

“FOREVER CHILDREN” AND AUTONOMOUS CITIZENS: COMPARING THE DEINSTITUTIONALIZATIONS OF PSYCHIATRIC PATIENTS AND DEVELOPMENTALLY DISABLED INDIVIDUALS IN THE UNITED STATES

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ABSTRACT

Purpose – We compare the deinstitutionalization of psychiatric patients and the developmentally disabled in the United States and demonstrate that there were two path-dependent processes with significant qualitative and quantitative differences, ultimately leading to better outcomes for developmentally disabled individuals.

50 Years after Deinstitutionalization: Mental Illness in Contemporary Communities
Advances in Medical Sociology, Volume 17, 27–61
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ISSN: 1057-6290/doi:10.1108/S1057-629020160000017002

Design — Using secondary literature, we construct a sustained comparison of the two processes in terms of outcomes, timing, tempo, extent, funding, demographic composition, and investment in community services. We then reconstruct the strategies of de-stigmatization and framings of moral worth deployed in the two cases, analyzing their effects on deinstitutionalization in terms of conceptions of risk, rights, and care.

Findings — Deinstitutionalization began later for developmentally disabled individuals than for psychiatric patients, and was a more gradual, protracted process. It was not driven by fiscal conservatism, discharges, and the trans-institutionalization of the senile aged, as was deinstitutionalization for psychiatric patients, but primarily by the prevention of institutionalization of young children, and increased investment in infrastructure. Consequently, the deinstitutionalization of the developmentally disabled was far more thorough and successful. The process was shaped by the framing of the developmentally disabled as “forever children” by parents’ organizations that demanded a balance between autonomy, protection, and the provision of care. In contrast, the deinstitutionalization of psychiatric patients was shaped by their framing as autonomous citizens temporarily suffering from “mental health problems” that could be prevented, treated, and cured. This frame foregrounded the right to choose (and also refuse) treatment, while undervaluing the provision of care.

Keywords: Deinstitutionalization; mental illness; mental retardation; developmental disability

INTRODUCTION

When researchers and commentators speak of “deinstitutionalization,” they often have in mind the processes by which psychiatric patients¹ in the United States were moved out of institutions. Perhaps implicitly, the deinstitutionalization of psychiatric patients is taken as the prototype for a generic process taking place in several fields. In consequence, attitudes toward deinstitutionalization are strongly shaped by the prevailing image of the spectacular emptying and dismantling of mental institutions; the revolving door of short-term admissions; the suspected prevalence of psychiatric disorders among the homeless and the incarcerated; and the phenomenon of

trans-institutionalization to nursing homes, hospitals and jails. This has contributed to an oft-repeated refrain that deinstitutionalization was a "stunning policy failure" (Durham, 1989; Mechanic & Rochefort, 1990), "re-institutionalization" (Bassuk & Gerson, 1978), "trans-institutionalization" (Fakhoury & Priebe, 2007), or a "transfer of care" (Brown, 1985) largely driven by economic considerations.

We would like to push back against what we believe to be the undue centrality of deinstitutionalization of psychiatric patients in the United States. If we would have taken the deinstitutionalization of the developmentally disabled as our prototype, we would have obtained a different image. Deinstitutionalization in this field has been far more gradual and deliberate, with sustained focus on creating residential and treatment arrangements in the community. Deinstitutionalization in the United States *does not* stand for a "single, unitary phenomenon" (Scull, 1984, p. 141), but for a loose agglomeration of different processes, resembling each other, but also diverging in fundamental respects. Researchers, commentators, and policy-makers should account for these differences and their underlying historical causes when they assess deinstitutionalization and debate future policy.

We offer the following rationale for the comparison of the deinstitutionalizations of psychiatric patients and the developmentally disabled:

- (1) *They were formally initiated by the same piece of legislation, namely, the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 (PL 88–164).* Indeed, the struggle to deinstitutionalize psychiatric patients "rode on the back" of the parallel struggle to deinstitutionalize the "retarded," as they were called at the time. Advocates for psychiatric patients desperately sought to link the campaigns so they would enjoy the "popularity and noncontroversial nature" of the far better organized and politically legitimate retardation provisions (Grob, 1991, pp. 219–231).
- (2) *Because of their common origins, the policies are financed by the same funding mechanisms, namely, Federal welfare programs such as Medicaid, Medicare, SSI, and SSDI (Lerman, 1982, pp. xiv–xv).*
- (3) *The populations served by the policies are not completely distinct from one another.* A sub-group among residents of State Mental Hospitals had a dual diagnosis of mental illness and mental retardation. They were among the most difficult to deinstitutionalize and among the last to be moved out (Geller, Fisher, Wirth-Cauchon, & Simon, 1990). By the same token, many of the developmentally disabled, whether in

institutions or outside, suffer from emotional and mental health problems and are prescribed psychoactive medications.

While comparisons are rare, research that does distinguish between these groups agree that the deinstitutionalization of the developmentally disabled has been “far less controversial” than that of psychiatric patients (Bagenstos, 2012), and more successful in the long-run.

The main difference is residential placement or living circumstances. In 2010, 56.5% of individuals with intellectual disability were living with family members, 8% were receiving residential support services in their own homes, and 5.4% of individuals with intellectual disability resided in public and private institutions (with 16+ individuals). The rest (about 30%) were in group homes and similar settings with 15 or less residents.² People with DD/ID have never been a significant group among the homeless (Bagenstos, 2012, p. 13). A lack of similar data for psychiatric patients speaks volumes about the differences between the two processes of deinstitutionalization. Individuals with ID/DD, even outside institutions, are still integrated within a fairly cohesive institutional matrix of service delivery and supervision: they are counted and followed. Individuals with psychiatric diagnoses (PD), on the other hand, navigate a fractured and disconnected “patchwork system” where the proverbial “white spots” of *terra incognita* are much larger than the areas known and mapped. Few settings have the oversight to track people with PD (Davis, Fulginiti, Kriegel, & Brekke, 2012, p. 260) and lack of centralization makes it difficult to compile aggregate data (Wong & Stanhope, 2009, p. 1378). Hence, the residential location of about 71% of individuals with serious mental illness (SMI) is “unknown.” From a libertarian point of view, this ignorance could be construed as a good outcome. *What is known*, however, is not encouraging: 13% are with family and friends, 6% are homeless, 4.4% in prisons and jails, 2% in nursing homes, 1.8% in mental hospitals, and 1.8% are in residential care facilities. Information on the composition of specific institutional settings is more enlightening: 9–20% of nursing home residents are estimated to have SMI. Nearly, 1 million people with PD are booked into jail every year but most are quickly released. Growth in the residential rolls of state hospitals is due almost entirely to transfers from correctional facilities. Stays at mental hospitals are short and 36% of those discharged become homeless within 6 months. Of the more than 2 million individuals who experience homelessness annually, roughly 25–33% have PD of some kind (Davis et al., 2012, pp. 260–262). The homeless, in turn, are likely to end up in a correctional facility, perpetuating a cycle in which many of the

70% whose location is unknown are likely stuck. In contrast, supportive housing for individuals with developmental disabilities (DDs) is more spatially dispersed, in less distressed, less unstable, and more secure neighborhoods than for people with psychiatric diagnoses (Wong & Stanhope, 2009).

These disparities translate to major differences in morbidity and mortality. People with SMI die, on average, 25 years earlier than the general population (30–40% is due to suicide and injury, the rest to chronic and acute medical conditions) (Parks, Svendsen, Singer, Foti, & Mauer, 2006). This is true for people with SMI living “in the community” as well as in institutions (Davis et al., 2012, p. 265). While there has been some debate whether deinstitutionalization in California increased the rate of mortality among DD individuals (Strauss & Kastner, 1996), the bulk of the research has documented increases in the life expectancy of people with ID. Improvements in medical care made a significant contribution to this increase, but life expectancy remains shorter among institutionalized individuals with ID/DD suggesting that community living also plays a role (Coppus, 2013, pp. 7, 13). This has contributed to an increase in the number of aging DD individuals who are at home with aging parents. We will return to this problem later.

