

Making Social Cohesion or Marking the Human Security Threat? Tracing Disciplines of Place in Community-Based Services for the “Developmentally Disabled”

M.S. Glennon, M.Soc.

Universiteit van Amsterdam's International School for Humanities and Social Science

Abstract: This paper is about how human services work people into place and how places are reworked by people. As an (auto)ethnographic research on community based services for “developmental disability”—seen as technologies for making social cohesion and development—it discusses rewards and risks when tooling knowledge to make people free.

Key Words: social cohesion, community services, developmental disability

Introduction

Social Cohesion is as venerable a sociological concept as there ever was, and is defined in practice as “the ongoing process of developing a community of shared values...based on a sense of trust, hope, and reciprocity” (Dayton-Johnson, 2003). It has been used to research the effectiveness of community organizations in economic development (Borgos & Douglas, 1996), of local cultures in fostering civic volunteerism (Sharon, 2003), and the dis/integrative effects of ethnic diversity (Healy, 2007). Yet, there remains an absence of social cohesion research on community services for the “developmentally disabled” (“DD”). One aim of this paper is to address this gap.

By “DD,” I mean what has been called “mental retardation,” “feeblemindedness,” and before that “idiocy.” In the past, it included vagrancy (Foucault, 2006; Hacking, 1998). In the present, it includes also categories like autism. I say “DD” primarily because it is the signifier used by the state of Nebraska to qualify people for treatment in human service spaces, such as group homes and sheltered workshops.

Though silent on social cohesion, research on “DD” has engaged with a related concept, “social capital”—the fabric of social networks which make social cohesion possible. In journals devoted to disability studies as well as rehabilitation and integrated education, research endeavors to account for social capitals present or absent between communities and families with “DD” children (Chenoweth & Stehlik, 2004), or between “DD” students and their universities (Farmakopoulou & Watson, 2003). Elsewhere it is theoretically explicated as a tool for measuring and strategically intervening in the development of a “DD” individual’s social network (Potts, 2005; Ward & Baker, 2005). The practical aim is generally to generate more opportunities for things like integrated employment (Potts, 2005; Ward & Baker, 2005), and to encourage policy makers to be more inclusive about how social capital’s parameters are to be defined (Pavey, 2006).

These discussions posit an affinity between sociological discussions of social capital with the long-standing missions of deinstitutionalization, community integration and social inclusion (Bates & Davis, 2004; Partington, 2005; Potts, 2005). These texts then adapt social capital for

use with an already extensive knowledge base for implementing community service systems for “DD” populations, a long standing mission of making social cohesion. “Over the past 30 years an informal network of writers...have shown how support can be provided so that people with disabilities can be employed rather than attend a sheltered workshop, live in their own home rather than in a hostel, and participate in friendships and community life with a diverse array of citizens” (Bates & Davis, 2004, p. 196). Such hegemonic human service epistemologies like Normalization/Social Role Valorization (SRV) do not specifically address the issue of social capital, but do seek to add value to roles disabled people play in society (Partington, 2005, p. 247). It must be noted that this affinity is true not only of research sympathetic to SRV, but to research from the social model of disability as well (Pavey, 2006; Partington, 2005). Pavey’s (2006) article in *Disability & Society* argues for the social model of disability not to refuse the concepts of social capital for its capitalist elements, but for an inclusive definition and application. This mutual affinity to a third thing by two ideologically opposed epistemologies makes sense if one is open to the possibility that Normalization is misrecognized as simply a “medical model.”

While these paradigms for making inclusion or integration out of “DD” practically beg questions like, “What do we mean by our community?” (Partington, 2005), the position of this paper is that it may be more fruitful to ask, what do we do as we mean our community to be? Historical studies draw attention to how public policies for institutionalization of deviant populations in places like France, the United States, and in my case Nebraska, now rightly and broadly considered inhumane, were not in spite of a will to social cohesion but rather in the pursuit of maintaining or safeguarding notions of it (Trent, 1994; Hacking, 1998; DeKraai, 2002). Care for social cohesion became linked with control very early on in the state schools for “feebleminded” youth, says Trent (1994), and this linkage has not been severed by the service systems of today.

