

**The dilemmas of deinstitutionalization globally
and as applied to Palestinians in the Israeli
occupied West Bank**

Literature Review - April 2023

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About Disability Under Siege

The Disability Under Siege Network+ Project is a co-created programme bringing together a community of researchers, educational practitioners, advocacy organisations and disability led groups in the UK and Middle East. It will contribute to research efforts by providing intellectual and logistical resources that local practitioners need to transform education provision for children with disabilities in conflict-affected countries.

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Abstract

This essay is intended to help understand what the concept of de-institutionalization is really about, and its benefits and burdens as applied in practice in both developed and developing countries. It is part of a larger project on de-institutionalization which has brought researchers together from Birmingham University in the UK, The Center for Lebanese Studies in Lebanon, the Islamic University of Gaza in the Gaza Strip, and us at the Institute of Community and Public Health, Birzeit University, the West Bank, Israeli occupied Palestinian territory. The essay begins by reviewing the international literature and then the grey literature as this pertains to the occupied West Bank, with an eye on de-institutionalization's successes and challenges so that we can learn from worldwide and local experiences in working towards relocating people with disabilities (the mentally ill in the main) from hospital to community and the provision of alternative community services.

A historical perspective

The deinstitutionalization of people with disabilities movement did not begin until the mid-20th century. (Scull, 2021) Before then, and during the 19th century, mental illnesses (and likely other disabilities although other disabilities are hardly mentioned by the deinstitutionalization literature) were of little concern for the public in Europe and the US, among other countries. Mentally ill people then were taken care of by families with responsibility to their welfare, with confinement of the mentally ill a rare exception. (Grob, 1994; Roets et al., 2022). From the 19th century till the first half of the 20th century, people with mental disability in particular were generally segregated in large scale residential care institutions described as being located 'at the edge of society'. (Mansell & Ericsson, 2013; Roets et al., 2022) Other than isolation, a primary focus was also to cure disability, using medical treatment and therapies. That is, the desire to eliminate disability and mental illness in particular from the population was the dominant scientific and medical thinking in Europe at the time.

However, by the 1960s things began to change, with strong criticism emerging of residential care in general. The deinstitutionalization movement and process primarily focused on those with mental disabilities as the international literature indicates, with very little, if any, focus on the other types of disabilities. The rationale behind the deinstitutionalization movement is multifaceted but linked by a common factor which is described as rejection of the segregation of people with mental disability from the rest of society, which fed stigmatization among other



problems. (Mansell & Ericsson, 2013) This shift into community care worldwide was also influenced by reports of repressive institutional professional culture and poor living conditions, (Roets et al., 2022) human rights violations and abuses at psychiatric institutions, (Das, 2014) and the general belief that mental hospitals were cruel and inhuman. At the same time, it was thought that new antipsychotic medications would offer a cure. (Yohanna, 2013) That is, the advent of pharmacotherapy and the introduction of effective psychotropic medications (Taylor Salisbury, Killaspy, & King, 2016) were thought to have the capacity to cure people from mental illness, (Yohanna, 2013) or to effectively control symptoms, and allow those mentally disabled to live in community without major problems.

Deinstitutionalization was also reported to be linked to the rise of neoliberal ideas, (Scull, 2021) with social and economic policies adopted by governments reflecting neoliberal goals and orientations with interest in reducing public spending on services and support. (Teghtsoonian, 2009) The move to deinstitutionalized was encouraged by the resource problems of national governments looking for less costly alternatives, and influenced by an ideology of neoliberalism during a fiscal crisis which hastened downsizing the psychiatric system under what is described as ‘the guise of community care.’ (Das, 2014) Others emphasized the rise of market based approaches to service provision, intended to structure welfare provisions so as to reduce welfare expenditures, (Mansell, 2006) and where entitlements to services as a right are replaced by access only in extreme crisis. In effect, however, the deinstitutionalization paradigm significantly shifted the notion of cure into the idea of care (Roets et al., 2022) and integration in society and ordinary life of all people with disability in as much as possible. This is how the social model of disability challenged medical and pathological views of disability in the 1970s’s in the UK, for example, and other countries, including Scandinavia the United States and elsewhere.