Research has also documented better behavioral and psychological outcomes for individuals with DD than for individuals with PD in consequence of deinstitutionalization. Overall, outcomes on a variety of behavioral and psychological measures – interaction in group activities, degree of self-reliance, independence and exercise of choice, maladaptive behavior, language development, self-care, and skills acquisition – were superior in community placements for individuals with DD (Beadle-Brown, Mansell, & Kozma, 2007; Edgerton, 1993; Kim, Larson, & Lakin, 2001; Kozma, Mansell, & Beadle-Brown, 2009; O’Neill, Brown, Gordon, & Schonhorn, 1985; Stancliffe & Abery, 1997; Walsh & Walsh, 1982). In comparison, there seems to be no such consensus for people with PD. One study noted that “participants were well aware of, and quite articulate about, several serious drawbacks of community living,” listing the benefits of inpatient care for the provision of basic needs even though they generally preferred the community (Davidson, Hoge, Godleski, Rakfeldt, & Griffith, 1996).

These different outcomes are a reflection of fundamental differences between the two *processes* of deinstitutionalization. As can be seen in Fig. 1,³ the population of state mental hospitals peaked in 1955, and began to decline precipitously from then onwards. By 1975, resident patients at county and state mental hospitals numbered 193,436, a decline

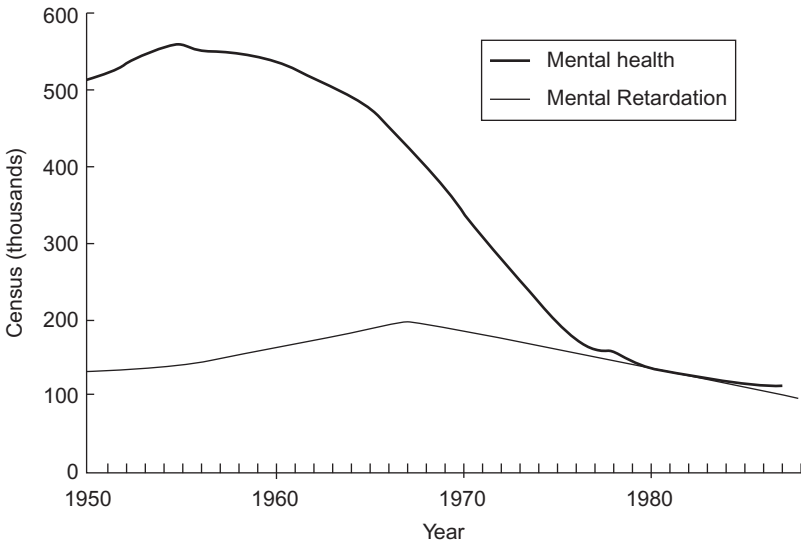


Fig. 1. Daily Census of State Mental Institutions: 1950–1988. *Source:* Mental health data from Witkin (1989); mental retardation data from Lakin (1980) for 1950–1976 and from Braddock et al. (1990) for 1977–1988.

of 65% from 1955. By 1985, they were 109,939, a decline of 81% (Davis et al., 2012, p. 259; Mechanic & Rochefort, 1990, p. 307). The rate of institutionalization of the developmentally disabled, on the other hand, peaked in 1967 (at 115.72 per 100,000). In 1977, there were still 167,056 individuals with MR/DD in large state MR or Psychiatric facilities, a reduction of 27% from 1967, and by 1986, they were 103,296, a decline of 55% (Braddock, 1992, pp. 175–176; Prouty, Smith, & Lakin, 2001, pp. 8–9).⁴

More revealing than numbers of residents are patterns of admissions, discharges, readmissions, average lengths of stay, and inpatients' episodes. While the number of residents in state and county mental hospitals in 1975 declined 65% from its peak in 1955, the number of admissions more than doubled, from 178,003 to 376,156. The number of total inpatient episodes declined 27% from 818,832 to 598,993 in the same time period. From 1969 to 1982, the average length of stay declined from 421 days to 143 days. These numbers demonstrate that the reduction in the population of institutionalized psychiatric patients was achieved primarily through a “revolving door” of readmissions

(composed of massive discharges, short stays, discharges, and back again) (Mechanic & Rochefort, 1990, pp. 307–308). By comparison, the absolute number of admissions to large state MR facilities was much more modest, declining after 1974 from 18,075 to 6,535 in 1986 and 2,338 in 1995. The number of discharges also declined (Prouty et al., 2001, pp. 14–15). Thus, the gradual reduction in the institutionalized MR/DD population was achieved through the *prevention of institutionalization*, and thus of readmissions (Landesman & Butterfield, 1987, pp. 810–811).

Statistics about levels of funding and the creation of community services support these contrasting patterns of deinstitutionalization. Until the 1970s, spending on mental health dwarfed spending on MR – likely because the prevalence of SMI was much larger than the prevalence of DD; in 1955 the psychiatric institutionalized population was at least four times larger than the population of MR institutions. By 1983, spending by state programs was roughly equal in absolute terms, and so much larger per capita for DDs (Braddock, 1992, pp. 175–176). In the following years, expenditures on community services for individuals with DDs increased substantially more than for individuals with PD, and in 1987 funding for DD community services was 72% higher *in absolute terms* than for psychiatric community services. Half of all DD funding by state programs was for community services, while for PD it was only a third. The number of DD community facilities (excluding nursing homes) grew from 4,390 in 1977, serving 62,397 residents, to 28,000 in 1988, serving 174,000 residents. The comparable development of community services for people with PD lagged far behind (*ibid.* pp. 176–179). Yet states also invested large sums in renovating MR institutions and improving the quality of care – during 1978–1980 almost a billion dollars was spent on renovation and 1.2 billion was spent on improving quality of care. While deinstitutionalization of psychiatric patients in the United States was tied to reductions in state funding for institutions, deinstitutionalization of individuals with DD involved increased investment in both institutions and community alternatives, *inclusive of increases specifically in States' funding for community services from about half a Billion dollars in 1977 to 3.2 Billion in 1987!* (Braddock, 1981, 1992, p. 181). So while the evidence is overwhelming that financial incentives to states to shift the fiscal burden to Federal programs played a crucial role in the deinstitutionalization of psychiatric patients in the United States (Bassuk & Gerson, 1978; Estes & Harrington, 1981; Lerman, 1982; Mechanic & Rochefort, 1990), it would be much harder to make the same argument for

the deinstitutionalization of DD individuals, where a vast funding increase has contributed to a 36% increase in total system capacity (Braddock, 1999).

These numbers do not fully capture the differences in deinstitutionalization. To put it bluntly, the prevention of institutionalization in DD was primarily prevention of the institutionalization of *children*, while the massive discharges of psychiatric patients were primarily trans-institutionalization of the *aged*. The proportion of children and youth (younger than 21) in state MR institutions peaked in 1965 at about 48.9%, declined to 35.8% in 1977 and 12.7% in 1987, while the mean age of first admission increased from 13.3 to 18 (Prouty, Smith, & Lakin, 2007, p. 41). At the same time, the largest category of first admissions to mental hospitals in 1962 was individuals aged 65 or older (163.7 per 100,000), while children under 15 were the smallest category (6 per 100,000). By 1972, the rate of first admissions of the aged decreased sharply to 69.2 per 100,000, while the 4 largest categories were now between the ages of 15 to 54, and the rate of first admissions for the young (0–24) actually increased (Grob, 1991, pp. 268–269).

The destinations for these groups were vastly different. Whereas the deinstitutionalization of adults with DD was a slow and protracted process, underlying it was a rapid transformation in the status of children who were kept at home rather than institutionalized. In 1987, 18.2% of all ID out-of-home placements were children and youth (under 21), declining to 7.6% in 1997, and to 6.2% in 2005 (Stancliffe, Lakin, & Prouty, 2005). DD children and adults staying at home are supported by a combination of Federal and State funds, with the latter increasing by a factor of 6 over the 1980s (Braddock, 1992, p. 181), a fact that reduces the significance of fiscal incentives in explaining the deinstitutionalization of DD individuals.⁵ On the other hand, the number of aged psychiatric patients in nursing homes doubled from 187,675 in 1963 to 367,586 in 1969 (Grob, 1991, pp. 268–269). In 1977, the vast majority (1.15 out of 1.7 million) of chronic psychiatric patients resided in nursing homes or board-and-care facilities funded primarily through Medicaid. By 1985, nursing homes housed over 600,000 people diagnosed with PD, and Medicaid was the largest federal program funding the long-term care of psychiatric patients (Grob, 1995, p. 54). Thirty percent of the 1.3 million residents of nursing homes had a diagnosis of chronic MI, and 57% had a diagnosis of chronic senility (Shadish, Lurigio, & Lewis, 1989, p. 3). This clearly supports the fiscal explanation for the deinstitutionalization of psychiatric patients.

