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DISABILITY AND COMMUNITY

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THE CONTESTED MEANING OF “COMMUNITY” IN DISCOURSES OF DEINSTITUTIONALIZATION AND COMMUNITY LIVING IN THE FIELD OF DEVELOPMENTAL DISABILITY

Liat Ben-Moshe

ABSTRACT

Purpose – This chapter focuses on notions of community as related to the discourse around “community living” for people with labels of developmental disabilities, especially as they emerged during and after deinstitutionalization. Following Foucault, this chapter asks whether institutionalization and community living should be conceived of as two separate epochs or as governed by similar logic. The second focus of the chapter is in the ways notions of “community” were evoked by various stakeholders such as parents of children with labels of mental retardation, professionals in the field of developmental disability, and those of formerly institutionalized peoples themselves.

Methodology/approach – This chapter employs the methodological aspects of the work of Michel Foucault and constructs a genealogy of

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notions of community in relation to deinstitutionalization and the field of developmental disabilities.

Findings – “Community” has been discursively produced in several forms: as a binary opposite of “institution,” as a set of human relationships, and as a paradigm shift in relation to the way developmental disabilities should be conceptualized. It remains unclear whether we have truly moved from an institutional model to a “community-based” model for those with developmental disabilities.

Originality/value of the chapter – Reconceptualizing deinstitutionalization and community living as discursive formations aids in the understanding of the difference between abolition of institutionalization as a mindset and other formulations of the concept of “community” in the field of developmental disabilities.

Keywords: Deinstitutionalization; Michel Foucault; developmental disability; community living

INTRODUCTION

This chapter focuses on notions of community as related to the discourses around “community living” for people with labels of developmental, intellectual, and complex disabilities,¹ especially as they emerged during and after the process of deinstitutionalization. Deinstitutionalization represents a major shift in policy and in the lives of those labeled intellectually, developmentally, and psychiatrically disabled. The shift entailed the closing of large state institutions and psychiatric hospitals beginning in the 1950s and the move of the institutionalized populations into housing and treatment programs “in the community.” The population of people with intellectual disabilities living in large public institutions peaked at 194,650 in 1967. By 2004, this number had declined to 41,653 (Prouty, Smith, & Lakin, 2005). This trend can also be gleaned by the number of institutions closures across most states. By 2002, the District of Columbia, Alaska, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont, and West Virginia had closed all of their public institutions for people with developmental disabilities. In contrast, 13 states have not closed any public institutions (Braddock, 2002). Overall, 140 closures were completed or were under way between 1960 and 2010 (Braddock, Hemp, & Rizzolo, 2008).²

Some view this shift as a victory, a move away from anachronistic approaches that segregate people with disabilities to humanistic discourses that advocate for equality, inclusion, and integration. Taking an analytical approach in the spirit of Foucault’s (1994/1963, 1977) genealogical inquiry, however, blurs the lines between what has come to be termed as “community living” and “institutional living.” Much of what we conceive of as advancement (e.g., releasing people who were deemed mad from asylums into psychiatric hospitals to receive treatment, the placement of people with cognitive disabilities labels away from large institutions and into group homes) are in fact not signs of progress, according to Foucault (1965). This chapter argues that the shift from custodial care and institutionalization to deinstitutionalization and community living should not be seen as the rise and fall of one epoch to be replaced by the other. This is because the effects of the former still linger on in the latter. In other words, this chapter asks whether institutionalization and community living should be conceived of as two separate epistemes, as Burrell and Trip (2011) seem to suggest in their genealogy of deinstitutionalization in New Zealand, or are they governed by a similar logic that operates in different ways?

The second focus of the chapter is on the various ways notions of “community” had been evoked by various stakeholders in this saga of deinstitutionalization and “community living” for those with developmental disabilities,³ most notably by parents of children with labels of mental retardation, professionals in the field of developmental disability, and formerly institutionalized peoples themselves. Following Foucault, I highlight various forms of subjugated knowledges, which for Foucault are knowledges that have been buried or disqualified as nonsensical or nonscientific. It is “the knowledge of the psychologized, the patient, the nurse, the doctor, that is parallel or marginal to, medical knowledge, the knowledge of the delinquent, what I would call, if you like, what people know” (Foucault, 2003, p. 7).⁴ By centering “what people know,” Foucault is not referring to the taken-for-granted or dominant form of knowledge circulating, but localized, particular, specific knowledges, what we might also call marginalized, experiential, or embodied knowledge.

Specifically, I try to uncover various knowledges or ways of framing what constitutes “community” in relation to those with developmental disabilities and the effects of such discursive formations. If one defines “community” as a binary opposite of “institution,” for example, the course of action would be to advocate for the closure of institutions or institutional reform to improve their quality. But if one defines “community” as the building of human relationships and not locale of services, then the effects of what

became to be known as "community living" should be rethought and problematized given that one can be quite isolated while living "in the community." To add another layer of complexity, I also highlight the knowledges of those who viewed deinstitutionalization as a paradigm shift in relation to the way developmental disabilities should be conceptualized. Such knowledges went beyond advocating for policy changes to stressing the need for a total abolition of the institutional mindset. The chapter therefore ends with a discussion of whether we have truly moved from an institutional model to a "community-based" model for those with developmental disabilities.