I use a grounded post-structuralist approach combining tools of ethnography and discourse analysis. Post-structuralist because I use analytic schemas adapted from a triad of scholars, Michel Foucault, Ian Hacking, and Deleuze and Guattari, in order to trace the trajectory of two “DD” people through the state of Nebraska’s community service system. Examples from Nebraska are instructive for it is there where Normalization based community services for “DD” populations in the United States first came into being (Schalock, 2002). Ethnographic because this research involved three years inside Nebraska’s community service system, first as a human service worker in 2002 and 2004; and then formally as ethnographer in 2007. In the next section I cover some recent discussion on community services for “DD” before moving on to the two cases at hand. In light of these cases I will discuss how social cohesion is better understood as a process of struggle over its terms of constitution rather than something intrinsically reciprocating and trustworthy.

“The Group Home Problem”

A group home is a residence where three to six “DD” individuals live who are expected to “work toward independence” and who are “supported and reported” by human service staff in their progress on independent living skills and maintaining good behavior (Croft, 1999; Levinson, 2005). Recent research literature on group homes for “DD” point to paradoxes of

power. Often an individual's "choices" are determined by bureaucratic contingency so that, for example, where one "chooses" to live or what housemates to live with may be merely a factor of where there is an available bed (MacEachen & Munby, 1996). The mission to free a people and make spaces for their independence furthermore comes into tension with an impulse to impose and enforce proper models and uses of freedom and to erect restrictions around an individual in the form of "safeguards" against the risk posed to their self and to others as vulnerable and unpredictable people (Crichton, 1998; Duvdevaney, Ben-Zur, & Ambar). Levinson's ethnographic paper analyses this instructively from a Neo-Foucauldian point of view as not a problem of power but rather a dilemma of freedom. A group home is not intrinsically oppressive, but is merely a technology intended for making a liberal model of citizenship work on/for a kind of people (Levinson, 2005). Unlike Levinson, however, I would submit this work is not clinical, but colonial, as it is performed whether or not it is invited by the citizen concerned.

Group homes are then places for a discipline of development. Disciplinary power "brings together citizenship and embodied identity with perpetual observation, writing, an unclear distinction between punishment and reward, projection of the psyche, the division between normal and abnormal...and fits embodied identity together with political power" (Foucault, 2006, p. 56). Discipline is the 'anatomo-political pole of development' which "centers on the individual as a speaking, working, procreating entity" (Hacking, 2002, p. 112). Bio-politics is the other pole which "focuses on the species body...the biological processes of a population in statistical form" (Foucault, as cited in Hacking, 2002, p. 112). Community services can be considered as an example of "the whole cluster of intermediary relations which link these poles together" (Hacking, 2002, p. 112). It is with this in mind I wish now to proceed with the two cases with which this paper is concerned.

The Traces of Two Placements

I consider the following two cases as singularities within a bio-political field of social cohesion. These two cases, Merciful Black and Zero President¹, exemplify the ongoing consequences of community care, entombment/containment and interpretive development. I explain this taxonomic intervention by way of discussion. Quoted material is either speech I witnessed in the field or text from documents I encountered.

Temples of Entombment for Merciful Black

Merciful Black was in her early childhood dually diagnosed as "having mild mental retardation" and a swathe of "behavioral disorders." She resents her position in Nebraska's human service system, whose group home network she entered in 2001. She refers to her group home as "the nuthouse." She voices loudly her desire "not [to] live in a group home no more," but she is not her own legal guardian and so has no legal authority over her processes of placement. She uses what powers are at her disposal to struggle against her placement, and these struggles are recorded onto hundreds of "incident reports" of her verbal and physical violence and aggression. These aggressions are generally directed against the property of staff or a roommate. She sometimes throws fists at their bodies, but more often throws rocks at staff's cars. Yet, for all of this she has never been reported exhibiting violent behavior in public when

enjoying her “independent time in the community”—a daily four hour privilege (according to her case records this was once an 8 hour privilege, also daily).

As a regime of group home discipline, Merciful Black’s can be read as processes of entombment and containment. Her placements began with a foster family in North Omaha, a low-income African-American portion of Nebraska’s largest city. As a teenager she constructed a social network vested in peripheral street gang affiliations. Social service workers intervened, and her foster mother placed Merciful in a group home. From there, and over the next seven years, Merciful’s placement processes drew her progressively further from the geography and culture of her community of identification—where she “was born an raiz’d in tha hood,” as she describes herself to me at a barbecue.