Framings of Social Worth

Most existing theories of deinstitutionalization are not sensitive to the profound differences between these two processes. Attempts to explain differences emphasize the role of advocacy groups in the progression of deinstitutionalization. Both Bagenstos (2012, pp. 18–19) and Braddock (1992, pp. 176–177) cite the superior clout of “consumer advocacy groups” such as the Association for Retarded Citizens (ARC) as an explanation for the better outcomes in this field. They attribute this clout not only to better organization and more experience, but also to the extensive involvement of family members, especially parents, in these organizations as compared to advocacy organizations for psychiatric patients.

With certain caveats, we agree that the role played by parents’ organizations in the deinstitutionalization of DD is a crucial variable differentiating the two processes. Family advocacy organizations on behalf of psychiatric patients do exist, but their impact is unlikely to have been equivalent to the ARC and similar organizations. The first reason is timing. The National Alliance for the Mentally Ill (NAMI) was formed by family members of psychiatric patients in 1981, 30 years after the formation of the National Association for Retarded Children (NARC, later renamed ARC), and 26 years after deinstitutionalization of psychiatric patients began. Before its formation, researchers felt that families of psychiatric patients were “probably the least organized and vocal of those groups affected” by deinstitutionalization (Doll, 1976, p. 386). Given this late formation, the focus of NAMI and similar organizations was not on shaping the process of deinstitutionalization, but on influencing NIMH to turn away from psychosocial toward brain-based research.

One could argue that this difference is explained by the greater stigma of “mental illness”; the greater legitimacy of the cause of DD; or by the singularity of focus of the ARC on community solutions (Braddock, 1992, p. 181; Grob, 1991, pp. 219–231). None of these explanations is very convincing. To begin with the matter of legitimacy, the argument is that the public saw DD children as innocent, vulnerable, and in need of help, while the same public feared psychiatric patients, had less sympathy for them, and blamed them for their plight. Politicians responding to NIMBY sentiments would not direct resources at community services for psychiatric patients. While services for DD faced similar hurdles, they were able to garner more sympathy, partly because of the political clout of parents’ organizations. If you take a freeze frame of the situation, let’s say, in the late

1980s, and you do not look too deeply, you might believe this. But the story is more complicated.

To begin with the obvious point: most individuals with ID/DD *are not children*, but adults. They are not *naturally* more sympathetic, less stigmatized, and less threatening than psychiatric patients. If we go back to the earlier decades of the 20th century we find that the “feeble-minded” and the “insane” were similarly stigmatized, feared, and shunned. Representing the same eugenic threat, they were placed in the same institutions. The prevailing image of the feeble-minded was as *delinquent adolescents*. Before the 1950s, there were hardly any very young children (5 years of age or under) in state MR institutions. Superintendents rejected applications to institutionalize very young children except as a last resort (Metzel, 2004, pp. 431–433). From 1904 to 1945, more than half of first admissions to state institutions were *older children and adolescents* (10–19 years of age), typically lower-class, minority, or immigrant “morons” (i.e., slightly below “normal” IQ). Truancy, delinquency, epilepsy, alcoholism, sexual promiscuity, even masturbation, served as pretexts to commitment as “mentally deficient.” The goal of institutionalization was social defense from “defective delinquents” and “morally imbecile” youth (Malzberg, 1952; Trent, 1994). The insane may have even attracted more sympathy and less stigma than the feeble-minded, because the institutionalized insane increasingly included the senile aged. Before the 1890s, the aged – infirm, needy and senile – were typically cared for at local almshouses at the expense of municipalities and counties. During the first decades of the 20th century, however, local officials began to “redefine senility as a psychiatric problem” and transferred the aged to mental institutions and state budgets: 18% of first admissions to NYS mental hospitals in 1920 were of individuals 65 years or older; 31% in 1940; 33.3% in 1951. Growth was similar in other states (Grob, 1977, 1995). Yet, it was mostly the case that the insane, even the aged among them, were viewed with suspicion and fear, and were tainted with the stain of degeneracy, poverty, and immorality (especially as many of the aged patients were syphilitic).

Our contention, therefore, is that the difference between the deinstitutionalizations of psychiatric patients and of the developmentally disabled is not because one condition is naturally less stigmatizing, but because each process of deinstitutionalization was continuous with a different path out of stigma and moral taint. In each of the two spheres, a different strategy of de-stigmatization, moral cleansing and valorization – endowing a once despised existence with a form of social worth – was attempted, and while it did not necessarily begin with the intent of deinstitutionalization, it

ultimately led to it and shaped its course. Our emphasis on the role played by framings of social worth is not a “culturalist” or “discursive” explanation. Framings of social worth are a crucial link between individuals and the distributive mechanisms of the welfare state, understood as a complex “economy of worth” (Boltanski & Thévenot, 2006). Welfare state categories-qua-framings of social worth determine not only how much gets distributed to whom, but also in what form, under which conditions, and to what purpose. Thus, the comparative analysis developed below is specific to the particular “world” of Anglo-American welfare capitalism (Esping-Andersen, 2013; Lerman, 1982).

The key to what happened in the sphere of DD is the framing of affected individuals as “forever children” in need of guardianship, education, and habilitation, a frame that dates back to at least 1950 and Pearl Buck’s *The Child who Never Grew Up*. This frame, adopted as the explicit strategy of NARC, must be understood in the context of the larger post-WWII invention of the child-centered family – what others have called the “reproductive consensus” of the era (Castles, 2004, pp. 359–360; Fass, 2012; Trent, 1994, pp. 231–241). That the 1950s were the time of straight-laced, middle-class, suburban families is of course a myth, but it was a powerful myth operative at the time. More precisely, it was a formula for assigning social worth (and for redistributing state resources) on the basis of “normality”: producing and raising healthy children as an ethical goal of middle class adulthood thereby making a “contribution” to society. Organizations of parents of “retarded” children formed during this time (Metzel, 2004, pp. 431–433) were mobilized to lay claim to services, but more generally to membership in this normality. Lee Marino, one of the founders of New Jersey’s Parents Group for Retarded Children, explained the purpose of his organization in these terms: “parents in this era invested heavily in their children ... but, for him and others like him, the investment did not carry the same dividends. Their families carried a special burden, one that seemed to put normal family relations out of reach, and they wanted to do something about it” (Jones, 2004, pp. 326–327). The term “dividends” used here should not be understood literally. The investment in children brought moral, not economic worth. The New Jersey parents lobbied for entitlements on the basis of being “exceptional families,” but at the same time they claimed recognition and moral worth on the basis of being equivalent to “normal” families, since they too invested in their children.

This explains why parents initially lobbied *for* institutionalization as a way of reclaiming normality for the family. It is well-known that doctors in this period encouraged parents to commit their very young children to

institutions for the mentally retarded. Surveys of parents in the late 1950s at MR clinics found that half were instructed by their doctors to institutionalize their retarded child (Castles, 2004, p. 363). Doctors, especially child psychiatrists, envisioned institutionalization as a crucial plank in a larger surveillance system for early childhood: a system that could detect abnormalities and assign children as early as possible to the right intervention — of which institutionalization was one possibility (Kanner, 1949; Schumacher, 1946). Consequently, there was a dramatic increase in the proportion of very young children (0–5) institutionalized: from 6% of first admissions in 1938 to 18% in 1951, while children 0–9 years of age became the largest group of first admissions: from 23% in 1938 to 42% in 1951 (Goldstein, 1959).