COMMUNITY AS "NONINSTITUTIONAL PLACEMENTS" FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

Within the debate over living arrangements and services for those with developmental disabilities, "the community" is often seen as negation: that which is not the institution (Carey, 2011). Under this formulation, "the community" represented an opportunity for people with specific labels and diagnoses to live with their peers and in a similar fashion as their peers. Community could thus be connected to a locale, that is, people who reside in the same territory and therefore share common practices and interactions. In relation to discourse around "community living" for those with developmental disability labels, this can be reflected in distinguishing between institutional placements and community ones (e.g., supported living, group homes, and living with family or roommates).

Most noticeably, parents' attitudes toward deinstitutionalization have been split between those who have been construed as "institutional parents" and those who advocated for community living for their children. The campaign to close down institutions for those labeled as mentally retarded in Canada, for example, was propelled by mothers who were active in the (later named) Canadian Association for Community Living. These were mothers of children diagnosed as developmentally disabled in the 1950s who resented the "choice" between keeping the kids at home with no supports and institutionalizing them in a state school (Panitch, 2008). The Association was composed of those deemed "institutional parents," who did not want a sea change in regard to their children's placement, and "community parents," who were more interested in alternatives, especially

smaller group homes. It is important to note, however, that according to Panitch (2008), such alternatives were originally sought because they would improve the overcrowding and other conditions in the institutions, not because of a shift related to perceptions of human value, worth, or quality of life of those labeled mentally retarded, as those had just begun to circulate at that time. In both the Canadian case and other U.S. court cases regarding deinstitutionalization, the parents were more prone to support reform efforts than abolishing the institutional system and mind-set as a whole, at least initially.

In the case of Willowbrook, the notorious institution for those labeled as mentally retarded in New York State, it was also parents who were mobilized by a renegade professional in the institution to affect change within the institution. At its peak in 1969, Willowbrook was the largest institution for people diagnosed with mental retardation in the world, holding 6,200 people (Taylor, 2009). After futile attempts at formal procedures such as grievances and petitions regarding the conditions in Willowbrook, professionals and lawyers decided to politicize the conditions in the inmates by making use of new professional assessments of children with developmental disabilities that viewed them as capable of growth (Rothman & Rothman, 1984). In other words, they not only spoke of the tragic conditions witnessed at Willowbrook but also provided the parents with medical opinions that differed significantly from what they were used to hearing, suggesting that their children were not deficient and hopeless but victims of neglect and institutional living. They also arranged for parents to meet with speakers who described model programs that employed these new perspectives and techniques to demonstrate that there are successful alternatives to institutionalization (Rothman & Rothman, 1984). A genealogical analysis in the spirit of Foucault therefore reveals the ways in which these unorthodox perspectives were used as subversive and alternative knowledges for both the lawyers and the parents to draw from in their advocacy for noninstitutional alternatives.

Parents who were opposed to deinstitutionalization of centers and institutions for those labeled as mentally retarded and to the concept of community living were concerned about a variety of processes and issues related to it. Some raised concerns about the quality and adequacy of services and housing available in the community in the 1970s, the time of mass deinstitutionalization. Fromboese and Sales (1980) comment that some particularly disturbing examples of inadequate or neglectful conditions in community services were circulating among groups of parents and then repeated and generalized to prove the inefficacy of the system as a whole.

Some parents were also concerned that community services and living was not a stable and sustainable option for their developmentally disabled children. These concerns were in part motivated by the fact that parents were aging and questioning the fate of their offspring after their death if indeed community support was not sustainable (Fronboese & Sales, 1980). Such concerns were fueled by professional opinions that perceived deinstitutionalization as a fad to be replaced by another policy in the near future, a viewpoint supported by some professionals in the field who supported institutionalization and segregation as the best option for people with certain disabilities (see Crissey and Rosen, 1986, for examples of such attitudes).

In addition, some opponents of institutional closures in the mental health and developmental disabilities arenas claimed that deinstitutionalization was an unrealistic policy and that its proponents should wait until the time was right for it (Crissey & Rosen, 1986). A related argument asserted that no alternatives were currently available in the community and that the community was not ready to receive mental patients or those labeled mentally retarded. This is a complex issue, and it is true that in most states there was not an array of community living options, especially publically funded programs of high quality. However, deinstitutionalization advocates (Taylor, 1995/1996) ask whether there will ever be an optimal time when such processes as deinstitutionalization and community living should take place and for whom the time would be optimal.

This issue could also be analyzed under the prism of abolition versus reform in relation to institutionalization and community living. The systems that were set to be abolished, such as institutions and mental hospitals, as well as institutional mind-sets, seem to have been in place for so long that many perceived them as the only legitimate option. It might be useful in this regard to draw on Norwegian sociologist Thomas Mathiesen's conceptualization of abolition as an alternative in the making: "The alternative lies in the 'unfinished', in the sketch, in what is not yet fully existing" (Mathiesen, 1974, p. 1). According to Mathiesen, abolition takes place when we break with the established order and simultaneously break new ground. Hence, abolition is akin to the unfinished, in that freedom is stepping into unmarked territory. Looking at abolition as "the unfinished," as Mathiesen suggests, implies that abolition should take place when not everything is in place. This is because by the time new conditions have been established, it is too late to learn lessons, make changes, and create a systematic and lasting change in a way that fundamentally alters the system and its core assumptions in relation to segregation, treatment, and the meaning of disability and community.