Few of Merciful’s human service workers and decision makers doubt her ability to live outside of a group home. Key decision makers on her “individual support team,” however, are nervous about the kind of people she seeks for association. Merciful’s guardian, a woman who lives out of state in Texas and was recommended to Merciful as a guardian by her social services case worker, advises me to stay away from Merciful’s “low rent” friends. Merciful’s social worker expresses similar views. In Merciful’s case book it is recorded that “these friends are a bad influence on Merciful, and will take advantage of her,” although the only example provided involves an episode where Merciful takes chicken from her group home to eat it at her friend’s house.

With Merciful, there are many episodes. But how her “independent time” functions in her case is telling. The following narrative is assembled and summarized from accounts in her case book as well as my own ethnographic engagement with Merciful, her friends, and her service workers.

Merciful’s friends invite her to a party. Support staff are directed by her “individual service program” to drive her nowhere other than medical appointments, her guardian, or other community service settings. To use her “independent time” Merciful must “independently” access the community. By this time Merciful has been placed in a group home in West Omaha, across town from “the hood.” To meet her friends Merciful must take the hour long bus ride. She does. But the bus system in Omaha is spare; with most bus lines closing early in the evening. She will need someone with a car to drive her back and her friends seldom have access to a car.

Half an hour before her independent time expires, around 11:30 pm, Merciful calls the group home to request a ride. The staff on duty cannot leave Merciful’s housemates unsupervised. Merciful calls the group home manager who advises a ride home from staff is “not part of her program.” Merciful misses her curfew and loses her “independent time” for a month. She becomes angry and, returning “home,” cycles into breaking things, shouting, throwing rocks at a staff’s car, and is eventually placed in a prone floor restraint.

Merciful is some time later invited out again. Planning ahead, she asks staff members if they will be able to drive her. The answer is programmatically “no.” Merciful contacts her social worker, who reminds Merciful she is responsible for her own transport when using “independent time.” Merciful offers to do extra chores to earn money for a taxi or to pay staff for gas, but she

is told she must earn money from a real job or at the sheltered workshop (which pays below minimum wage). The social worker's contact record reads: "Spoke to Manager. Merciful did well at home...made the decision on her own not to go on the bus because the buses quit running at 5 pm and she would not have a way home. No physical aggression."

Merciful nominally has independent time and is nominally permitted to use it how she wishes, but a combination of contingencies - the Omaha bus lines, the location of her placement, the social identity of her friends as "bad influences" in the eyes of human service authorities - become a constellation of programmatic points which prevent her from realizing her time of independence and circulating her social capital in a manner and with a community meaningful to her. The program wants her desires to steer toward particular social capitals and models of responsible conduct. A responsible decision for Merciful, in the eyes of her social worker, is to learn docility and acceptance of her identification as being in need of a group home.

Similar episodes are repeated until one evening Merciful pins her staff to the floor while one of her housemates smashes over the worker a glass coffee table; shattering both kneecaps of the young woman concerned. Merciful is re-placed. Her new group home is in a suburb of the state capital another 60 miles west from her identified home. Merciful calls this "exile." Merciful's guardian says in the contact record, "This can be a new start." The "new start" is an ominous nine miles from the "Nebraska State Developmental Center." She loses all "independent time."

The Interpretive Development of Zero President

Zero is a much needed counter-example. He has not been placed and re-placed ever closer to the heart of human service bureaucracy and so maintained in an entombed/contained state. He has lived in the same home since 1978 more or less adopted by a foster family, which has enabled him to claim the terms of his identity and constructively challenge the roles expected of him by Nebraska's community services system. And no shortage of support has come from his adoptive father figure, Peaceful Ruler². Peaceful worked, among other things (pastor, poet, professor, activist), as an Intake Officer for Nebraska's community service system during its formative years of the late 1970s. In that capacity, he became alerted to Zero.