It is less well known, however, that often *the parents themselves* exerted strong pressure on (sometimes reluctant) pediatricians to institutionalize their children (Brockley, 2004, pp. 144–45; Castles, 2004, pp. 352–53, 361–63). Donald Jolly (1952, pp. 632–635), a physician in a state school for the mentally retarded, reported that in his experience the main reason for the large increase in the institutionalization of very young children was the strong pressure exerted by parents. Both doctors and parents, however, articulated the same rationale for institutionalization: no longer social defense, but *a concern for the well-being of the child and of the middle class family*. Regarding the child, Jolly explained that the positive features of institutional life were the fact that he or she were protected from the frustration of competition; that they received special training adjusted to their needs; and that they could rely on continued care after their parents' death. While benefits were dependent on the commitment being voluntary, Jolly was confident that parents eventually would see institutionalization as “proper positive action in planning for the future of the exceptional child.” Institutionalization also benefited overburdened parents, neglected siblings, and marriages threatened by divorce. John and Lorraine Frank, who after much agonizing decided to institutionalize their young daughter, explained that they did not wish to sacrifice “the chance for a normal life for our expected [second] child” (Quoted in Jones, 2004, pp. 326). In short, doctors recommended institutionalization, and many parents concurred, in order to allow families to attain the middle-class normality that was the linchpin of the postwar social bargain (Brockley, 2004, p. 148–49; Castles, 2004, pp. 361–63).

Hence parents' organizations lobbied to repeal bans on the institutionalization of very young children, to shorten institutional waiting lists, to build new institutions, that is, to relieve middle-class families of the burden

of caring for their disabled children and allow them to be "normal" (Malzberg, 1952, p. 30; Trent, 1994, pp. 236–41). The secretary of the local chapter at New Brunswick "used her position in the group to advance the cause of institutionalization and to urge greater support ... for the state system of institutions." She explained that she decided to institutionalize her own daughter "to preserve the family unit," but that her daughter was "still a valuable part of her family." Indeed, the quest for normalcy did not permit to "simply put children away and forget about them." On the contrary, the parents groups included institutionalized children in "scripts of togetherness": there were family bus trips to the state institutions; fathers organized a building and grounds committee to build a playground; mothers took turns in giving haircuts to institutionalized children; there were holiday parties and gift exchanges (Jones, 2004, pp. 331–33). Institutionalization thus allowed the family unit to become normal not simply by removing the disabled child, but also by serving as a focal point around which family rituals of domesticity and community rituals of civic activism were reenacted, thereby re-including the disabled child.

This was the background for the emergence of the "forever children" frame. Not only were there indeed many more children in state institutions for the mentally retarded, so the frame was anchored by a certain reality, but to cast the developmentally disabled as children accorded with the post-war formula for assigning social worth. The middle-class parents who formed advocacy organizations were demanding the chance to be "normal Americans" like everybody else, which meant being able to lead a normal family life centered on "investing" in their children, cultivating and maximizing their health and potential. It was in the name of this ideal that children were institutionalized – no longer to protect "society" from the danger represented by adolescent morons, but to provide "forever children" with a sheltering, nurturing environment that substituted as best as possible for the middle-class family, while protecting the family itself from the burden they represented.

The historical irony is that the very same values and energies that the "forever children" frame first mobilized in favor of institutionalization were ultimately a catalyst for deinstitutionalization. The aspirations for "normality" turned into the rhetoric of "normalization." It was against this frame of "forever children" and the ideal of middle-class normality, that the institution was criticized as "warehousing" and a form of social waste (Castles, 2004; Jones, 2004). The ideal of middle-class, "normal" parenting, and the activism to which it gave rise in NARC was not only in search of conformity (as it is often depicted in simplistic accounts), but also in

pursuit of an ethical goal: through the activism of the parents, their child's existence would be valorized and transformed into a social contribution. Pearl Buck, for example, wrote that she decided against doctors' advice — not to institutionalize her daughter because “I resolved that ... my child ... was not to be wasted ... her existence as it was and as it is today, must be of use to human beings” (quoted in Trent, p. 231). The same message was echoed by parent advocates such as Dale Evans Rogers or Maria Egg. The task was to valorize this existence; to turn it from a burden into something with social meaning and value. A family grows and matures spiritually by caring for the child. In turn, this care provides a beautiful and inspiring example to others, creating societal value (Brockley, 2004, pp. 154–156; Egg, 1964, pp. 38–40). The institution was found wanting not only because it failed to cultivate the child, but also because it was secretive, a place where children were hidden away instead of becoming a “blessing for others.” Through the “forever children” frame, the retarded child was transformed from a destructive and disintegrative influence, into a factor of family strength and cohesion. Her presence represented a moral test through which the family could emerge stronger, more harmonious, having given their existence a more beautiful and authentic shape (Egg, 1964, p. 42).

There was thus a fundamental continuity between institutionalization and deinstitutionalization in how the “forever children” frame was mobilized to assign social worth to parents, their activism and their claims toward the state. By the same token, community treatment was not the opposite of the drive to create a comprehensive surveillance system for early childhood, but its continuation by other means. The main discontinuity was in the role of medical expertise. While at the height of the institutionalization wave, child psychiatry seemed to claim for itself the authority to diagnose the social destiny (and hence social worth) of very young children, deinstitutionalization, and the parent-led valorization of retarded existence repudiated this claim, and centered early detection and early intervention in the family, surrounded by various auxiliary agencies (Eyal et al., 2010, pp. 91–97).

So is it the case, as Braddock (1992, p. 181) suggested that the key difference between the deinstitutionalizations of these two groups was the singular focus of parents' organizations on community solutions? We think this is a serious misunderstanding. In reality, these organizations were never unified in uncompromising support for community solutions. As Gunnar Dybwad (1961), NARC's Executive Director from 1957 to 1963 argued, the frame of the “forever child,” which NARC helped to disseminate, could

be detrimental to the formation of community services for its “hesitancy to recognize the retarded as adults capable of sustained productive effort.” We believe that what made the deinstitutionalization of DDs ultimately more successful was neither a single-minded focus on a community approach, nor an opposite reluctance and suspicion toward it, but this tension, this unique push-and-pull, stop-and-go process vacillating between the two.

While NARC and other parents’ groups were among the most vocal supporters of deinstitutionalization, initiating the process through class action lawsuits, there were many other parents’ organizations (sometimes the same organizations that initiated the lawsuits) that were opposed to institution closings, or who insisted that for some children residential placements were the more appropriate solution, or who wondered aloud what would become of the “children” when their parents pass away (Egg, 1964, p. 148; Sullivan, 1981). Bagenstos (2012, pp. 18–19) calls their opposition, in alliance with unions of state employees, “the most significant obstacle to further deinstitutionalization of people with DDs.” This was especially true in States where the local ARC was itself a service provider, operating residential schools and nursing homes (Parish, 2005).

The key for explaining what happened to psychiatric patients is the framing of insanity as “mental illness” or even “mental health problem” continuous with less severe emotional problems and personality disorders. Unlike the taint of degeneracy, organic and moral defect associated with insanity, the post-war reformers depicted mental illness as something that could happen to anybody but that could be prevented, treated, and cured like any other illness (Grob, 1991, p. 263, 271, 303–304). This frame too is a formula for assigning social worth and should be understood in the post-WWII context. Earlier in the century, the British physician and eugenicist Alfred Frank Tredgold (1908) compared “mental disorder” and “mental deficiency”; thus, the mentally disordered were like a person in temporary financial embarrassment while the “mentally deficient” were like the poorest of the poor, who never possessed a bank account. The first have temporarily lost the means, the mental wherewithal, they previously possessed, but could hope to regain it; the second never had any means; they were literally “without a mind” (“amentia”). Along with the fiscal incentives discussed earlier, this point of view explains the massive institutionalization of the senile aged in the pre-WWII period, just as it justified the institutionalization of “morons” as social defense. The economic metaphor implies that it is worth society’s while to invest resources in the intensive treatment and prevention of mental disorder, since the payoff – in terms of autonomous

social contribution – will be several multiples larger upon recovery. Individuals who can no longer recover from their bankruptcy (because they were “mentally decayed,” as Tredgold called the senile aged), however, or who were never able to care for themselves, should be provided enlightened custody.