Opposition to community living for those with developmental disabilities was not only founded on the basis of problems with policy implementation and the lack of current infrastructure that supported community living. Some of the critics of the concept of community living (parents, professionals in the field of developmental disability, and others) also opposed the principles of normalization and the push toward inclusion and integration more generally. The idea that people with developmental disabilities should be raised and live in normalized settings resembling those of their peers, as suggested by the principle of normalization, was an idea that was fiercely resisted at its time and in some factions to this day. It was a paradigm shift that seemed almost unimaginable in the 1960s and early 1970s, because the prevailing solutions of the era were to improve or reform institutional living by creating smaller, better managed, and less geographically remote settings, or to divert more money to segregated housing and special education. The notion that people with disabilities should not be segregated in the first place was nearly unfathomable.

Wolf Wolfensberger, who is one of the formulators of the principle of normalization (1972), attributes⁵ this lack of imagination to factors such as the lingering effects of eugenics and the belief that people who were labeled as mentally retarded could never change or learn. Additionally, at the time, most experts in the field had never seen people with developmental disabilities in positive contexts that enable them to thrive, not just live. The attachment that people had to institutionalization, Wolfensberger suggests, was emotional rather than rational. In essence, people were fanatical in their loyalties to the concepts and practices of segregation and institutionalization. He recalls receiving hate mail about the topic as well as being a part of heated academic debates that almost digressed into physical violence. These types of professional knowledges, which Foucault refers to as "buried and disqualified," had been discredited as utopian, unscientific, and dangerous, and they had been fiercely resisted over the years.

One important criticism of the principle of normalization is that it focuses too much on trying to change the individual so that she/he will fit into societal standards (Oliver, 1994). Under this formulation, it is really a principle of assimilation (a point discussed in greater detail in the discussion of "community" as assimilationist). In other formulations, like the original one proposed by Bengt Nirje (1969), the environment needs to be as normalized as possible, not the person. The early theorists of the principle of normalization, such as Nirje, were part of what became known as "the parent movement in developmental disabilities." They advocated for change in institutions, but institutions could satisfy the rules of the normalization

principal by making them more "home like." Wolfensberger (1991) therefore emphasized, not the environment, but the value of the roles (actual or perceived) given to an individual, a theoretical formulation called Social Role Valorization.

Critics of normalization believed proponents of these ideologies were idealists and extremists who had no idea what was realistic for people with developmental disabilities, especially for those labeled "severely" disabled. Some critics argued that people with mental and developmental disability labels who were placed in community settings were forced to be "normalized" to fit a norm they could not and should not be asked to uphold. In some ways then, both parents and some professionals critiqued the push for assimilation embedded in notions of "community living." From a disability rights stance, this may seem like quite a progressive view, one which proposes that norms are socially constructed, just like the labels they produce, and that those who are so labeled should not be expected to change themselves to fit a societal norm not of their creation. A second look at the platforms of organizations opposed to the shift from institutions to community services (such as The Congress of Advocates and the Voice of the Retarded) does not yield itself to such interpretation. What these parents organizations seem to strive for is a segregated space in which "people have the right to be retarded." The label is never contested, and it creates not only difference but also inherent inferiority as it is assumed that those who carry the label are lacking in some way. It is very interesting that the rights discourse is still inherent in such statements, albeit perhaps in opposition to the one promoted by the disability rights movements (Carey, 2009).

Following the initial steps of deinstitutionalization, people with developmental disabilities found themselves with increased levels of both freedom and isolation from people likely situated. Thus, they sought others who shared their experiences of learning to (re)live in the community (Carey, 2009). These were the sprouts of many developing self-advocacy groups and associations. In turn, these groups advocated for the closure of more (or all) institutions and the move of all their peers into community living settings. As they were most affected by institutional closure, self-advocates became the most vocal and insistent voices in the fight for the abolition of institutions for people with developmental disabilities, as opposed to calls to reform such institutions and make them more livable. For example, People First Nebraska (Williams & Shoulz, 1982) demanded the closure of all institutions in the state, and former residents of Pennhurst in Pennsylvania established Speaking for Ourselves with the goal of deinstitutionalization and the receipt of services in the community for all institutionalized patients.

These knowledges of the service users themselves remain often hidden, or in Foucault's terms "buried," in the debate over deinstitutionalization and community living, as they are perceived as "biased" or nonscientific in comparison to the knowledge of professionals (Burrell & Trip, 2011).

Within all these formulations, whether they supported deinstitutionalization and community living or resisted them, what remained stable is the notion of community as "noninstitutional" placements for those with developmental disabilities. Parents of children with disabilities, self-advocates, and professionals in the field of developmental disabilities were fiercely active in the debate over community living and in the process created specific meaning of what gets to be defined as "community." This meaning was defined through negation, the exodus out of the institution and the institutional mind-set. The next section highlights more expansive formulations of community, some construed by the very same actors.