Zero was raised in a Polish-American working class neighborhood in South Omaha. His parents were both "DD" as well as one of his two brothers. He himself is diagnosed as having "mild mental retardation" and "ADHD," was 17 when his parents passed away. The eldest of his two brothers, "very capable," was working and trying to keep things together for his siblings, but to no avail. The house fell into severe disrepair: broken toilets, clots of trash; cockroaches crawling all about. Now Zero's other brother, also "DD," would have nothing to do with community services and as his own guardian chose to live the next ten years with "thugs" who exploited his Social Security check. Zero, still being a minor, required by law some kind of human service placement. Peaceful organized foster homes for him, but removed him from each one when he witnessed signs of entombment/containment on follow-up visits. Eventually out of foster options and afraid to move the emotionally distraught individual, Peaceful took Zero to stay in his home, at least for a few months until he was emotionally stabilized. During this time,

Peaceful advocated a place for Zero at public school and taught him, among other things, how to read. By the time a few months of stabilization had passed, Zero began to call Peaceful “dad.”

Peaceful says, “. . . It just became clear we [*he and his partner*] were having a ball parenting. So I went to child protection services and I said, ‘You know, we’ve kind of invested a lot of time with the boy. And because he wasn’t a client we weren’t treating him like a client, we always treated him like a kid.’ Peaceful and his partner became Zero’s family. Eventually Zero’s “DD” brother decided to leave the “thug life” and moved in with the Peaceful family. Thirty-two years later, Zero says if Peaceful had not found him, he would have “fallen through the cracks.”

Zero now works for a recycling facility built on grant money for “DD” people to have a place of employment that offers valued work in an environment of “dignity and respect.” Though it is a “segregated” workplace it is not a sheltered workshop such as Merciful is compelled to attend, i.e., it is “real work for real pay.” Yet, as Zero’s work skills developed in this environment, it became imperative of his vocational staff to encourage him to try and seek “competitive employment in the community.” After seven attempts, either sufficient support was lacking, or, as Peaceful suggests, Zero’s “ADHD” proved too strong a force. In any case, Zero could not perform in the “competitive” workforce. The stream of “failures” wounded so intensely his psyche that, after its seventh repetition, he availed himself of a psychic self-healing process with a therapist which lasted several months.

Instead of trying an eighth time for competitive work, Zero began to advocate for more responsibilities at the recycling facility; not only for himself, but for his co-workers as well. A new position was carved for him to train new workers on machines. He was also taught basic word processing skills. He broadened his advocacy and began to organize an employee association so that the “DD” workers of his recycling facility might claim greater authority over the work-space and slowly take over the responsibilities of support staff. He came downstairs one day during my fieldwork, as I was dusting Peaceful’s study, to share with me the progress of his work:

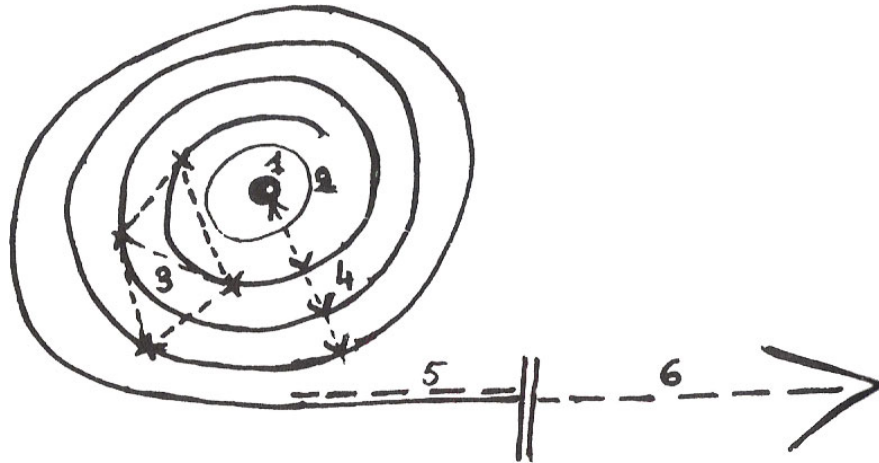
“Decisions lie behind all the actions that people take. . . . the forman (sic) coaching. . . described something that ‘conveyed valued people from where they are to where they want to go’ . . . but many coaches\ forman (sic) give their followers more information than they can digest at one time. . . . the rationale is that ‘we don’t have time to this in ‘digestible’ (sic) for’ [text breaks off].