This point of view became especially poignant during and after WWII (Grob, 1991, pp. 5–23). Young psychiatrists serving in the war were exposed to a much larger range of neuro-psychiatric disorders, presenting in a larger population than previously recognized. Moreover, many of the disorders were clearly the result of stress associated with combat situations. Having proven themselves “socially capable” of societal contribution, returning GIs were clearly deserving of treatment. They were socially worthy on condition that they could be successfully treated and cured. Destigmatization and valorization, therefore, went through a different route and a different image than in the field of DD: not the image of the “forever child,” but the image of the self-reliant, autonomous citizen, temporarily hobbled by stress and illness, but ultimately capable of self-control and choice if assisted. At the heart of this frame, there was thus a paradox or catch-22: the only way to be treated as a rational and autonomous person, that is, not sick, is to admit that one is sick, since denying that one is sick is the most quintessential symptom of “mental illness.” To admit that one is sick is to aspire to become a “person with an illness,” a citizen fully possessed of the faculty of choice and the capacity for autonomy, who also happens to have a sick body. This frame is inherently unstable as it relies on a fictitious separation between the citizen and her body (Estroff, 1981; Luhrmann, 2000).

Nonetheless, on the basis of this image of a continuum of “mental health problems,” a group of elite professionals (psychiatrists and psychologists) and health policy leaders (at NIMH, APA, etc.) embarked on a campaign to modernize treatment and destigmatize mental illness, integrating it more fully within a rational public health policy.⁶ At the heart of the campaign was the claim that insanity was the last and most severe stage of mental illness, initiated and perpetuated (if untreated) by a combination of genetic, environmental and social factors. The instability at the heart of the concept of “mental illness,” however, meant that the notion of a “continuum” worked best for the reformers when the focus was on identifying mild presentations early, among non-institutionalized populations, and acting to remediate their environmental and social causes. If applied to institutionalized populations, it merely led to paradoxes and often collapsed because a claim to be healthy was also a

failure to rationally recognize illness. Thus, the reformers became champions of deinstitutionalization because institutionalization meant that treatment came doubly too late (Grob, 1991, p. 5, 302): too late to be effective and economic, and too late because the patient could no longer be stably construed on the model of the autonomous citizen with a sick body. It is understandable, therefore, why evidence emerged later that the reforms involved a shift of focus in mental health policy from the severely mentally ill to a more diffuse target population in the community with milder and more episodic presentations (*ibid.* pp. 251–261).

Finally, this framing also meant that the connection between “care” and “treatment” was severed. While the institution was supposed to provide both, the focus of Community Mental Health Clinics (CMHC) was to be on providing outpatient therapeutic services to a broad population. Their jurisdiction did not include most of the more quotidian care needs of recently released psychiatric patients – residential services, supervision, sheltered employment, etc. To put it in a nutshell: the senile aged, trans-institutionalized to nursing homes, were provided care, but not treatment; younger, mostly schizophrenic, patients discharged to CMHCs received treatment, but not care (Grob, 1991, pp. 303–304, 271).

While articulating a social mission for psychiatry and seeking to modernize its outlook and practices, young elite psychiatrists had to overcome both the resistance of older psychiatrists serving as superintendents of mental asylums and the skepticism of many of the rank-and-file who saw prevention as too ambitious, and a threat to their normal practice. For this reason, the reformers built an inter-professional coalition incorporating psychologists, advocacy organizations and foundations, legislators and their staffers and the administrative leadership of several Federal agencies. Mental health policy became a “hinge” issue linking the professional and state “ecologies.” The “social psychiatry” articulated by the reformers, and with it deinstitutionalization, became linked to the “liberal” or “progressive” outlook that sought to shift responsibility for health and welfare policy from states to the Federal Government (Grob, 1991, pp. 93–123).

It would be tempting to say that the continuum model “medicalized” insanity, but this would be an oversimplification. Earlier constructions of insanity and degeneracy were integral parts of medical science in the early 20th century, and the “continuum model” was not necessarily medical, but relied on notions of environmental and social causation. More importantly, the mental illness frame was (and is) inherently unstable. The psychiatric patient with a merely medical diagnosis, the citizen with a sick body,

frequently collapses back to a morally suspect and stigmatized individual, because the very means by which one demonstrates autonomy and self-possession — speech, communication, self-descriptions, reports, sureties provided, choices made — are suspect. Indeed, it was this very suspicion that initially made one's illness or complaint "mental" rather than physical (Foucault, 2006). Consequently, morality and stigma are always around the corner, contaminating the medical means and symbolisms that were meant to chase them away. The individual who fails to act with self-control and autonomy when discharged becomes morally culpable for failing to adhere to his/her treatment schedule for reasons understood at one and the same time as symptoms of illness and as moral faults.

We can return now to the role played by psychoactive medications in the deinstitutionalization of psychiatric patients. To attribute deinstitutionalization to their discovery is no doubt a fallacy. More precisely, it was a story told in order to accelerate reform (Grob, 1991; Scull, 1984). Great enthusiasm for the drugs stemmed less from their demonstrated effects than from the fact that they fit within the rational frame of mental illness, holding the promise of proving that insanity was nothing but illness — treatable, preventable, and curable — and that psychiatric patients were simply citizens with a sick body. Yet, for all their utility, the side-effects of the drugs soon became contaminated with the stigma they sought to exorcise. By the late 1960s, side-effects, namely, tardive dyskinesia, were effectively stigmata of mental illness. Even as the "meds" were improved and their side-effects minimized or made less visible, it was also acknowledged that they do not "cure" mental illness so much as imperfectly control its symptoms. And if patients failed to take their meds, was it due to willfulness or a symptom of their illness? Soon, "taking your meds," was a moral act, intermittently mixed with, substituted by or for, forms of substance abuse: evidence simultaneously of mental illness and moral fault.

In what remains of this chapter, we would like to spell out the implications of these framings of social worth in terms of shaping divergent processes of deinstitutionalization. The main difference we identified earlier between the two processes was the fact that community services for DD individuals were far more developed and much better funded than community services for psychiatric patients, who tend to circulate between short-term hospitalizations, incarceration, substance abuse, and homelessness. Our argument is that this difference follows from how each frame configures the moral worth of "care" and of being cared for. The divergent worth of "care," however, is itself partly dependent on whether

it is understood to impinge, or not, on the rights of the affected individuals; and on whether it is understood to be necessary in order to protect vulnerable individuals from risk, or on the contrary to protect others from the threat they pose. Hence, we organize the discussion below beginning with how each frame configures who is risky and to whom, proceeding to how it construes the rights of disabled individuals, and finally ending with the moral worth of “care” within each frame.

Risk

To put it simply from the outset: the frame of “forever children” foregrounded the risks that the community environment posed to the DD. In comparison, the frame of “mental health problems” minimized both the risk to psychiatric patients and the risk they posed to others, presenting deinstitutionalization as safe. Yet, it also led to other processes that accentuated perceptions of the risk psychiatric patients posed to others.

The institution embodied this tension between risk and protection. (Fakhoury & Priebe, 2007). Earlier in the 19th century, residential schools for the feeble-minded and asylums for the insane were justified as providing protective custody for individuals who could not fend for themselves. Later, during the first decades of the 20th century, the justification shifted to focus on the risks that the insane or the feeble-minded posed to society. The theory of degeneration cast both as representing a eugenic threat to the long-term viability of the (white) race, while theories of social defense attributed to them a disproportionate share of crime, sexual promiscuity, idleness, poverty, etc.

