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About the Lives of Other Human Beings: The benefits of deinstitutionalization for people with mental retardation

Abstract

Deinstitutionalization is more than a policy issue and a matter for empirical research. It is an issue that, at its most fundamental level, has to do with human beings and the quality of life to which human beings should be entitled. This paper explores the benefits of deinstitutionalization in human terms and discusses the impact of implementing deinstitutionalization as a public policy for people who have mental retardation. Empirical support, both for deinstitutionalization and for ameliorating problems that have occurred in the movement toward community-based models of service delivery, is presented.

Résumé

La réinsertion sociale est davantage qu'une question politique ou de recherche empirique. À son niveau le plus fondamental, cette question concerne les êtres humains et la qualité de vie à laquelle ils ont droit. Le présent document traite des avantages de la réinsertion en termes humains et examine l'impact de la mise en application d'une politique publique de réinsertion sociale des personnes atteintes d'arriération mentale. Nous présentons un appui empirique aussi bien à cette réinsertion qu'à la solution des problèmes associés au mouvement d'adoption de modèles de prestation de services axés sur la collectivité.

Recently, while doing my banking, I overheard a woman ask her teller if she could cash the paper she had in her hand. It turned out to be a notice that she had a federal income tax refund due but would need to file a return in order to collect it. Two other bank employees who knew this woman by name offered to help; one of them explained in detail what the notice said and what the woman should do next. During this transaction, I recognized this woman but the last time I saw her she was in a large ward at a state institution where she was in restraints.

In the grocery store the other day, I overheard one clerk telling another about a ball game at Boston's Fenway Park that he had attended. His description of the game was animated and his co-worker hung on every word with equal excitement, sharing the joy of the game. The clerk who had not gone to the game is a student at a local community college. The clerk who had gone is a former resident of a state institution.

Several months ago, I ran into an older woman whom I had known very well. She told me she was shopping with friends. Afterwards, she was going out to a bar with her boyfriend because they liked to go dancing. She also invited me and my family to come visit her apartment that she had furnished by herself and that she described with great pride as being "absolutely beautiful." I knew this woman because I used to be the recreation aide at the "training school" where she lived. I had previously taken her on group field trips to the zoo, the park, and the playground. I also brought her to my family's home one year for Christmas and once just she and I went out to dinner and to a musical. She reminded me of this when we met.

The story of deinstitutionalization indeed reflects one of the more pressing public policy issues of our time and certainly has been the subject of considerable research. More importantly, the story of deinstitutionalization is the story of people . . . people like the three just described whom I happen to know personally and who are some of the 100,000 or so individuals who, in the past 20 years, have benefited from moving out of large facilities and into home-like settings in typical communities (Braddock, Fujiura, Hemp, Mitchell, & Bachelder, 1991; Scheerenberger, 1982). The story of deinstitutionalization is about people taking care of themselves, being empowered to make their own decisions, handling their own finances, having the freedom to do the things they like, having friends and lovers, living in a "real" home, and having a meaningful job.

The History of Deinstitutionalization

The popularity of institutions for people with mental retardation and other disabilities has waxed and waned during different periods of history (Zigler & Hodapp, 1986). The wave of unpopularity behind the present

deinstitutionalization movement can be traced to several factors present in the 1960s and 1970s that in combination focused the attention of policy-makers on the atrocious conditions present in large institutions for people with mental retardation and other disabilities (Nisbet, Clark, & Covert, 1991).

One factor was the public's shock at such exposés as *Christmas in Purgatory* (Blatt & Kaplan, 1966) and Geraldo Rivera's national broadcast in 1972 about New York's Willowbrook State School (cited in Rothman & Rothman, 1984). These accurately depicted human warehouses in which inhabitants were unclothed, barely fed, constantly in restraint, and left to languish in filthy environments. Other factors included the increasing political activity of many advocacy groups representing and including people with disabilities and their families (Knight, 1980); increased federal awareness of, and initiatives to address, the service needs of people with disabilities beginning with the establishment of John F. Kennedy's President's Panel on Mental Retardation in 1961 (Braddock, 1986a; Braddock, 1986b); and litigation in many states including such landmark cases as *Wyatt v. Stickney* (1972) in Alabama and *Haldermann v. Pennhurst State School and Hospital* (1977) in Pennsylvania. Fueling the deinstitutionalization movement internally was a growing tension between the behavioural orientation of most mental retardation professionals (Baldwin, 1985) and the views of humanistic psychologists (McGee, Menousek, & Hobbs, 1987) and social role theorists (Wolfensberger, 1991) who challenged service delivery models that stripped the people they claimed to help of respect and dignity.