Here Zero rethinks “development” as something which need not be a firm application of hierarchical models for measuring workplace achievement. Work need be neither “competitive,” nor “integrated” to be dignifying. Zero’s experience is that social cohesion is best made where he makes not only community work, but also works an affirmative meaning of community through his labor and the application of this labor at his desired pace and toward a tangible outcome. “I don’t want any landfills,” he says.

A Coil of Social (In)Coherencies

My taxonomic intervention, “entombment/containment” and “interpretive development,” is adapted from *A Thousand Plateaus* (Deleuze & Guattari, 1987, p. 150). For clarity, I reproduce one of Deleuze & Guattari’s diagrams below as Figure 1.

Figure 1: Deleuzian Inspired Diagram of a Social Cohesion



(1) “The Center or the Signifier”: in this case *developmental progress*. (2) “The Temple or Palace with priests and bureaucrats”: offices of health and human services, the Nebraska State Developmental Center; the direction toward which Merciful Black is being pulled. (3) “...the sign referring to other signs on the same circle or on different circles”: epistemological and practical struggles over ‘what community means.’ (4) “The interpretive development of signifier into signified which...reimparts the signifier”: Zero President moving away from the Center; Merciful Black moving toward the Center. (5) “The expiatory animal; the blocking of the line of flight”: The contained element of Merciful Black, blocked from fully identifying with her community. (6) “The scapegoat or the negative sign of the line of flight”: the act of escape Merciful would need to fully enter into her desired regime of coherency.

Once the mission of forging a cohesion called “community” is declared, the question must remain as to who has identified its signs and values for belonging, imputed their absence upon whom, and to what consequence? Christopher Lasch, twice in his work, *The True and Only Heaven: Progress and Its Critics* (1991), quotes a 1932 statement made by Christian ethicist, Reinold Niebuhr, “If social cohesion is impossible without coercion, and coercion is impossible without the creation of social injustice, and the destruction of injustice is impossible without the use of further coercion, are we not in an endless cycle of social conflict?” (Lasch, 1991, p. 377).

Universal Ideologies and Radical Contingencies

Although each case here is different from the other they both have in common the coil of social cohesion upon which their processes of place are manifest. Both live in spaces consequent to a Normalization movement which began Nebraska’s deinstitutionalization process in 1968 with promises of the “return of the mentally retarded to society as *productive* citizens” (Terry, 1968). It was a promise of progress—the economic progress of earning independence, the cultural progress of performing the signs for valued citizenship, and the ethical progress of implementing right knowledge for practices of making-up this progressive citizenship through humanist values and a communitarian political praxis (Schalock, 2002).

Problems with Normalization-based community services in Nebraska became manifest (Schalock, 2002) when, despite the promises, the reality sunk in that not all “mentally retarded” people can or want to work in the “competitive” workplace and/or obtain the culture of independence community experts and humanists imagined as desirable for them. This compounded with the structural reality of globalization as the 1980s onward saw many of the manual labor jobs traditionally pursued by “higher functioning DD” individuals moved out of state. Responding to this stagnation the State of Nebraska assumed tighter control over the service system to account for the dollars spent on it; to encourage people to be made to move through the system more measurably and if not moving be accounted for and treated by a form of behavioral discipline believed able to make them move. As happened with the state schools for “feebleminded” youth, “Well intentioned advocates of productivity through education became unintentionally the mediators of disabling, unproductive institutionalization” (Trent, 1994, p. 3).

Merciful’s service workers do not see themselves as a conspiracy of control, but rather as agents of protection from immanent pathways into the criminal justice system. But Normalization here begets frustrating consequences in part because the articulation of its system will not affirm Merciful’s work toward becoming her desired identity. There is no allowance for normalization into ghetto life. This omission becomes the commission of entombment/containment when it pathologizes not only Merciful’s resistance to these blockages, but also when it actively and un/intentionally erects more blockages by pathologizing of her behavior. They should advocate for more thorough systems of mass-transit, or really teach Merciful to drive such as the social model of disability would (Oliver 1990). Yet, while the social model of disability might be more efficacious in practical terms here, theoretically it would need tweaking. The social model counts as the voices of disability those who self identify as disabled and resist structures of normalization in that name. But Merciful does not self-identify as disabled; and especially not as having “DD,” the people who belong to “the nuthouse” with which she refuses to identify. When with her “non-DD” friends she actively obscures any part of her past and her identity related to her “behavioral disorder” or her “mild mental retardation.” She tries, and often succeeds at “passing.” In a sense she truly pursues normalization, and with it desires the Social Role Valorization of a kind of ghetto life.