This tension between risk and protection has resolved itself in two ways. To begin with psychiatric patients, the frame of “mental health problems” de-emphasized their need for protection as well as the risk they posed to others. Yet, the separation of “treatment” from “care” ultimately led to increased worries about the risk they represented to the communities into which they were discharged. As we saw earlier, deinstitutionalization involved a massive trans-institutionalization of the aged in need of care to nursing homes. Individuals with both DD and organic (as opposed to functional) illnesses were also discharged to nursing homes and ICF-MRs. In short, those most obviously in need of *protection* were trans-institutionalized to various care facilities. By the same token, the bulk of those who were discharged to be treated in CMHCs were individuals more likely to be perceived as posing some level of risk to those around them: young

schizophrenics and what came to be known as “borderline personality disorder.” Moreover, the first generation of psychiatric patients to reach adulthood in the community was baby boomers. Like their “normal” age peers they questioned authority and experimented with new life styles. Consequently, they were characterized by higher levels of substance abuse and homelessness, aggressiveness, and noncompliance (Geller et al., 1990; Grob, 1995).

As a result, commentators have paid a great deal of attention to the risky behaviors of former psychiatric patients and to the risks they posed to others. While some researchers pointed out that those who pose a risk to society were a minority and that most should be understood as vulnerable (Allen & Nairn, 1997; Laws & Dear, 1988), many researchers and commentators, highlighted the overlap between psychiatric diagnosis, homelessness, substance abuse, and crime which served as strong evidence of the failure of community-based care (Durham, 1989; Steadman, Monahan, Duffee, & Hartstone, 1984).

The opposite is true of the DD. Given their framing as “forever children,” the focus of advocates, lawmakers, service providers, and especially of parents’ organizations was on risks they faced outside the institution. Under the Willowbrook consent decree, for example, residents were not released until there was an adequate residential alternative available. In fact, precisely because of the previous experience with the deinstitutionalization of psychiatric patients, reformers were concerned that the state would attempt to simply “dump” Willowbrook residents, which it tried to do before the consent decree was signed. After it was signed, the court-appointed review panel had to overcome the resistance of parents’ organizations, who preferred trans-institutionalization to borough “developmental centers.” Throughout the process, the governing language was one of concerns to prevent “harm.” Similar precautions were taken during the mandated deinstitutionalization of Pennhurst and other institutions. Reformers articulated a theory according to which institutional environments caused “intellectual, social, and emotional harms,” while parents emphasized the potential for harm outside a protective environment (Carey, 2009; Rothman & Rothman, 2005, pp. 70, 90–93, 102–103, 106–111, 127–141, 151–174, 200). The most poignant commentary and critique came from *Voice of the Retarded* (VOR), a parents’ group. They drew on the “forever children” frame to accentuate the risks to the DD, and to ridicule the discourse of “rights.” VOR quipped that the insistence on the civil rights and freedom of choice of the DD would merely become “the rights of people with DDs to eat too many doughnuts and take a nap” (Bannerman, Sheldon, Sherman, & Harchik, 1990). If

the DD needed rights at all, said VOR activists, it was a "right to be retarded," namely, a right not to be placed at risk because of a misguided insistence on autonomy (Bagenstos, 2012).

The leadership of NARC, on the other hand, while firmly in favor of deinstitutionalization, searched for the right balance between protection and autonomy, the right level of "acceptable risk." Perske (1972) argued that protecting the disabled person from all types of risk limited their access to a "normal life" and violated the main principle of normalization theory – "letting the mentally retarded obtain an existence as close to the normal as possible." A certain level of risk was normal and endowed those exposed to it with social worth, what Perske called the "dignity of risk." Ultimately, the 1975 Developmentally Disabled Assistance and Bill of Rights Act reflected this balanced stance on risk in their mandated selective deinstitutionalization of developmentally disabled individuals "who have been prepared through programs of habilitation and training to function adequately in appropriate local settings" (Landesman & Butterfield, 1987, pp. 810–811). While there was fierce debate among parent activists and advocates about how to balance risk, there did not seem to be similar levels of worry about the risk that DD individuals posed to others.

These differentials focus on risk no doubt shaped decisions about the location of residences for psychiatric patients and DD individuals. While survey research found that citizens were in theory supportive of having both psychiatric patients and DD individuals live in the community (Gallup, 1976; Gottwald, 1970), the actual placement of community residences in neighborhoods typically led to protests based on the anticipated impact on property values, safety, and health risks to the community (Kastner, Reppucci, & Pezzoli, 1979; Piat, 2000). Once DD individuals actually moved into a neighborhood and became a regular presence, the opposition typically subsided. Concerns about the risk psychiatric patients posed remained more entrenched (Lubin, Schwartz, Zigman, & Janicki, 1982). Moreover, concern about risks posed to the developmentally disabled by community placement dictated a great deal of care in choosing "safe" community settings for permanent residences while psychiatric patients tended to be pushed toward dilapidated urban areas, welfare hotels, and similar temporary residences that house also former convicts, people in substance abuse programs, etc. (Wong & Stanhope, 2009). This has reinforced the perception of psychiatric patients as "risky," and contributed to a vicious cycle in which various forms of confinement and "secure accommodations" become a preferred residential placement for "mentally disordered offenders" (Moon, 2000).

Rights

In both fields, deinstitutionalization was driven in large part by concern for the civil rights of inmates (Accordino, Porter, & Morse, 2001; Estes & Harrington, 1981). Exposés of abuse, maltreatment, and coercion at institutions highlighted that people were being held against their will without treatment or care (Kugel & Wolfensberger, 1969; Blatt & Kaplan, 1974). Legal activists, reformers, and civil libertarians, inspired by the larger civil rights movement of the 1960s, drew on these reports to launch a wide-ranging legal attack on institutions (Mechanic & Rochefort, 1990).

Despite similarities, there were also important and telltale differences in the legal argumentation and rhetoric of rights deployed in the two fields. Bagenstos (2012) introduces a useful distinction between two lines of due process doctrine used in early litigation. One was an argument for “negative rights”: a “right against treatment” which targeted involuntary commitment (and involuntary medication) and attempted to impose procedural limitations so individuals could not be held against their will unless they were dangerous to themselves or others. This strategy was prominent in litigation regarding psychiatric patients. It was articulated by civil libertarian lawyers, who saw “institutionalization as an end run around the criminal procedure revolution” (Bagenstos, 2012, pp. 24–25). For this reason, they were highly suspicious of the expert opinion of professionals and sought to limit the authority psychiatrists exercised as public health officials. Autonomous citizens are not compelled to be treated; they choose whether to follow a doctor’s advice regarding course of treatment. Hence, the rights of psychiatric patients were framed as civil rights: the right to choice and the right to be free from coercion. Denied in the institution, movement to the community was the only way to restore them. While this reasoning leads naturally to closing institutions and fairly rapidly moving individuals into the community, it is silent about how individuals should be assisted to cope and thrive in the community⁷ (Bagenstos, 2012, p. 15, n. 61).

The other litigation strategy articulated a positive “right to treatment”.⁸ This strategy did not target involuntary commitment but the substantive *quid pro quo* underlying it: if you confine somebody with the justification of providing treatment, then you must indeed provide treatment that aligns with professional standards: “only the fulfillment of the therapeutic promise in fact can justify the deprivation of fundamental human liberties” (Schwitzgebel, 1973, p. 535). Moreover, treatment must provide “minimally adequate habilitation” and should “be designed to promote the acquisition

of skills necessary to live outside of an institution.” This strategy was far more effective than the “right against treatment.” DD claimants and their families were able to win compensation for harm because of failure to provide habilitation (*Halderman v. Pennhurst State School & Hospital*). There are three points we would like to make about this strategy: first, note that its implications are more ambiguous than the “right against treatment.” It could be used either to close institutions or to improve them. Unlike the “right against treatment,” the right to treatment cannot be interpreted as providing license to disinvest in services – institutional or community – for the DD. Second, instead of sidelining expert opinion as the right against treatment does, what qualifies as “minimally adequate habilitation” depends on “accepted professional judgment, practice, or standards” (Bagenstos, 2012, pp. 25–26), around which legal activists, patients, parents, and professionals can form an enduring coalition.

