
DE-INSTITUTIONALIZATION OF PEOPLE WITH DISABILITIES IN THE CONTEXT OF A DEVELOPING COUNTRY IN CHRONIC WARLIKE CONDITIONS

**A Preliminary Policy Report from the West Bank, Israeli Occupied
Palestinian Territory**

Rita Giacaman, Professor, Institute of Community
and Public Health, Birzeit University, occupied
Palestinian Territory

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

Suzan Mitwalli, Academic Researcher, Institute of
Community and Public Health, Birzeit University,
Occupied Palestinian Territory

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Preliminary Policy Guidelines Based on Findings from Three Pilot Studies on De-institutionalization

1] There is compelling evidence that a critical issue requiring immediate action by the Palestinian Ministry of Social Development (PMSD) is addressing the problem of violence against people with disabilities housed in residential institutions. While the qualitative interviews with people with disabilities who have experienced life in institutions provide pilot research findings, the consistent reports of violence and undignified treatment of people with disabilities in these institutions among most of the research participants cannot wait for further research. It is clear that this is an issue which needs immediate attention at both the policy and implementation levels. The PMSD is responsible for people with disabilities and social protection in general and must pay attention to and deal with the problem of violence in people with disabilities institutions. This is part of its responsibility as clarified in the below linked document on its role and responsibilities towards people with disabilities (<https://www.ohchr.org/Documents/Issues/Disability/ProvisionSupport/Palestine.docx>)

Discussions should be initiated by the PMSD with the management and staff of residential institutions housing people with disabilities, and people with disabilities themselves and their families to uncover the underlying reasons for the use of violence in these institutions which is sometimes wrongly understood as discipline. This includes physical violence such as beating, hitting, or slapping, verbal/psychological violence such as shaming or humiliation, or deprivation of rights, such as neglect, deprivation from food or deprivation from play. Discussion should first focus on clarifying that service provision to people with disabilities is a right and not a charity or favor, then ways to deal with discipline without the use of violence. Based on such discussions, there is a need for: the training of staff to interact with people with disabilities without resorting to violence, implementing schemes for the regular support and supervision of staff and periodic inspection by MOSD, and ensuring MOSD enforcement of regulations which prohibit the use of violence in these institutions.

Similarly, the Palestinian Ministry of Education (PME), which is responsible for all schools and educational services in the country, should make sure that violence is prohibited in residential institutions of people with disability which offer schooling services; and, indeed, in all schools, whether those designated for people with disabilities or otherwise. In fact, the PME's Inclusive Education Policy prioritizes disability inclusion and including students with disabilities into the public educational system (<https://education-profiles.org/northern-africa-and-western-asia/state-of-palestine/~inclusion>). This requires improving educational access to regular schools for people with disabilities, and can gradually bring us closer to de-institutionalization as adequate essential services are provided in the community.

2] Local institutions and international donors must exercise caution when implementing de-institutionalization programs for people with disabilities which are imported from abroad. Such programs may not be suitable for implementation in the local context due to the absence of necessary local infrastructure, services, and ongoing financial and other forms of support from government crucial for the success of such schemes. While the notion of de-institutionalization is indeed attractive in principle, in reality, it has proven to be a problematic concept when implemented among people with mental illnesses locally and even in Western and more endowed countries, as the need for communal services and support continues to be lacking or insufficient.

3] There is an initial indication that local residential institutions serving the needs of people with disabilities offer vital services, such as education, which are not offered at the community level. And as such seem to provide an important service to people with disabilities. Residents can also mingle

with other people with disabilities and communicate and play together in ways not possible in the community (isolation by family, or, no sign language, no Braille etcetera). However, complaints about families of people with disabilities neglecting their children once admitted to residential institution was noted. In addition, institutions providing services to people with disabilities were in general described by respondents, who themselves worked in such institutions, as with staff lacking qualifications, insufficient supervision of food quality and among some, and even lacking cleanliness, all of which call on the PMSD and the PME to intervene in a participatory method by including people with disabilities, their families, and institutional representatives in discussion on how to improve living conditions in these institutions.

4] Based on these initial findings, further research is required to consolidate our understanding of the problems, difficulties and needs of people with disabilities who must live in institutions to receive essential services; to ascertain if, when, and how de-institutionalization can be implemented in the local context; and to investigate further the difficulties encountered by the staff and management of institutions housing people with disabilities and ways to resolve or minimize these difficulties.

Introduction

This preliminary report collates the results of three pieces of pilot research intended to provide insights into the issues related to the de-institutionalization of people with disabilities in the context of a developing country enduring chronic warlike conditions, the West Bank of the Israeli occupied Palestinian territory. We completed these pilot research pieces as a prelude for conducting more thorough studies on the subject. Their initial findings, however, offer the opportunity to provide preliminary policy recommendations geared towards institutions providing services to people with disabilities, in addition to the Palestinian Ministry of Education which is responsible for all schools in the country; and especially the Palestinian Ministry of Social Development which is responsible for the social protection of people with disabilities, and overseeing and supervising social welfare programs and services, including the provision of selected services to people with disabilities.

The pilot results of this report include findings from: 1] a review of the international and local Palestinian literature on the de-institutionalization of people with mental illnesses completed by Rita Giacaman; 2] results from eight pilot interviews with people with disabilities investigating their experiences living in institutions for people with disabilities and the pros and cons of such a living arrangement, completed by Shatha Abu Srour who is herself a person with disability and an activist in the disability rights movement in the occupied Palestinian territory; and 3] pilot visits to institutions caring for people with disability which were restricted to the Ramallah area because of unsafe out of town (and sometimes in town) road conditions at the time of these visits in the first part of 2024. This is when the Israeli war on the Gaza Strip beginning 7 October 2023 was raging, and at the same time, when attacks on Palestinians on West Bank roads (and inside West Bank cities, towns and villages) by the Israeli army and illegal Israeli settlers on Palestinian land were common, making it impossible to visit other disability institutions beyond those housed in the city of Ramallah. This last study was completed by Suzan Mitwalli.