For Zero, the discipline of place was parental rather than programmatic. “You won’t do your homework, then no dinner!” is one strategy Peaceful shares for how he set Zero on the trajectory of literacy. Here too is coercion, and in the eyes of some case workers I have come to know it would constitute abuse. Yet, it was this tactic of parental coercion which helped create the very conditions and skills necessary for Zero’s present approach to self-advocacy—a self-advocacy he performs outside the purview of “DD peoples’ parliaments” but on the very place of his community work where he now sees himself as a leader in the sense of a “monk” or a “coach.” The social model of disability desires and encourages people to consider or make outcomes such as Zero’s (Goodley & Lawthom, 2005). But, like Merciful’s case, Zero’s comes as a consequence of Nebraska’s Normalization Movement. When Peaceful Ruler became Zero’s paternal touchstone in 1978, he had been active as an intake officer and community advocate for Nebraska’s Normalization based community services. And, in fact, Peaceful Ruler was close to key leaders of Nebraska’s Normalization movement so that Zero’s legal guardian is no less than the woman cited as the “silent but powerful conscience of Nebraska’s Normalization movement”

(Schalock, 2002). And so, the question strikes me, is there more to Normalization than a caricature of medicalization and state control?

Coda

“The recent enthusiasm for social capital,” says one discussion vis-à-vis a resurgent popularity in the work of Durkheim, “Is an example of a theory whose rhetoric is often more liberating than its application” (Kishner & Sterk, 2005, p. 1142). Social cohesion paradigms tempt policy makers and research workers because its terms appear to render the desirable mechanisms of community transparent. While these tools may be useful in some cases making visible certain needs or desires, they run always the risk of imposing a form, or rendering invisible and unaddressed that which fails forms where personhood is accounted through universals of good or bad, black or white, stagnant or developed, included or excluded, valorized or devalued.

Universal models for making social cohesion out of a “DD” population fail not only because the variables of an individual “DD” case are too multiple and contingent to fit into a single mold for making community work, but also because resilient individuals of a population which has come to be defined by its very lack of development will differentially and actively defy disservices received in the name of making through state discipline this absent thing. Another sign is needed; one less ready to point to individual villains, whether “DD,” an epistemology, a state, or staff.

Seeing how community services can wind people into ever tighter networks of police, it may be time to let the coils of social cohesion unravel just a bit; to let individuals unravel it in a manner which makes sense to them—whether it is normalization into the ghetto, or rethinking the orders of valued work. Though “DD” is not madness, the wisdom may be the same. “[I]t is this circle that antipsychiatry undertakes to unravel...giving the individual the task and right of taking his madness to the limit, of taking it right to the end, in an experience to which others may contribute, but never in the name of a power conferred on them by their reason or normality” (Foucault, 2006, p. 346). Sociology just as well as human services has been down coils of social coherency many times before. Civilization is not borne of bloodless motion.

“My consolation and my happiness are to be found in service of all that lives, because the divine essence is the sum total of all life.” M. Gandhi (quoted from Peaceful Ruler’s journal of daily meditations).

Michael Stephen Glennon, M.Soc., is a Research Master’s student at the Universiteit van Amsterdam’s International School for Humanities and Social Science. He graduated from this same institution in 2007 with a Master’s in Science of Sociology concentrating in social theory and public affairs. His current research is on autistic rights awareness and engages autistic subjectivity as making spaces for cultural translation and becoming exterior to the state apparatus. It focuses specifically on (self)advocacy in virtual ethnographic spaces like Second Life and the 1960s subgenre of *social* science-fiction as exemplified by the writings of Philip K.

Dick. Holding a Bachelor of Fine Arts in poetic composition from the University of Nebraska at Omaha. mglennon24@msn.

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Endnotes

¹Merciful Black and Zero President are pseudonyms.

²Peaceful Warrior is a pseudonym.