Finally, whereas the world conjured by the right against treatment is binary, the terms in which the right to treatment are phrased construct a continuum between the institution and the community. The key development was the switch to a “right to habilitation.” Early commentary pointed out that the right to treatment was phrased in medical terms that were irrelevant and unrealistic for DD individuals because they assumed cure as an end goal. Habilitation, on the other hand, would assist the DD individual in acquiring and maintaining skills to cope with the demands of life in the community (Mason, Menolascino, & Galvin, 1976). This right to habilitation was further expanded by *Welsch v. Likins*, which established the right to habilitation in the *Least Restrictive Environment* (LRE), incorporating the right against treatment in a less destructive way. Not only was it possible to sue institutions because they did not provide adequate habilitation, it was also possible to sue them if – according to professional opinion – the same habilitation could be provided in a more “normal” setting (*Horacek v. Exon*). Unlike “cure” or “recovery,” “habilitation” – namely, “making able” – is potentially never-ending and consonant with the “forever children” frame. We educate and train children so they acquire self-care skills, extending their sphere of autonomy slowly and cautiously, with an adult always close by. “Making able” to live and work outside the institution would happen through supportive services that mirrored this care of children. This is poignantly captured in the concept of the “prosthetic environment” coined by the Director of the Eden School for Autistic Children (Holmes, 1990), which indicates that between protective custody and full-fledged autonomy stretches a whole range of hybrid and ambivalent arrangements: “supports” in the double sense of protecting incomplete

beings (the developmentally disabled-as-children) and making them able, allowing them to develop.

These litigation strategies had a profound impact on the process of deinstitutionalization. The greater emphasis on due process and the right of psychiatric patients to refuse treatment reinforced the distinction between treatment and care and created a binary opposition between coerced institutionalization and voluntary community treatment. It thus inhibited the development of hybrid services that – because they focus on care and continuous habilitation – appear paternalistic. Additionally, many hospitals were cautious about admitting people with psychiatric diagnosis lest they be accused of violating the rights of patients who may not be able to fully consent to commitment (Mason et al., 1976; Teplin, 1984).

In contrast, emphasis on positive rights to habilitation for DD individuals required attention to support services in the community as part of providing adequate care into and through adulthood. To habilitate the developmentally disabled is not to “cure” them, restoring a sanity or normalcy they once possessed, but is to move along an ascending gradient of acquiring new skills and abilities through therapies that are often much closer to training and education than to medical treatment. Pressing for the right of the developmentally disabled for “minimally adequate habilitation” was to press for arrangements that combined treatment, care, and everything in between.

Litigation in the name of a right to habilitation, in which positive and negative rights clashed, acted as a brake on deinstitutionalization for the developmentally disabled (Carey, 2009). For psychiatric patients, the strong emphasis on negative rights emptied positive rights of their content. By the same token, for the developmentally disabled, the pursuit of positive rights often limited and even completely eliminated negative rights. If adequate habilitation could not be provided in the community with family, DD adults were kept in the institution until an appropriate placement was available (Rothman & Rothman, 2005). The very same advocates who litigated in the name of a right to habilitation, would sometimes contest the extension of civil rights for the developmentally disabled (Landesman & Butterfield, 1987). For example, while parents fought for the right to habilitation for their children, they also fought for guardianship rights and in some cases, for the right to keep their child in the institution (Rothman & Rothman, 2005). Normalization theory could be understood as an (only partly successful) attempt to mediate this tension, since it implies that limitations on negative rights could also be injurious to the positive right to habilitation, while the closest possible approximation to full civil rights has

therapeutic value. This middle-way argument never satisfied all the sides in the debate, yet was able to facilitate the formation of workable coalitions in favor of a "continuum of care."

Care

As we saw earlier, the framing of psychiatric patients as autonomous citizens temporarily hobbled by "mental health problems" meant that their deinstitutionalization led to a separation between "treatment" and "care" (Grob, 1991). The senile aged, those with complex disabilities, or those who required follow-up after hospitalization, were transferred to nursing homes, where they received care, but little by way of treatment. The relatively younger schizophrenics, who were discharged into the "community," received only treatment, but no care (Scull, 1984; Bachrach, 1976; Bassuk & Gerson, 1978). This model worked for some, if their problems were not too severe; if their illness was episodic; and if they had medical insurance, since Federal funding for the CMHCs dried up over time (Davis et al., 2012). For the large group of poor, chronic, severely disabled, however, this model proved a vicious circle. Condemned to a precarious and stigmatized existence, they are perceived as complicit in their own situation (on account of their right to refuse treatment and because of high rates of substance abuse, incarceration, and welfare dependence) and as a public nuisance (because of high rates of homelessness, poverty, and unemployment). This has resulted in less public support for comprehensive care, and the segregation of individuals in areas where the care infrastructure is non-existent (Durham, 1989; Grob, 1995).

Care without treatment; treatment without care; this seems to be the fate of psychiatric patients; their Scylla and Charybdis. Yet, the comparison with the deinstitutionalization of DD demonstrates that this predicament is historically contingent.

One could object and say that the real difference lies in the fact that unlike psychiatric patients, DD individuals discharged from institutions often had family homes waiting for them (Braddock, Emerson, Felce, & Stancliffe, 2001). This is partly true. In many cases, the families of psychiatric patients did not assume responsibility for their discharged kin. In contrast, as we saw, the deinstitutionalization of DD individuals began with parents who took the public stance of keeping their children home, while the first to be discharged from institutions were typically children and younger adults who were reabsorbed at home (Best-Sigford, Bruininks,

Lakin, K.C., Hill & Heal, 1982). Contemporary research on mentally ill and developmentally disabled living at home has shown that parents of the developmentally disabled report more satisfaction social support in doing so, even into old age (Seltzer, Greenberg, Krauss, & Hong, 1997). Indeed, the problem of DD individuals living at home with aging parents has become a serious policy concern. In 2010, 56.5% of individuals with intellectual disability were living with family members at home (RISP, 2010). About a quarter and perhaps more were living with family members over 60 years old. This phenomenon of aging parents with continuing caregiving responsibilities for their disabled children has been attributed to an increased lifespan for the disabled, the consequences of deinstitutionalization, and a shortage of residential options for adults with DDs (Braddock, 1999; Eyman & Borthwick-Duffy, 1994; Lefley, 1987). While psychiatric patients certainly face similar barriers to securing services and moving out of the family home, it is striking that both families and government programs assume that the housing needs of the developmentally disabled should be explicitly planned for and that families should take a leading role.

Ultimately, however, the differences in how care is conceived and organized are not simply a function of DD individuals being absorbed at home, while psychiatric patients are not, but of the framing of developmentally disabled individuals as “forever children,” where treatment is construed as habilitation and modeled upon the care and cultivation that the “normal” family provides. In this frame, treatment-qua-habilitation and care are not easily distinguished, and certainly not easily separated. Courts interpreted the right to habilitation as a requirement that States develop comprehensive community-based services, because the developmentally disabled were perceived as in need of care. At the same time, there was an effort to balance this need for care with the presumed therapeutic effects of genuine (even if somewhat risky) integration. When it became clear that the mere location of services in the community did not guarantee integration (e.g., the continued segregation of special education within public schools, or the fact that many group homes did not provide community experiences), the 1984 Developmental Disabilities Assistance and Bill of Rights Act redefined community integration as residence in proximity to community resources, in home-like settings, regular contacts with non-handicapped, use of all community resources and participation in all community activities. The legislation was guided by the ideal of a “continuum of care,” a continuum of residential settings and services with varying combinations and levels of care and treatment, protection and integration, supervision and autonomy (Wolfensberger & Nirje, 1972).