Research Results

1] The Literature Review on De-institutionalization:

The review highlights the limitations of de-institutionalization as a principle and practice derived from Western paradigms and colonial psychiatric impositions on the country, and problematically implemented in non-Western settings, including the Israeli occupied West Bank. It is reminiscent of the imposition on southern countries of the notion of independent living of people with disabilities, when, in the Palestinian context and elsewhere surely, no one lives independently. Instead, persons are integrally linked with rights and responsibilities to family and community!

While as a principle de-institutionalization and life in the community seems like a good solution to the problems and sometimes, serious difficulties people with disabilities experience during institutionalization (see below), and can pose as an appropriate solution to the needs of people with disabilities, much must be done at the community level first in order to allow people with disabilities communal living where they can readily access services and live in dignity. However, this was shown not to be the case when de-institutionalization was implemented for Palestinians with mental illnesses/disabilities in the West Bank, a process largely pushed by international donors encouraging implementation with temporary funding. While the Palestinians professionals staffing primary health care clinics providing services to people with mental illnesses living in the community are doing their utmost to provide the needed support, people with mental illnesses and their families, struggle in the face of minimal supportive services at the community level other than the distribution of psychotropic medications through primary health care clinics. And even then, such medications are not always available. This Palestinian experience demonstrates the difficulties and limitations of implementing de-institutionalization programs for people with disabilities in the West Bank.

At the same time, the literature review also points to the problems and limitations of de-institutionalization in so called 'free' and prosperous countries and cities, including in the United States. It raises questions about how to deal with the needs of people with disabilities in the face of this community support and integration failure, yet with institutionalization, as we will see below, continuing to present various problems making life difficult if not unbearable for people with disabilities.

2] Experiences of People with Disabilities with Life in Institutions

This pilot study reveals that people with disabilities who have experienced institutionalization describe their experience of life in institutions as neither easy nor smooth at the physical, educational, psychological and social levels. It seems that being sent to an institution was generally reported as not the decision of the person with disability, but that of parents. Deaf respondents reported that when they were integrated into regular schools, they were rejected or faced bullying by students, making the school administration push parents to transfer them to special schools for the deaf. In general, people with disabilities disliked the strict system implemented in these special institutions. They reported feelings of fear especially at the early stages of institutionalization, feelings of deprivation, and complaining about the unjustified cruelty of teachers.

The majority of respondents revealed that the most prominent practices were violent, discriminatory, controlling, dominating, and included ignoring the comments and remarks of those living in these institutions. They reported on the abuse, maltreatment and discrimination exhibited by the staff at

these institutions. Notably, respondents found the question on suggestions to make institutions more comfortable and satisfying hard to answer and in a way a useless question, as some could not envisage change as an option.

Nevertheless, some emphasized changing the administration and staff at the institution, setting clear professional standards for selecting employees, changing the treatment of staff towards students, developing control and accountability systems, improving the quality of

food, improving the quality of education, implementing extra-curricular activities such as music and sports, and enhancing communication with parents and friends outside school as priorities for improvement.

While institutionalization was reported as having its burdens, it also has its benefits. On one hand, staff practices in these institutions can be described as lacking respect for human dignity and not compliant with people with disabilities rights to personal safety and protection from violence and abuse. Yet, at the same time, institutionalization also creates a micro community among people with disabilities with life described as in a state of cohesion, solidarity and rapport based on the commonality and collective identity developed because of the experience with disability; in contrast to the lack of such feelings in their own local communities and surrounding institutional and social structures.

Notwithstanding these stated benefits, most respondents opted for deinstitutionalization, despite the friendships they form and the services they receive in these institutions.

A person with hearing disability explained:

“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 person with visual disability reported that:

“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.”

The results finally underscored the need for future thorough research on this subject which should include people with disabilities, their families, staff at disability institutions and regular schools, actors in the disability sector such as

activists, in addition to official and international bodies. All play a vital role in shaping the institutional approach and need to be included in future research and discussion so that a comprehensive understanding of how institutions could better address the needs of people with disabilities can be reached.

3] PWD institutions' visit

Discussions took place with either the principal or manager of these institutions providing services to people with disabilities, and focused on understanding what type of services are offered, but more importantly for this report, their views about the advantages and disadvantages of the institutionalization of people with disabilities.

An advantage of institutionalization was reported as students mingling with each other, communicating and playing together, other than of course being educated. It was emphasized that children who use residential services do better than those staying at home academically, as not all mothers know how to teacher their children (for example with knowing Braille) or do not care much. In

addition, institutionalization relieves students and their families from having to pay the cost of travel and general travel difficulties and road problems (prevalent on the West Bank because of Israeli army checkpoints and periodic army and illegal Israeli settler attacks and exposure to their violence on roads). It was noted that institutions have more facilities for use by people with disabilities compared to homes, making them more accessible. Additionally, institutionalization is important for people with disabilities who need protection if they experience violence at home, or have no one to care for them financially or otherwise.

The disadvantages of institutionalization reported included being away from families depriving students from 'tenderness'. It was indicated that generally students like to stay at home, not in an institution. Complaints about families were noted: some families were reported to neglect their children with disabilities; sometimes no extra clothes are brought for children staying overnight, so the institution buys them clothes. Some institutions were described as lacking cleanliness staff qualification, food quality, and insufficient supervision.

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