"COMMUNITY" AS MORE THAN A NEGATION

Within some formulations of community living and community services (especially as conceptualized by entities in charge of their implementation), "community" seems to be an entity that can be separated by physical means and can be symbolically marked by the walls of the institution, the "special" school or other facilities. In reality however, at least some of those living in such segregated placements are still a part of their communities, especially through their families. The lines between "the community" and the "institution" are therefore blurry, even though they have been constructed as rigid by some as a way to demarcate and establish the terms of the debate as binary opposites, as the examples above demonstrate.

For those who have been institutionalized or marked as in need of segregation, "community" goes well beyond geographical boundaries. Therefore, the definition of it as a "noninstitutional placement" seems both inaccurate and insufficient. Community seems more about support and acceptance, and therefore about personal and interpersonal characteristics, rather than size or place. In this regard, Pam Walker's (1996) work on a sense of place of people with developmental disabilities is useful. Walker (1996, p. 18) defines community as "a sense of membership and belonging whether that be derived based on geographic location, kinship, friendship, common interest, or other connections and bonds."

If the meaning of "community" seems to be contested, so is the definition of what counts, and what can be counted as, an institution. Some, including

governmental agencies, define institutions primarily in relation to the number of people housed therein. Thus, some might look at group homes as mini-institutions, but others would claim that they are homes for people with shared characteristics who act as roommates. In such instances, it might be most useful listening to people who reside in these locales to define whether they think of them as institutional in mind-set, practice, and procedure. Liz, a self-advocate who now lives in Massachusetts, recounts her experience living in a setting in New Jersey:

I stayed at Bancroft for nine years. Yes, most of that time I was in the community, but the first six months I was in what I called a "mini-institution." You entered this place by a long driveway and at the bottom was a cluster of 10-15 small houses. I lived with two other people, but all of my neighbors were people with disabilities. I remember one night when I came home, my roommate threw out my dinner because I was ten minutes late from my job. When I first got to this place, my parents and the staff at Bancroft called this place "the community." I ask you: does this sound like a community that you would like to live in? (Center on Human Policy, 2004)

Self Advocates Becoming Empowered (SABE), a national advocacy group of people with developmental disabilities, states that "An institution is any facility or program where people do not have control over their lives. A facility or program can mean a private or public institution, nursing home, group home, foster care home, day-treatment program, or sheltered workshop" (Center on Human Policy, 2004). SABE's definition emphasizes agency and control over decision-making as the decisive factor of whether one lives in an institutional setting. For instance, many group homes have features that remind one of an institution or hospital such as set of rules that hang on the wall, emergency exits with lighted signs, regimented activities, and schedules designed by staff. In that sense, a single home could act as much as an institution as a large facility housing dozens of people.

Social geographer Deborah Metzel (2004) suggests defining community by following Agnew (1987), the prominent geographer, in the classification of space as encompassing location, locale, and a sense of place. Community as location would mean the antithesis of confinement and the conceptualization of community as the sites of goods and services. This conceptualization is the one that can be interpreted from the writings of earlier proponents of anti-institutionalization in the field of developmental disabilities such as Gunner Dybwad and Wolf Wolfensberger, for example. But merely having access to goods and services is surely not enough for the full participation of people in community life.

Conceptualizing community as a locale adds to the definition of community the need for social interaction or a combination of human and

physical features. This follows the work of inclusionists in the field of education and early proponents of social integration, such as Bergt Nirje. These advocates emphasize that physical integration is only the first step to integration. To achieve full inclusion, the person needs to be afforded the same opportunities as their peers, including the social realm. It also entails a change in perspective, because inclusion, much like deinstitutionalization and community living, is a mind-set rather than a space. Finally, community as a sense of place means identification and a sense of association with a place. This can be observed in the policies that encourage community membership among disabled people. It is these kinds of associations and friendships that many advocates of deinstitutionalization had in mind when they pushed for community integration of those with developmental disabilities.

Community organizer and sociologist John McKnight (1995) goes even further to state that the usage of the term "community" by modern bureaucracies actually masks its opposite. The new language of community, as in community reentry, community mental health, and community living, obscures the fact that people who use these services get more isolated from community the more they are surrounded by "community services." McKnight emphasizes that services provided in noninstitutional settings should not be called community services unless they involve the users in meaningful community relationships. These types of services should be referred to, at best, as local services.

McKnight (1995) thus distinguishes between "community" and "community services." The problem with current services, according to McKnight, is not that they are lacking but that they are too powerful, plentiful, and authoritative. He warns that service-granting institutions have commodified the care of community. They can never be reformed to be more caring, because care is the relation between consenting members, and it cannot be manufactured by a service entity. The more the community is co-opted and invaded by service-granting institutions, the more the community will fall in its operation as a community, according to McKnight (1995).

There are various kinds of associations that create a community, such as formal organizations (like the Elks or a bowling league), a gathering of residents (such as a block party), or a gathering of places of business and leisure (such as restaurants). McKnight (1995) claims that it is these types of associations from which people with disability labels are most often excluded. McKnight therefore suggests that instead of speaking of policies of deinstitutionalization, we think about recommunityization, or the re-creation

of meaningful community relationships. As we shall see later, the move toward integration of people with disabilities, in the spirit of inclusion and increased human bonds, did not go without its own share of struggle. Perhaps not surprisingly, the boundaries of those who deem themselves as a community tightened as the push toward integration increased.