This process had considerable consequences on thinking and practices, where, for instance, ‘insanity’ became a social problem, with new sociopolitical ideas about disability in general beginning to counter the medicalized approaches, leading to the de-institutionalization of thousands incarcerated in nursing homes and hospitals. (Tremain, 2005) Mental hospitals began to be seen as a figment of the past, a ‘bygone age’, with the provision of care relevant to communities and communal institutions. (Grob, 1995) ‘Resettlement’ policies, from hospital to community, began to be introduced for people with mental disabilities so that they



can live in arrangements which are more personalized than those of hospitals.(Kelly, McConkey, & Craig, 2019)

The shift to the community care ideology affected not only Northern but Southern countries as well, with various countries beginning to follow suit, including a range of countries across the globe including, for example, India, (Das, 2014), South Africa,(Petersen et al., 2009) Brazil, (Candiago, da Silva Saraiva, Gonçalves, & Belmonte-de-Abreu, 2011) Uzbekistan and Lithuania (Aliev & Salisbury, 2020)and elsewhere, and even the Israeli occupied Palestinian territory, that is. the West Bank and Gaza Strip, as will be discussed below for the West Bank. In the case of the West Bank, and many southern countries, the move towards deinstitutionalisation and community care was influenced by the knowledge produced in northern countries and the recommendations, funding and technical support of the World Health Organization,(World Health Organization, 2021) the European Union (Aliev & Salisbury, 2020)and other international aid and humanitarian groups working in the area. By 2008 the World Health Organization produced the mhGAP intervention guide(Organization, 2008) to help low and middle income countries assess and manage mental, neurological and substance use disorders in the community by non-specialized primary health care personnel because of the dearth of specialized personnel in what is called resource poor countries.

Deinstitutionalization in practice

The process of deinstitutionalization proved to be fraught with problems however, which were experienced in both northern and southern countries, although perhaps more severely so in the south; and with the claims of the effectiveness of community care remaining a question mark. There was no testing of the philosophical basis of de-institutionalization, that is, the idea that it is better to treat people with mental health conditions closer to their families and work; no planning for alternative facilities and services; or addressing the inadequacies of the mental health delivery system in general. (Talbot, 2004) In fact, the underlying assumptions of this model of care proved to be problematic and described as rhetoric. This includes, for example, the assumption that the mentally ill had homes with sympathetic families, with organized households to support, and with the presence of the patient not causing hardship to the families. (Grob, 1994) In the United States, mentally ill patients were discharged from hospitals into urban community unable to meet their minimal needs, leading to some being admitted to penal and correction institutions, and others living



as homeless people in the streets. (Grob, 1994) In Norway, a study demonstrated that psychiatric problems remained frequent with a significant increase in behavioral problems in spite of total deinstitutionalization and improved living conditions. In fact, the study concluded that most mental health problems among those with intellectual disabilities are not solved by reorganization or deinstitutionalization, and those with intellectual disability had low social contact outside family and hardly any leisure activities other than watching television and listening to the radio, (Nøttestad & Linaker, 1999) in stark contrast to the assumptions made by the deinstitutionalization movement.

