hence they find it useless to consider the question. The other respondents failed to envisage change as an option. In both cases, expressions like (but institutionalization still exists) or (if only change was in your hands) came after the question. In both cases, responses revolved around several points such as: changing the administration and the staff, improving the quality of food, developing control and accountability systems, improving the quality of education especially the teachers of the deaf students. Some added developing the skills of the faculty in the use of the sign language and in explaining some subjects. Furthermore, implementing a number of extra-curricular activities such as music and sports; setting clear, professional and accurate standards for selection of employees, in the administration, faculty or accommodation supervisors and enhancing communication with parents and friends outside school and changing the treatment of the staff (towards students). Some also mentioned canceling the boarding sections completely.

Respondent views on the possibility of adopting inclusion or deinstitutionalization in the near future

In responding to this question, the respondents were split between those who believe that deinstitutionalization and inclusion constitute a necessary and possible approach, and others who firmly believe that it is not possible, so long as the reasons that pushed them towards institutionalization have not been radically addressed. One respondent said:

“It is not possible unless teachers learn the sign language and have clear and comprehendible pronunciation. There are concerns towards this idea and I doubt that it is possible (to implement). I am willing to travel so that my son learns in the best place”.

(A young man with hearing disability, 17 years old).

Another respondent said:

“In the near future no. So long as the system, policies, and government are the same, definitely not”.

(A woman with visual disability, 40 years old).

On the other hand, the contrasting view indicates that:

“Yes, definitely, it is a must to have deaf and hearing persons in the same environment”.

(A young woman with hearing disability, 25 years old).

Another respondent said:

“Yes, definitely, because of the development of technology and even of the community. There are activities that explain ideas to the community. The day will come when there will be radical change, because of the activities and the research that all of us do. This will strengthen the educational opportunities outside those schools”.

(A young man with visual disability, 23 years old).

One respondent who works as a teacher at a public school described the current situation as follows:

“Currently this is the situation, but the students do not get the necessary academic services that we received. In Hebron, they go back home every week now, however the academic services at (S) Society in Hebron are not like the services we used to receive. Nowadays, there is institutionalization up to a certain age or class, for example Class 7. However, the students leave while still in need for further special attention. In public schools, the blind students must be very smart so that they do not get lost. This has particular importance/specificity in cases of disability. It is harder to obtain the educational material such as books, summaries or other material (in public schools) in comparison with institutions”.

(A woman with visual disability, 42 years old).

Finally, responding to the question on additional subjects they wish to address, two respondents identified two issues: the architectural environment at institutions and the extent to which they cater for individual differences, and comparing those institutions with regular schools, particularly by the persons who had the opportunity to attend both.

The young man described the institution at which he stayed a follows:

“The building’s design was very bad. It was interconnected, a blind person would get mixed up between the different entries. There were pillars in the middle of hallways or rooms, to the extent that my friend who was jogging hit a pillar and had seven stitches in his head”.

(A young man with visual disability, 23 years old).

Another respondent said, in an attempt to compare between institutionalization and regular or public schools:

“It is more like, how can I say it, we were restricted to dealing with persons with disabilities. There I started to learn about persons with different social backgrounds, I started to know better about our traditions, even though I reject them, but I got to know them better. Competition in regular schools among students is stronger, as I noticed, I do not recall that at the institution I was competing with anyone. Of course because of the large number not all students get sufficient attention. There were 35 to 40 students in class, but the important thing is that I used to go back home, and I started to know my family. I had two sisters, and for some time I felt like they were strangers to me, as if I did not know them”.

(A woman with visual disability, 40 years old).

DISCUSSION AND CONCLUSIONS

As a person with disability who had been institutionalized for over ten years, I can say that much of the above research participant reports resonate with me, with many common factors in describing the institutionalization experience. (Yet) it is not possible to generalize those experiences unless we conduct research that targets representative samples and explores this experience from its different perspectives. However, based on the data at hand, it is possible to say that institutionalization is not necessarily an easy and smoothly accepted experience for persons with disabilities at the psychological and social levels. At the same time, institutionalization creates a state of confusion and disorder in the minds of several persons with disabilities, as on one hand, it entails many details and practices of the staff at the institutions, which may be described as lacking in the respect for human dignity and not compliant with the right to personal safety and protection from violence and abuse. On the other hand, institutionalization creates a micro community among the students with disabilities in which they live a state of cohesion, solidarity and rapport, based on the commonalities and the collective identity that crystallizes as a result of their experience with disability on one hand, and the lack of such feelings with their local communities and the surrounding institutional and social structures on the other hand.

This does not necessarily mean that the families are not loving or accepting, but they simply do not use the suitable language, be it the sign language for persons with hearing disability or another language for interaction, and this is reflected in the conduct or practices that restrict mutual understanding and sense of belonging among the persons who have other forms of disabilities. I recall facing several situations where the respondents of this study also pointed out, such as verbal, physical, psychological and sexual violence at the institution in which I stayed. I also remember the internal conflict I suffered from at the intellectual and emotional levels, which made the day I left the institution a very difficult day. This was followed by a long summer vacation, with a lot of intellectual and psychological stress, isolation, and the feeling that part of me has been severed. I had to face that alone, until I made the decision that I had to rise again, pull myself together, and make up new motives that would help me build a life other than the one I knew. This blend of pros and cons of institutionalization must has its toll on the thoughts and feelings of persons with disabilities, which requires further probing and studying.

In general, the contours of institutional experiences which can be discerned in this report revolves around essential issues as follows:

- The larger number of respondents opted and opt for deinstitutionalization, despite their confusion because of the friendships they make on one hand, and the services they receive in appropriate ways on the other hand.
- Few respondents indicated that they were partners in taking the decision to join institutions, while the parents took the decisions on institutionalization in most of the cases, because they were rejected at the schools that are close to their places of residence.
- Although the sample is small, it is worth noting that seven out of nine respondents, one way or another, mentioned abuse, maltreatment and discrimination of the staff at the institutions, including respondents who left the institutions thirty years ago and those who are still institutionalized until now.

Finally, it is necessary to develop a comprehensive and thoughtful methodology that enables the participation of all stakeholders including the persons with disabilities, their families, staff at institutions, and other actors in the disability sector such as activists, in addition to official and international parties. All those parties play varying important roles in shaping this experience and in either enhancing or restricting the institutionalization approach, and are important in order to arrive at a detailed and useful understanding of the institutionalization approach. Furthermore, this pilot research did not provide sufficient opportunity to deeply explore the perceptions of persons with disabilities towards de-institutionalization. In responding to some questions, participants exhibited some confusion about the concept of deinstitutionalization and inclusion. Hence, it is important to conduct a study that identifies the differences between the notions of de-institutionalization versus inclusion from the perspective of people with disabilities, and how their views reflect on work strategies of relevance, and which is more favored by them, in addition to examining the reasons behind such views on the one hand and how such strategies should be implemented on the other.