RESISTANCE FROM "THE COMMUNITY" AND THE CREATION OF BOUNDARIES THROUGH IN/EXCLUSION

When people with disabilities started to demand equal rights in regard to housing, employment, and education, in other words to be integrated within various facets of society but also change these facets by necessitating this integration, then objections started to be raised by the "general public." In fact, it seems that the most vicious attacks on disabled people were and are in relation to community living, community services, and the construction of group homes in the community. In Washington, DC, and Staten Island, potential housing that would have been used for group homes were actually firebombed, in a way reminiscent of church bombing in the South in the era of civil rights and the beginning of racial integration.

The resistance to community living had been so staunch and violent that it led Taylor and Searl (2001) to connect it with eugenic ideologies and stereotypes, including the rallying cries of politicians and editorial writers about the release of "dangerous" persons into the general public because of deinstitutionalization. Provoking these notions of danger and criminality as conflated with disability should be quite familiar to students of eugenics, who saw people who were labeled feebleminded and mentally deficient as biologically prone to violence and debauchery and therefore in need of being segregated from the rest of the population. Thus, the legacy of eugenics seems to be alive and well when one observes protests against the integration of people with disabilities in the community.

Protests against group homes in residential areas seem to follow such similar patterns, that the validity of the claims of the protesters needs to be questioned, according to Rothman and Rothman (1984). The objections to the placement of group homes usually follow seemingly pragmatic lines and the initial concern raised is always about the supposed well-being of the disabled residents. Examples of these arguments include raising issues such as lack of sufficient space, no adequate signage, increased traffic area,

existence of dogs in the area, and the absence of a yard (Rothman & Rothman, 1984). All of these arguments are raised as issues that will hinder the safety of the new residents and therefore should prohibit them from moving into that house or the neighborhood. It is interesting that the same concerns are not raised about other residents who live in the same area, despite the fact that their safety might also be compromised if "lack of yard" is indeed such a major source of concern. The other line of argument, usually stated in closed neighborhood meetings, is the fear of losing property values following the construction of a group home in the area. However, the claim that group homes decrease property value was never substantiated. New York State actually listed the help of Julian Wolpert, a renowned urban geographer from Princeton University, to research the validity of such claims, and they were disproved in his study (Rothman & Rothman, 1984).

A useful approach to analyzing the way "community" is perceived in the "community living" discourse is to utilize the work of theorist Sarah Ahmed. Ahmed (2004) challenges the assumption that emotions are individual matters that come from "within." Instead, she suggests that they create the boundaries of bodies, collectives, and discourses. It is the passion of negative attachments to others that produces an imagined community, to use Benedict Anderson's (1991) term, of those who possess such attachments. At the same time, these borders construct those who are the bearers of negative attachments as Others, not of the collective. It is the emotional reading of fear and hatred that binds the community together and indeed constructs it as "a community." Thus, emotions are not inanimate; they produce things. Therefore, Ahmed suggests that we speak of them in an economic sense, as affective economies.

Ahmed (2004) demonstrates that these attachments work best when the "ordinary citizen" is perceived to be in crisis and under attack. In the case of the struggle against the construction of group homes and the production of Not in My Back Yard (NIMBY) attitudes, it is not so much the "ordinary citizen" but normalcy itself that is seen as being under attack. There are the notions of living in suburbia and all that it entails (the American dream, historically white segregated communities of "like-minded people," etc.) as well as prejudice regarding disability, ex-offenders, and addiction. When these notions converge, emotional attachments are produced that construct those who are opposed to integration as "your average citizen" whose core values are now under attack. Such affective discourses shift the locus of victimhood from those who are not allowed into those who present themselves as wounded by integration efforts. The affective economy of fear

creates not only a sense of shared community (community in crisis struggling to maintain its core values) but also what it is not – the object that is seen as threatening its existence. Thus, the fear of the Other and of integration is not only involved in the defense of the boundaries of the community but it also in effect creates these borders. By using affective economies, the “community” creates itself by standing apart from the objects it fears or feels threatened by, that is, those labeled as developmentally or psychiatrically disabled, and those requiring welfare and medical services. This helps explain the way in which communities construct themselves as different from these entities, even though as a whole they have always already contained these entities.

DEINSTITUTIONALIZATION AND COMMUNITY LIVING BETWEEN REFORM AND ABOLITION

Deinstitutionalization and its accompanying shift to community living could be characterized not only as a process or an exodus of oppressed people outside the walls of institutions. In the eyes of those who pushed for institutional closure and community living, deinstitutionalization was perceived as a shift in episteme, the formation of a new power/knowledge regime (to use Foucault's terminology). The resistance to institutionalization and psychiatric hospitals arose from a broader social critique of medicalization and medical authority (Conrad, 2007; Conrad & Schneider, 1992; Zola, 1991); a new understanding of human value, especially in regard to people with disabilities, as seen in the principles of normalization (Wolfensberger, 1972, 1974); and the anti-psychiatry, ex-patients' (Chamberlin, 1978; Szasz, 1974), and People First movement (Williams & Shoulz, 1982). Although these ideological shifts did not solely bring about deinstitutionalization and insistence on community living nationwide, I believe that any significant decrease in institutionalized populations would have been impossible without them. Furthermore, deinstitutionalization is not just something that happened, but something for which many were relentlessly advocating. As such, deinstitutionalization can be construed as an active form of activism and as an unacknowledged social movement.