Others reported barriers to the successful integration of the mentally ill and the scale up of pilots, including the low acceptability of such a model by communities, poor engagement processes of clinicians responsible for the mentally ill coming in the way of adequate therapy, lack of targeted resources and poor stakeholder and policy support (Chibanda, 2018) among other problems. In the meanwhile some reported that community care was perceived as a failure by the general population, explained in terms of the increased homelessness in the minds of the public as linked to the closure of the asylums, and the perception that people with mental disability are violent. (Leff, 2001) Some report that community based system benefitted middle class people with less severe illnesses, leaving poor people and those with severe mental illness with inadequate services and difficulties in integrating into community. (Davis, Fulginiti, Kriegel, & Brekke, 2012; Merrick J, Uldall P, & Volther J, 2014; Yohanna, 2013)

Indeed, the rhetoric of deinstitutionalization and community care covered up the reality of the abandonment of the seriously mentally ill to their fate, (Scull, 2021). Importantly, the literature does not seem to sufficiently raise the issue of homelessness being associated with poverty and not merely mental health problems, and where solving the homelessness problem can bring about major improvements in communal living for those with and without mental health problems. Likewise, the literature does not seem to address a key gender related problem, that of the consequences of the deinstitutionalization of people with disability on the labor of women primarily and secondarily the family at home, as women especially are the main provider of free of charge care in the large majority of cases.

Thus several problems impeded the effective transition to disability community care, including the need for alternatives to the mental hospital which had to be provided before institutional



closure could take place and community care could be achieved successfully. To be sure, the notion of institutionalization is complex, and is not about simply reducing hospitalization or the reduction in psychiatric beds. (Shen, 2013) It must be coupled with improvements in the quality of care in hospitals, but at the same time increase access to quality care in community settings. Such moves should also include comprehensive social and other needed services, very much part of deinstitutionalization in order to support the mentally ill and their families as they integrate in community. In addition long term stay spaces are required for those who need ongoing residence, and this should take the form of smaller group homes integrated in the community instead of large institutions. (World Health Organization, 2014) These are only some of the requirements for communal living which seem to have been omitted from practice in the main.

Indeed, policy changes need to be coupled with financial inputs to support a range of community related care and services, requiring what is called bridging monies to facilitate new placements. That is, alternatives have to be provided before closure (or even downsizing) takes place. This includes different types of support at the community level, including day care, and various other types of home support, (Yohanna, 2013) including the training, (and supervision!) and the provision of community support workers (Mansell & Ericsson, 2013) as well as the effective training of doctors, nurses, social workers and teachers (Gavlak, 2016) at the primary health care level in addition to their effective supervision in order to assist the disabled and their families in dealing with daily life and arising problems. All this requires necessary resources, not easily found in times of austerity, and reduction in government funding.(Das, 2014; Kelly et al., 2019; World Health Organization, 2014)

Efforts must also be placed in solving unemployment and homelessness problems among the disabled who make the transition to the community, which if not address, can contribute to relapse and what is called the revolving door syndrome, i.e. the move back to mental hospital.(Hamden, Newton, McCauley-Elsom, & Cross, 2011) Likewise there is a need to address the issue of communal acceptability and dealing with the stigma associated with disability in community.(Chibanda, 2018; Leff, 2001; World Health Organization, 2014) Otherwise, if such preconditions are not met and as has been shown for southern countries in particular, (Das, 2014; Petersen et al., 2009) community care turns into selective and verticalized programming of pill distribution instead of addressing universal access and



embodying participation, an experience which has prompted some to call back for hospital care by building better state hospitals given that deinstitutionalization has failed. (Gralnick, 1985)

Overall, while the concept of de-institutionalization has merit, is compatible with human rights and ethical principles, is attractive and can captivate the imagination over what could be, a panacea of sorts, in reality, its implementation is generally sub-ideal, often translating into verticalized programming and the dishing out of psychotropic medications at the primary health care level, leaving people with disabilities and their families to endure the consequences of the lack of effective support for life outside the hospital and in the community. And, this is indeed the situation of the Palestinian Israeli occupied West Bank.