We can state the difference between how “care” is configured by the two processes of deinstitutionalization in the terms we suggested earlier. The strategy by which reformers and advocates sought to endow stigmatized psychiatric patients with social worth belongs to an economy of worth (Boltanski & Thévenot, 2006), in which “care” stands for lack of worth. Those who are cared for are unworthy beings because they are not autonomous. They are “dependent” and consequently their capacity to exercise “control, command, choices, self-determination ... aspects of competent selfhood in our society” is diminished even in the framework of community treatment (Estroff, 1981, p. 175). The charge of the reformers against mental hospitals was that they “promote weakness and dependency ... Patients become unable to trust their own judgement, become indecisive, overly submissive to authority, frightened of the outside world” (Chamberlin, 1978, p. 6). As these patients moved outside institutions, the opposition between care and autonomy remained. CMHC clients were strongly discouraged by the staff from receiving anything from their parents, since this would reinforce their dependency, their unworthy status as semi-“minors.” (Estroff, 1981, p. 161). The similarity to the critique of “welfare dependency” is not accidental. The point is not that deinstitutionalization was motivated by libertarian or neo-conservative ideology (though there were definitely significant influences between the two), but that both were articulated within the same economy of worth, within the same “world” of Anglo-American welfare capitalism, where redistribution takes place through the stigmatizing mechanism of means-testing and is understood as “assistance” or “relief” (Esping-Andersen, 2013; Lerman, 1982). The characteristic catch-22 of this world applies in this case as well: if you are worthy (i.e., working or sane), you do not need assistance or care; if you need assistance or care (you are poor, unemployed, insane, homeless), you are unworthy, because you are no longer autonomous, and therefore you are only deserving of paltry assistance (e.g., SSI, sheltered employment), which will be immediately withdrawn if you attempt to regain your worth (by working, by being discharged) – unless this assistance could be construed strictly on the model of “medical treatment” (e.g., “meds,” preferably self-administered and self-monitored) (Estroff, 1981, pp. 169–173). By the same token, moreover, those who care for dependents are also liable to be seen as unworthy to the extent that they are perceived as illegitimately encroaching upon the autonomy of others. The accusation of “tyranny” has been leveled at institutions’ staff, CMHC’s staff, board-and-care homes’ operators, group homes’ attendants, and welfare bureaucrats.

What from one side appears as the necessary supervision and guardianship involved in providing care, appears from the other side as tyranny and “social control.”

The strategy by which parents and advocates sought to endow stigmatized DD individuals with social worth belongs to a completely different economy of worth, wherein “care” transmits and augments worth. Those who care for weaker beings are worthy because they contribute to a greater good – whether this good is understood in the secular frame of societal well-being and cohesion, or in the religious frame of *caritas*. NARC parents were told that “a fine and beautiful mission awaits you, [because] the cross we bear can become a blessing for others” (Egg, 1964, pp. 38–42). Those who are cared for are valorized because their lives, their struggles, their experiences, and the very care they received become a moral example – in Pearl Buck’s words, “of use to human beings.” In NARC literature, as well as in on-line postings of parents of autistic children (Fleischmann, 2005), disabled children are depicted as “teachers” from whom their parents, the whole family, or even others learn the true meaning of life, or discover powers and abilities they did not know they possess. This economy of worth developed, as we have argued, on the basis of the “reproductive consensus” of the postwar years and by framing the developmentally disabled as children.

CONCLUSIONS

We have demonstrated that the processes of deinstitutionalization of psychiatric patients and of DD individuals have unfolded in drastically different ways depending on framings of social worth and strategies of destigmatization. While it is indisputable that financial incentives played a crucial role in shaping the deinstitutionalization of psychiatric patients, they did not have the same effect in the case of DD individuals, where the framing was different. This contrast allows us to see that the framing of psychiatric patients as autonomous individuals temporarily suffering from “mental health problems” served as a precondition for the alignment of interests between advocates, experts, and fiscal conservatives. Deinstitutionalization was fought on the basis of the right to decline treatment, and an opposition between autonomy and care. It led to a process that was swift and concentrated on discharging patients, rather than arranging for care in the community. The deinstitutionalization of psychiatric

patients is largely considered a failure because of this lack of supportive services in the community and because it has created a system in which psychiatric patients are moved through a “revolving door” of incomprehensive services.

Deinstitutionalization of DD individuals, on the other hand, has been considered a qualified success because alongside gradual and careful discharges it involved also significant investment in and the concurrent development of community-based services. The framing of DD individuals as “forever children,” however paternalistic, meant that deinstitutionalization was fought on the basis of a right to habilitation, which did not oppose care to autonomy or separate it from treatment. It also meant that the alignment of interests behind deinstitutionalization was only partial, and the process was characterized by a constant push-and-pull which made it far more gradual. This has laid the groundwork for the creation of a continuum of both institution-based *and* community services at varying levels of support. We believe that this expanded picture of deinstitutionalization should inform discussion of civil rights, entitlements, and responsibilities as we continue to develop community-based services for both psychiatric patients and the developmentally disabled.

NOTES

1. We use the terms “psychiatric patients” and “developmentally disabled” to refer to the broadest possible groups of individuals who would have been institutionalized in the past on the basis of a diagnosis respectively of “mental illness” or “mental retardation” (MR). The 1969 legislation that created the category of “developmental disability” (DD) included three groups – those diagnosed with mental retardation, epilepsy and/or cerebral palsy. In 1977, autism was added. We occasionally use the terms “insanity”, “mental illness,” “mental retardation” or “feeble-mindedness” when it is historically accurate to do so, namely when we need to refer to the categories and terminology used by people at the time that we are discussing. Finally, we use the term “intellectual disability” (ID) to refer specifically to individuals who currently are diagnosed with such disability on the basis of a lower score on an IQ test, and who are counted as such in official statistics.

2. Figures are based on the data collected by the National Residential Information Systems Project (RISP, 2010) at the Research and Training Center on Community Living at the University of Minnesota. <http://rtc3.umn.edu/risp/build/index.asp> (Last accessed 5.20.2015).

3. Taken from Braddock (1992)

4. An additional illustration of the differences between the two processes of deinstitutionalization could be provided by comparing the numbers of individuals with MR diagnosis in state MR and psychiatric facilities. The bulk of residents with MR diagnosis were housed in state MR facilities and the trend there tracks closely the numbers presented above. Some, however, were housed in state *psychiatric* facilities, i.e. together with psychiatric patients, and were discharged earlier and faster than those in state MR facilities. The number of individuals with MR diagnosis at state psychiatric facilities peaked in 1960, and declined rather quickly to 15,524 in 1977, a 59% decrease from the peak. By 1986 there were only 3,106, a 91% decrease. The corresponding decreases for individuals with in state MR facilities were 22% and 49% respectively (Prouty et al., 2001, pp. 8–9). It is quite possible that many of the individuals who resided in state psychiatric facilities were transferred to state MR facilities.

5. An important caveat is that there was huge variation between states in levels of funding (Braddock, 1992, p. 178), suggesting that the fiscal explanation is perhaps more valid in some states, but much less so in others. We would expect, however, that states with low levels of funding for community services also had lower levels of funding for institutions and a lower rate of institutionalization in the past. On state differences in rates of institutionalization, and their relationship to deinstitutionalization, see Eyal, Hart, Onculer, Oren, and Rossi (2010, pp. 64–67)

6. Grob's otherwise excellent and thorough account ignores, however, another source of this focus on prevention and understanding of mental illness as caused by early emotional problems, namely, the mental hygiene and child guidance movements. While child guidance began with a focus on "saving" immigrant and lower-class children from the risk of delinquency, by the time of WWII it was thoroughly focused on early identification of emotional problems before they turned into adult forms of mental illness. (Kanner 1941/1964, pp. 171–172; Nadesan, 2005, pp. 44–45, 58–73; Nehring, 2004, pp. 371–372)

7. Incidentally, this suggests that Scull's claim that deinstitutionalization constituted a single, unified phenomenon is better understood not as an explanation or hypothesis that could be verified or refuted, but as an "account" in the ethnomethodological sense, a narrative articulated by some of the key actors, namely civil libertarian lawyers. From their point of view there was a formal analogy between commitment procedures in all the distinct spheres of "social control". Their litigation strategy was based on an analogy between commitment and "arrest". Whether deinstitutionalization was a unified phenomenon or not depends on whether they managed to prevail, and whether this account could translate the interests of all the other parties involved and could hold the deinstitutionalization coalition together. As already indicated above, clearly it could not do so in the field of developmental disabilities.

8. Rothman and Rothman (2005, pp. 87–88, 106–111), however, explain that since the "right to treatment" was not accepted by the judge presiding over the Willowbrook case, the reformers' strategy was to extend "the right of protection from harm...until it was the equivalent of a right to treatment." Tellingly, this was done through an analogy to children's right to education – without which they are harmed because their development is stymied.

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