There are many ways in which one can fight for social justice or social change. In the struggle against institutions for those labeled as developmentally disabled and for community living and community-based services, there were myriad possibilities through which the struggle could have taken

place. What is illuminating in these cases is that some took the view that the only route for successful social change was to close and abolish these institutions, some advocated for reforming them, and still others fought to maintain the system without major changes.

The tension between abolition and reform in relation to institutionalization and community living can be traced historically and ideologically. Critics of institutions in the 1960s were advocates of the notion of the continuum of services (even before it was conceptualized as such) because they pushed for more services in the community coupled with institutional reform. But by the 1970s, a small number of professionals in the field of developmental disabilities started to promote the notion that reform of institutions was a futile enterprise, and abolition was the only solution. In the minds of these critics, the time for residential care had ended. As Burton Blatt, the prominent educator and advocate in the field of special education, stated in 1979: “If there is hope in what we have learned in our examination of institutionalization, it is not in any improvement of institutional life—imprisonment and segregation can be made more comfortable, but they can never be made into freedom and participation” (quoted in Taylor, 2005).

By the end of the 1970s, it was becoming clear in the field of developmental disabilities that community living was desirable, but yet the institutionalized population was not decreasing in most states. The “inevitable” change professionals, activists, and parents sought was late in coming. The most pervasive new tactic was turning to the judicial realm (Carey, 2009). The use of legal advocacy was based on the belief that massive legal pressure would collapse the walls of the institution. This pressure would come from dual tracks: the inmates filing lawsuits based on constitutional laws, as well as advocates, family members, and activist-lawyers applying pressure from outside the institution.

A landmark case in deinstitutionalization litigation was New York's Willowbrook case (*New York State Association for Retarded Children v. Rockefeller*, 1973). One of the reasons this became such a landmark case was that at its peak in 1969, Willowbrook was the largest institution for people diagnosed with mental retardation in the world, holding 6,200 people (Taylor, 2009). Noting that federal courts had ruled that prisoners had a right to be free from cruel and unusual punishment, the judge in the Willowbrook case reasoned that mentally retarded people confined to Willowbrook must be entitled to at least the same rights. For Judge Judd, the right to protection from harm entitled residents to safety, a tolerable living environment, medical care, and freedom from substandard living

conditions (*New York State Association for Retarded Children v. Rockefeller*, 1973).

Perhaps, the most notable case of deinstitutionalization and its relation to community living is Pennsylvania's *Halderman v. Pennhurst State School and Hospital*, filed in 1974. The plaintiffs, and ultimately the judge, did not seek reparations or a change in the condition of institutions, but sought to prove that they are inherently unnecessary, unconstitutional, and in need of being closed down altogether. The decision was based on both the equal protection clause of the Fourteenth Amendment of the Constitution and the 1973 Section 504 of the Rehabilitation Act that was enacted to prohibit discrimination against people with disabilities by recipients of federal funds. The ruling touched mostly on the right to nondiscriminatory rehabilitation, which the court felt could not be achieved in a segregated setting: "the confinement and isolation of the retarded in the institution called Pennhurst is segregation in a facility that clearly is separate and not equal" (*Pennhurst v. Halderman*, 1984). Judge Broderick was of course enacting the famous wording from the 1954 school desegregation case, *Brown v. Board of Education*. With this usage, the connection was made that this too was a desegregation case about the right to live in integrated settings, that is, "in the community," based on this time not on color but on disability.

Judge Broderick ordered Pennsylvania to provide community living arrangements for the inmates now residing at Pennhurst and, in essence, to close down Pennhurst and by implication all such institutions. Judge Broderick's decision was upheld by the Third Circuit court, but the Supreme Court twice overturned the Third Circuit's opinion on narrow legal grounds without engaging with the profound questions raised by this case and its implications for other institutions (Taylor, 2009). Although other individuals sued facilities for lack of services or inability to live in the community, Pennhurst was the only court case that actually challenged the institutional model through an abolitionary mind-set that declared institutions as unconstitutional. As such, it is the only case I can think of that came close to an abolitionary stance in regard to institutionalization. The problem with the litigation strategy, however, is that at its best it leads to the closure of one specific institution or unit. Inmates are then moved to other facilities that are more compliant with federal and state regulations and seem less substandard but are just as segregated.

David Ferleger, the attorney who brought forth the case of Pennhurst, claims that there was strategic merit in using deinstitutionalization instead of an anti-institutional stance in these legal cases and in the public sphere more generally (Ferleger & Boyd, 1979). Deinstitutionalization, as opposed

to institutional abolition and the shift to community living, symbolizes to advocates and the general public that a reduction in the number of inmates and an increase in the staff-inmate ratios in institutions may be enough. It also signals that some people with psychiatric and cognitive disabilities need to be institutionalized, whereas others can be released. But most importantly, deinstitutionalization, as opposed to abolition, suggests that it is about individuals and the need to release them, not about systematic oppression and the need to eliminate that system as a whole (Ferleger & Boyd, 1979). As such, deinstitutionalization became more sustainable and achievable as a policy and activist goal than total abolition of the institutional system. The problem with this position is that the relics of the old institutional system can be seen in "community living" models today.