De-institutionalization of people with mental disabilities on the West Bank

Historically, Arab societies, including Palestinian society, were described as being tolerant and caring of the mentally ill, (Harvey & Ibrahim, 2005) with a long tradition of caring for the mentally ill in hospitals and the community. When non-violent, the mentally ill were allowed to walk in streets but were confined at home only when violent. (Keller, 2001) While such a description is likely a romanticized version of reality which does not take into consideration the labor of and burden on families, especially women, in caring for the mentally ill at home, it is nevertheless a contrast to the historical condemnation and exclusion of mental illness in European Societies. (Murad & Gordon, 2002). This changed with the advent of colonialism and the British Mandate over Palestine of 1920, signaling the introduction of colonial psychiatry, and the arrival to the country of an era of more coercive practices.

Because of the need for addressing mental health problems, likely influenced by the zeal of the British Mandate personnel for wanting to demonstrate that they are good administrators, and the likely impulsive idea of replicating what is in Britain in the newly colonized area as part of its 'mission civilizatrice', the British colonial administration opened a governmental hospital in Bethlehem in 1922. (Giacaman et al., 2011) It established a system modeled after the British system to admit what they called 'lunatics' to asylum. It may not have been a coincidence that the hospital was opened in Bethlehem, Palestine, in tribute to the first asylum for the mentally ill in the UK, the Bedlam hospital which was founded in 1247, and known at the time as the



Priory of St. Mary of Bethlehem, where the variant Bedlam came from. ("Bedlahm," 2013)

This was a turning point where European psychiatry helped shape policy of the mentally ill and confinement was introduced to Palestine as has happened elsewhere.

Confinement policy continued during the Jordanian period beginning in 1950 when the West Bank was forcibly annexed to Jordan as a result of the 1948 Arab Israeli war, the dismemberment of Palestine with the establishment of Israel over half of Palestine at the time, with the expulsion of at least two thirds of the Palestinian population to neighboring countries. The policy of confinement of the mentally ill continued through the period when the occupied Palestinian territory or (oPt, or the West Bank and Gaza Strip) fell under Israeli military rule beginning in 1967. (Giacaman et al., 2011) While Israel had already developed a Mental Health Act, it was not applied to the oPt although Israel as an occupier is deemed responsible for the health of the occupied Palestinian population by the United Nations. Thus limited psychiatric outpatient services were provide to the population under military occupation.

The Oslo Accords between the Palestinian Liberation Organization and Israel led to the handing over of selected spheres to a nascent Palestinian Authority, alternatively called a quasi-state or failed state and indicating its lack of control over land, borders, water, resources, indeed most aspects of life which continued to be controlled by the Israeli military until this day, and with ongoing land confiscation and the building of illegal Jewish settlements on Palestinian Land. (Nakhleh, 2014) The need for the provision of care for those with mental illness became evident especially after the Second Palestinian Uprising of 2000. Evidence indicates that there was an increase in affective disorders and neurosis during the period, which may have reflected the deterioration of life's quality for Palestinians and sever exposure to Israeli violence, siege, shelling, and targeted attacks. (Giacaman et al., 2011)

Based on an initial assessment by WHO in 2001 (MHIN & A Global Community of Mental Health Innovators, 2011) a strategic operation plan was drawn supported by the French and Italians to deinstitutionalize mental health services and house the mentally ill in community. Once again, psychiatric knowledge produced in the West was thus introduced to the country again by international and humanitarian groups working in the area with a 180 degree turn from previous policies. By 2002-2003 a mental health policy for the West Bank and Gaza strip was formulated. (World Health Organization & Ministry of Health Palestinian National



Authority, 2006) By 2004, with international donors providing technical and financial support, the Palestinian Minister of Health signed an agreement with WHO and other international donors which contained plans for the reorganization of mental health services. In line with the change in approach in the West, namely from mental hospital to community care, the plan aimed to deinstitutionalize mental health services, redistribute mental health resources and provide a local comprehensive mental health service system based on the establishment of community mental health teams and centers, acute inpatient beds, day care services, specialized services for children and specialized care for the elderly, (Al-Ashhab, 2005) and ten community mental health centers were established in the West Bank staff by mental health teams.