Settlements of lawsuits, in particular, led to a fundamental change in the quality of life for individuals with disabilities in establishing rights that previously were unrecognized for people "incarcerated" on an involuntary basis in large institutions solely for reasons of disability. These legal rights include adequate food, shelter, clothing, medical care, safety, freedom from unnecessarily restrictive confinement, such as "non-therapeutic" use of restraint, and minimal habilitative programming (*Youngberg v. Romeo*, 1982). In practice, however, involvement of the judicial system has resulted in more substantial changes in the way services were to be delivered, and policy makers inside and out of the disability field sought alternatives in the form of community services (Scheerenberger, 1980).

Current Status and Trends

As a result, institutional populations in the United States for people with mental retardation declined from approximately 190,000 nationwide in 1970 (Scheerenberger, 1982) to 90,000 in 1988 (Braddock, Fujiura, Hemp, Mitchell, & Bachelder, 1991). During the same two decades, there was a decline in the rate of placement into such settings corresponding to growth in the number of community residential facilities (Lakin, White, Hill, Bruininks, & Wright,

1990). In 1988, for example, there were almost 180,000 community residences compared to less than 25,000 in the late 1960s. Additionally, at least 18 large institutions have closed since 1980 compared to only six shut down between 1970 and 1980 (Braddock & Heller, 1985a). Trends similar to those in the United States are found in other nations such as Sweden (Pedlar, 1990) and Canada (Flynn & Nitsch, 1980; Roehner, 1980).

Originally, the concept of deinstitutionalization focused on three issues: 1) making institutions more humane and homelike, 2) decreasing institutional populations through placement of residents into community facilities, and 3) prevention of institutionalization (Turnbull, 1988). Today, the focus has shifted away from making institutions more homelike due to the high costs of institutional care and the dual expense of maintaining both institutional and community-based services simultaneously (Braddock & Fujiura, 1991; Castellani, 1987). Given that 85% of people with mental retardation have always lived in their communities (Bruininks, 1991) and given models of successful delivery of community-based services to individuals with severe medical and behavioural challenges (cf. Smith, 1990), the philosophical and programmatic justification for this trend is a growing recognition that little can be accomplished in segregated settings that cannot be done as well or better in more typical environments.

Another trend has roots in the lack of operational definitions of community residences at the beginning of the deinstitutionalization movement (Hill & Bruininks, 1986). Motivated by the availability in the United States of Medicaid reimbursement, a number of states initially "deinstitutionalized" residents of large public institutions to smaller private facilities such as regional centres, nursing homes, and group residences of 16 or more beds (Lakin, Hill, White, Wright, & Bruininks, 1989; Mitchell & Braddock, 1990; Neufeld, 1977; State of Connecticut Department of Mental Retardation, 1979). Although labeled community-based programs, these smaller facilities were nonetheless institutions offering little relief from the problems associated with large public settings. Thus, the current trend is toward small community residences such as family living arrangements or group residences of six or fewer beds (Nisbet, Clark, & Covert, 1991).

Empirical Evidence of Benefits

Individuals who remain in institutions typically display increases in maladaptive behaviour (Conroy, Efthimou, & Lemanowicz, 1982) and decreases in cognitive functioning (Eyman & Widaman, 1987). In comparison, people who have been deinstitutionalized to smaller community settings show increases in overall adaptive behaviour (Conroy, Efthimou, & Lemanowicz, 1982; Fine, Tangeman, & Woodard, 1990); hopefulness, self-confidence, and independence (Edgerton, Bollinger, & Herr, 1984); academic skills, social

interactions, community orientation, use of free time, and vocational pursuits (Eastwood & Fisher, 1988); involvement in activities (Braddock & Heller, 1985b); and responsibility and language development (Kleinberg & Galligan, 1988).