The concept of community-based services was supposed to be more than a change in the location of the provision of services, at least in the eyes of those advocating for the abolition of the institutional mind-set. It was meant as an epistemic shift in regard to the hierarchical system of care and the lack of meaningful relationships offered to people with disabilities. In theory, community-based services were supposed to help in bringing down the barriers that prevent full participation of people with disabilities from all aspects of life. In reality, as was demonstrated earlier, "community" often became a negation, that which is not the institution or mental hospital (Carey, 2011).

From an abolitionist perspective, it was primarily a negative abolition, and the attempt to create something new out of the ashes of the old institutions, that is, achieving meaningful relationships and living in the community, was not always successful. When a system is abolished, there is a danger that other systems with the same goals will arise to fill in the void left by the abolished system. Famed sociologist W.E. B Du Bois, in his book *Black reconstruction* (1956), discusses abolition as more than a mere negative process, one of tearing down. It is ultimately about creating new mechanisms that assure equality. Du Bois was very insistent that to abolish slavery in modern times, new democratic institutions had to be established and maintained. From such a perspective, it is clear that just "tearing down the walls" of institutions for people with disabilities is insufficient as a form of liberation, and neither is moving the same services, unchanged, to a different locale outside of the institution. Community services thus became smaller and more dispersed than the ones provided in institutions and hospitals, but the relations of power/knowledge at their core remained intact.

THE ASSIMILATIONIST IMPETUS OF "COMMUNITY"

Community seems to refer to practices that attempt to produce identity, unity, and often solidarity. It evokes notions of caring, belonging, and collectivity. As queer theory scholar Miranda Joseph (2002) exemplifies, community is a powerful concept as it acts as a tool for political mobilization and alignment as well as self-identifications. As such, it creates unity, but at the cost of universalizing and essentializing identities and varied in-group experiences. Critics have pointed to various oppressions and exclusions that result from such attempts or practices, as "community" seems to always be constituted in relation to internal or external Others. Community is always set against something it is not, its Other, which does not belong within the community. Although it seemingly unifies its members, it excludes others from joining in, as we have seen in the examples of the fierce resistance to the construction of group homes.

Joseph (2002) warns, however, against going back to premodern notions of community and the political. After all, the central practices of modernity, such as the nation-state, liberalism, and rationality, are constituted by oppressive communal discourses. Community acts to universalize social expectations and "those who are different from that norm will be disabled in their participation, forced to change, or even fully excluded" (Joseph, 2002, p. xxi). Thus, community in and of itself could be both an abelist and disabling practice for those who wish to "break new grounds" in the words of Mathiesen, and not only be integrated and assimilated in the current system. This is a similar force to the rehabilitative ideal espoused by institutional discourses and now reproduced by the allure of "community services."

According to philosopher Henri-Jacques Stiker, rehabilitation is the cultural desire for identification, for making things identical. "This act will cause the disabled to disappear and with them all that is lacking, in order to assimilate them, drown them, dissolve them, in the greater and single social whole" (Stiker, 1999, p. 128). In Stiker's critical formulation of rehabilitation, integration of disability always necessitates assimilation, as the integration is to a society as is and under its own terms. For rehabilitation to be effective, "disability cannot be a confrontational position" (Stiker, 1999, p. 137). If applied to the debate over community living for those with developmental disabilities, one can conclude that inclusion in a "community" implies assimilation in it. It is no wonder then that the abolitionary

The Contested Meaning of "Community"

approach to community living, as an epistemic change that breaks down the institutional model, did not occur overall, as it was perceived indeed as a "confrontational position" as Stiker indicates.

We are left then with a conceptualization of community as a negation of the institution, but with remnants of the institutional discourse intact. Chris Drinkwater (2005) uses a Foucauldian analysis on supported living arrangements (in group homes for those labeled as intellectually disabled) to demonstrate that although these represent alternatives to institutional living, they do not guarantee emancipation for those who live in them. The proliferation of group homes and supported living begs the question of what new forms of power are invested in practices of inclusion. The productive aspects of power, as opposed to the repressive aspects, are the ones that become more visible in these new seemingly noninstitutional settings. What is ultimately produced, according to Drinkwater (2005), in these settings are well-integrated citizens, people with valued social roles (as described by Wolfensberger's Social Role Valorization principles). This is achieved by cultivating various tactics such as different bodily regimens around the user (in relation to hygiene, conduct, sexuality, etc.); different techniques of surveillance to monitor the user of services and their actions; and other techniques that are supposed to elicit compliance from the service user. Drinkwater's analysis is useful because it goes beyond the critique that supported living or group homes are smaller institutions in the community. Drinkwater (2005), following Foucault, suggests that there is something else going on in the power relations operating in these settings that is not the same as what is happening in institutions. I want to suggest that the change may be related to a shift from medical control to professional and administrative control over the lives of those labeled as developmentally disabled. For those who live under this control, however, it may not feel like much of a change at all.