As one would expect given the vagaries of funding especially to the occupied Palestinian territory, which is highly influenced by the political context, in 2006, the lack of international fund and financial support became a main problem the Palestinian government faced, and community mental health and the training of mental health professionals were not designated as a priority.(Marie, Hannigan, & Jones, 2016). Support came in 2007 after a period of interruption with EU support to WHO and the Ministry of Health, and a three year program assisted the scheme in moving forward. The plan entailed moving away from inpatient hospital services, and the establishment of community mental health centers in every city.(Marie et al., 2016) The hospital began to be downsized. From a 280 bed psychiatric hospital in Bethlehem, there were 180 beds there in 2010.(MHIN & A Global Community of Mental Health Innovators, 2011) In the meanwhile, WHO signed another three year agreement with the EU to continue. It was expected that by 2015 mental health care would have been integrated in PHC, stigma and discrimination programs would have been established, and mental health professionals trained, monitored and evaluated. By 2013 there were 13 community mental health centers operating in the West Bank. However, the community mental health services continued to face overload, lack of medications, and lack of training and continuing education of staff.

Currently, the psychiatric hospital in Bethlehem, the West Bank, contains 180 beds. However, 40 beds are apparently not in operation because of the lack of professionals. Unfortunately however, the psychiatric hospital is managed by the director of all hospitals at the Palestinian Ministry of Health, while the community mental health centers are managed by the director



of the Mental Health Unit at the Ministry of Health, making effective coordination of policies, plans and interventions a problem. There are 14 community mental health centers which are also in operation on the West Bank according to officials in the Palestinian Ministry of Health.¹ These provide psychiatric care and medications to patients. It is acknowledged that medical care and the provision of medications are the main strand of community mental health care in operation today in these clinics. In addition to doctors and nurses, two persons, one trained as a social worker and another in psychology provide basic counseling services to patients, but they too the needed resources for effective patient management. In addition, there are no resource available for continuing education of those previously trained, proper supervision of staff, and other essential programs to make community care a success, such as the provision of rehabilitation, especially occupational therapy services, combatting stigma in community, addressing poverty, education and employment, and dealing with inadequate or lack of housing among other measures needed for the effective operation of community mental health services. The Palestinian Ministry of Health is currently in the process of developing its mental health strategy. However, as is the case of several other strategies (The European Union, State of Palestine, & World Health Organization, 2015) (Ministry of Health, 2016) it is highly unlikely that such a strategy would be in fact implemented, because of problems with the provision of resources required for its implementation, and also problems with the proper training and supervision of staff, other than structural problems coming in the way of effective implementation.

Other than the Bethlehem Psychiatric Hospital and the community mental health centers, there are other smaller level institutions which are reported to deal with the needs of people with disabilities. An unofficial report published by one of the local media outlets indicates that there are 31 institutions who care for older people primarily. Distressingly, such institutions are reported to house not only older people, but seem to lump all who need shelter together, including young people with disabilities, ‘paralyzed’ children, children with physical disabilities, Alzheimer patients, other types of patients, what is called mental retardation patients, and orphan children, etc. (Wafa News Agency, 2023) Of those, 13 are shelters housing people day and night, and the rest provide day care services, home services, and counseling services.

¹ Information obtained from Dr. Samah Jabr, director of the Mental Health Unit of the Palestinian Ministry of Health.



Not much is known about such institutions otherwise, which call for urgent future investigation.

In addition, 96 local and 17 international institutions on the West Bank² report that they provide a range of support for people with disability, with many offering what is called psychosocial mental health services, which sometimes turn into a band aid on an infected wound given that to address psychosocial problems emanating out of exposure to political violence in the main, Palestinians need justice, freedom, and self-determination instead of therapies. To be sure, a political cause of trauma and ill health requires a political resolution. Be it as it may, most of these institutions caring for people with disability seem to provide day care services as opposed to housing people with disabilities day and night. We do not know much about these institutions, whether their programs are continuous or come and go in line with the vagaries of funding and priorities for this country defined by international aid groups. Likewise very little is known about institutions caring for older people primarily as noted above, again emphasizing the need for a systematic investigation of all institutions providing services to people with disabilities to try to make sense out of the disability landscape in the West Bank.