Improvements in adaptive behaviour are greatest immediately following community placement and continue at a slower rate thereafter (Conroy & Bradley, 1985; Hemming, 1986). Greatest gains are exhibited by people who originally have lower adaptive behaviour scores (Conroy & Bradley, 1985) and are dramatic even for short-term visits to typical environments (Baker & Salon, 1986). Indeed, in their review of the literature, Larson and Lakin (1989) concluded that the available research denies support for the assertion that people obtain greater or even equal benefits in increased adaptive behaviour from living in large public institutions. In fact, this research suggests that those benefits very consistently accrue more to people who leave public institutions to live in small community residences (p. 330).

In a series of studies in several states, Conroy and Feinstein Associates and the Temple University Developmental Disabilities Center/University Affiliated Facility showed that these benefits accrue in two ways to people with mental retardation who have been placed in community residences (Conroy & Feinstein, 1986). The first is by enabling individuals to use skills they apparently had prior to institutionalization but were restricted from applying in the institutional environment. The second is in acquisition of new skills, including skills that had been targeted for instruction in institutional programs but were never mastered by the program participant. This is consistent with the literature documenting the greater success of teaching skills to people with mental retardation in natural, as compared to contrived, contexts (Dunn, 1991; Freagon & Rotatori, 1982).

In addition to improvements in personal competence, consideration of the benefits of deinstitutionalization must take into account indicators of quality of life and consumer satisfaction (Landesman, 1986). The quality of life of people with mental retardation has been found to improve following deinstitutionalization as individuals have greater control over the environment, more opportunities for social interaction, and increased use of community resources (Schalock & Lilley, 1984); live in more home-like living environments (Thompson, Robinson, Graff, & Ingenmey, 1990); and are in proximity to population clusters and neighborhood resources (Janicki & Zigman, 1984). Compared to large institutions, smaller community-based facilities offer more encouragement for individual autonomy, more things to do, greater use of community facilities, and more satisfied direct-care staff (Rotegard, Hill, & Bruininks, 1983). People living in them benefit from higher rates and longer duration of staff interactions and more engagement in purposeful activity (Felce, deKock, & Repp, 1986).

With respect to consumer satisfaction, individuals who live in institutional settings express greater dissatisfaction with their living arrangements than do individuals living in smaller community-based residences (Conroy & Bradley, 1985; Eisenberg & Rammler, 1989). Studies have documented both the negative opinions about community living of family members when their relatives still are in institutions (Spreat, Telles, Conroy, Feinstein, & Colombatto, 1987) and the significant change in positive attitudes toward deinstitutionalization that occurs among family members following their relatives' community placement (Braddock & Heller, 1985b; Conroy & Bradley, 1985. See Larson & Lakin, 1991, for a review). Families also have been shown to have higher expectations for their relatives following deinstitutionalization (Grimes & Vitello, 1990) and perceive their relatives as being significantly happier in community settings than they were in the institution (Conroy & Feinstein, 1985).

Deinstitutionalization has benefited people with mental retardation by markedly increasing the numbers who are contributing to society through competitive or supported employment (Rusch, Chadsey-Rusch, & Johnson, 1991). Individuals with disabilities, including mental retardation, themselves now participate in public policy-making as program evaluators (Allen & Gardner, 1985; Rammler, 1986), as members of agency executive boards (Gibbon & Osborne, 1981), and as expert witnesses before congressional committees and other policy-making bodies (Kennedy, 1991).

Problems and Solutions

Clearly, small community facilities have many benefits over large institutions for people with mental retardation yet they have not been exempt from problems. For example, not all community placements have been successful. Recidivism is highest among individuals who have more problem behaviours and decreased behavioural control (Intagliata & Willer, 1982); who are older, have poorer sensori-motor functioning, have lower IQs, or have less family involvement (Schalock & Lilley, 1986); and have unmet needs for dental, medical, and therapy services (Jacobson & Schwartz, 1983). The likelihood that individuals who never have been institutionalized will be admitted for the first time is less than the likelihood that individuals with a prior history of institutionalization will be re-admitted (Black, Cohn, Smull, & Crites, 1985).