Therefore, community living cannot be perceived solely as a policy change to be successful, as it is a complex discourse with various stakeholders who hold partial and sometimes contradictory knowledges with unequal effects. The knowledge of the service users, for examples, is not valued as highly as that of the medical professional or even the administrator or insurance actuarial. If seen as a shift in episteme, and not only a shift in policy or locale, the debate over community living for those with developmental disabilities needs to be connected to larger shifts in public discourse especially surrounding the ideas of individualism and dependence as well as budgetary priorities. In Italy, for example, where all psychiatric hospitals closed in the 1970s, the closure came as a result of a larger struggle related to

leftist organizing against tyranny and oppression (Shadish, 1984). From an abolitionary perspective, any change encompassing only one unit, such as institutions, will not be effective unless accompanied by systemic change in the discursive formations of categories such as community, segregation, and disability itself.

COMMUNITY AS A PLACE, POLICY OR PARADIGM SHIFT? RE THINKING "COMMUNITY LIVING" TODAY

Deinstitutionalization and the shift to community living of people with developmental disabilities was ideally meant to create a change in perspective about human value and the need to create humane services that support all people. As Metzger (2004) argues, however, this change may have occurred mostly within the small community of professionals and family members that were familiar with the issues in the field of developmental disabilities. This epistemic change did not necessarily expand to all members of communities to which people with disabilities were returned or in which they grew up.

Thus, deinstitutionalization could be characterized not only as a paradigmatic shift from the traditional institutional mind-set but also as a reform-based effort to close down institutions. Over the years, some of the figures given for deinstitutionalization of public institutions have been misleading, because significant proportions of people were transferred to other types of institutions including nursing homes. In 2000, for example, there were 53,913 individuals with developmental disabilities living in residential settings with between 7 and 15 people. Although these are not typically counted as "institutional" placements, due to their size as well as daily routines and other aspects of life in these settings, many people with disabilities, family members, and advocates consider them to be mini-institutions within the community (Center on Human Policy, 2004). The consequences over who gets to define what qualifies as "community" are not just analytical but have practical and material effects on those who get labeled as in need of "community services." The mere closure of large state institutions for people labeled as mentally retarded or the evocation of community in relation to housing do not necessarily entail a radical change in the discursive formations of developmental disability and the lived experiences of those so labeled. In the ethnography *Deinstitutionalizing women*, Johnson (1998) describes the lives of women in a locked ward within

an institution for people with developmental and intellectual disabilities. When a decision to close the institution was made, most of the women studied asked to be placed with family or their advocates. For the most part, their requests were ignored; out of 21 women, one-third were moved to other institutions and the remaining were placed in group homes. As a result, Johnson (1998) contends that although the institution finally closed, its deinstitutionalization was a failure. In essence, Johnson claims, it was not deinstitutionalization but institutional closure. The move to changing policies to support community living and the epistemic shift that needed to accompany the closure were late in coming. Johnson (1998) suggests that even after deinstitutionalization, only when disabled women will be viewed as equal human beings with their own desires and capabilities, then they will be truly free.

Therefore, the effectiveness of deinstitutionalization as a movement depends on ensuring community living, of which the closure of the institution is only a first step. This is why advocates in the movement stress the importance of conceptualizing deinstitutionalization and community living as mind-set, not a process or locale. It is unclear, however, whether this conceptualization had been taken up by people outside the field of developmental disability or disability rights movement into a general framework used by policy makers, parents, and the general public. As long as "community" remains a negation, it seems that so will disability remain constituted only in relation to its Other – "the normal" and not be explored on its own terms.

NOTES

1. A related discourse is that of "community mental health" and deinstitutionalization in psychiatry, which is discussed elsewhere (Ben-Moshe, 2011) and is outside the scope of this chapter.
2. Although not the focus of this chapter, it is important to note that an accompanying shift occurred in the field of mental health with the establishment of community mental health centers in the 1960s and the closure of large state mental hospitals in most major cities. In 1955, the mental health population in state institutions was 559,000 (nearly as large on a per capita basis as the prison population today). By 2000, it had fallen to below 100,000, a drop of more than 90 percent (Gottschalk, 2010; Harcourt, 2011).
3. Throughout the chapter, I refer to people with intellectual and developmental disabilities and people with labels of mental retardation. These refer to the same population but using different terminology derived from either the people first movement (i.e., people with developmental disabilities) or more historically accurate

terminology derived from the way people were referred to in public policy up until a few years ago (i.e., the category of mental retardation). Most of the time I chose to use the terms derived from Disability Studies and labeling theory that view these categories of "disability" as socially constructed. I therefore mostly refer to people as "people labeled developmentally disabled" or "people labeled mentally retarded" to indicate that I perceive these categorizations to be situational and varied across time, culture, and power dynamics as to who gets to define and who gets to be defined under these categories.

4. It is important to note that Foucault included under the prism of subjugated knowledge the epistemology of both the doctor and the patient. It is not only the person who became the object of knowledge and was subjected to medical authority but also the one who administered it. Because medical discourse is authoritative and has the power to tell us the truth about ourselves, it is exclusionary to other medical knowledges as well.

5. Personal communication.
6. Personal communication.

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