Undeniably however, the story of disability deinstitutionalization in the West Bank is complex, multifaceted, and entangled with the involvement of various international parties assisting the Palestinian Authority to deinstitutionalize in a context of a weak and toothless Authority which is chronically accused of corruption, cronyism and mismanagement, (Mataria et al., 2009) and operating in a situation which is highly constrained by the existence and control of Israeli military rule of land, water, resources, in fact control of life under Israeli Apartheid; and where the Palestinian population is chronically exposed to political violence and trauma. All these factors make it difficult to implement sustainable programs as was desired by international groups with touch and go funding and involvement, as, in truth, the entire country is non-sustainable. This review also makes one realize the difficulty of grasping who did what, based on what type of assumptions and evidence, how, and why.

² A list of these institutions was provided by our partners at the Center for Lebanese Studies who have searched for institutions supporting people with disability in Lebanon, Jordan and Palestine.



However, what we can also understand from this review is that moves towards institutionalization then the turn towards de-institutionalization have been primarily influenced by western knowledge production, and the financial aid and technical and other forms of support of international groups. This in itself may not be a problem if all the other requirements for relevance to context, importance, effectiveness and sustainability after international aid stops its support are met. In reality, the end of international financial support has negatively affected the community based mental health program in the West Bank, where the support from the EU, the WHO, the Italians and the French all directed to building a care in the community system ended up with a program of medication distribution at the community level without the requisite other supports and services noted above.

Conclusions

Overall, it is clear that mental health services and programs in the West Bank are under-resourced, under researched, and underfunded, perhaps even disheveled with the involvement of too many international groups wanting to do what works in the West, which may or may not work in the Palestinian context of ongoing colonization and apartheid conditions. Therefore the results of this review calls for a systematic investigation to firstly find out what is being done, by who, how, why and who is served; and second, to understand the problems and impediments of de-institutionalization in the area, as the intention is not to throw the baby with the bathwater, given that the concept of de-institutionalization has value, is compatible with views related to basic human rights, and should continue to be considered.

The results of this review also raise questions as to what role the Palestinian Authority has in providing for and protecting people with disabilities, just as we ask the question of the type of social contract between us Palestinians and the Palestinian authority delineating rights, and also responsibilities, and where people with disability should fall within such a framework. Without effective long term resource provision to ensure that the different aspects of community based care implementation can be achieved and continuously, we are likely to be pushed towards creating worse living conditions for people with disability, especially mental disability. And this is precisely why we need to complement this review with an actual field investigation. But, with a difference, with an eye on understanding the local, its context, needs and priorities first and foremost.



Finally, the Trieste model which emphasizes that people with mental illness should live in the community, (Portacolone, Segal, Mezzina, Scheper-Hughes, & Okin, 2015) has not worked in the Israeli occupied West Bank, just as it has not worked even in well-endowed cities like San Francisco in the United States. When the initiative on the West Bank was supported financially and otherwise by international aid, it worked well, with day care established as well as other programs to help people with mental illness and their families to deal with life in communities during the day. However, once financial support dried up, the deinstitutionalization programme quickly turned into medication provision with little program support, and resources continue to be lacking for the continuing education of those trained, and the adequate supervision of staff despite the commendable and substantial efforts of those in charge of and working in the community mental health program to maintain as much as can be maintained in the absence of international financial support. However, as is the case with other programs, the problems are structural rather than related to personnel. And on top of such structural constraints is the ongoing Israeli military rule and Apartheid conditions. That is, such structural constraints have to be addressed before Palestinian are able to achieve what they want to achieve and realize their potential. In the meanwhile, we are destined to continue to be dependent on international aid for survival and development.

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