Despite quantitative indicators of success in community placements (e.g., decreased use of medication and greater participation in home life), individuals who have moved to community settings have reported having little in common with their housemates, being disconnected from real participation in their communities, having to depend entirely on staff for social and

emotional support, having little power to make decisions, and not being able to relocate to another residence if they wish (Lord & Pedlar, 1991). Compared to typical adults, group home residents have fewer choices on such basic matters as when to do certain things like go to bed, what to eat for meals and snacks, and how to spend their money and leisure time (Kishi, Teelucksingh, Zollers, Park-Lee, & Meyer, 1988).

Quality of life outcomes are experienced differentially. Not as well off are individuals with fewer skills (Kishi, Teelucksingh, Zollers, Park-Lee, & Meyer, 1988), residents of larger community residences, and individuals in sheltered as compared to supported employment settings (Schalock, Keith, Hoffman, & Karan, 1989). More stringent standards for care and treatment in group homes with federal intermediate care facility for the mentally retarded (ICF/MR) certification makes such residences more like institutions than homes (Fernald, 1986).

The research comparing individuals in institutional settings to those living in community residences strongly suggests that a "right" to community living has been recognized only for certain groups of individuals. These groups include people with higher overall levels of adaptive behaviour (Vitello, Atthowe, & Cadwell, 1983); fewer problems in the areas of ambulation, self-care, and communication (Hauber *et al.*, 1984); higher IQs and fewer medical, mobility, and visual impairments (Selzer & Krauss, 1984); and fewer behaviour problems (Borthwick-Duffy, Eyman, & White, 1987). Differential placement appears to occur despite evidence that individuals' institutional behaviours and medical conditions are not predictive of their success or failure in community settings (Baker & Salon, 1986; Karan & Gardner, 1984). Priority for placement also often is given to individuals "returning" to communities from target institutions. This occurs frequently at the expense of individuals who live in other institutional facilities or have never been institutionalized (Castellani, 1987; State of Connecticut Department of Mental Retardation, 1985).

Placement into a community-based facility does not safeguard against major medical or behavioural incidents that injure or pose the threat of harm to individuals (Spangler & Gilman, 1985) and abuse certainly occurs (Hewitt, 1987; State of Connecticut Office of Protection and Advocacy for Persons with Disabilities, 1990). Nor are there guarantees to family members who remain concerned about the permanency of community residences (Conroy & Bradley, 1985; Hearn, 1986). For example, Hill, Bruininks, Lakin, Hauber, & McGuire (1985) showed that community residential facilities, although more stable than typical living units in comparable neighborhoods, did close at annual rates ranging from a low of 5.6% for group residences to a high of 42.6% for foster home placements. There is higher turnover and less longevity among group home as compared to institutional staff, although rates of absenteeism are lower

(Baumeister & Zaharia, 1987). Despite research showing no decrease in either quality of life or property values following establishment of neighborhood community residences (Gelman, Epp, Downing, Twark, & Eyerly, 1989; Ryan & Coyne, 1985), public fear and uncertainty has led to difficulty in opening some facilities (Cnaan, Adler, & Ramot, 1986; Conroy & Bradley, 1985; Pedlar, 1990; Selzer, 1984; Selzer & Selzer, 1987).

Development of appropriate community services is hampered by self-perceptions of residential staff as providers of custodial care rather than as trainers (Slater & Bunyard, 1983); decreased family visits following community placement because the new residences were too far away (Grimes & Vitello, 1990); restrictions on the diversity and frequency of activities imposed by funding regulations (O'Neill *et al.*, 1990); and financial disincentives to states (Braddock & Fujiura, 1991).

From a public policy perspective, the claims that deinstitutionalization would be less expensive than institutional care (Howse, 1980) have not been substantiated because of the growth in spending on mental retardation and developmental disabilities services. National expenditures in the United States escalated from \$910 million in 1977 at the apex of the deinstitutionalization movement (Braddock, Hemp, & Howes, 1987) to \$5.64 billion in 1988 (Braddock & Fujiura, 1991). The reality is that individuals with more involved needs require more intensive services (Wieck, 1988), regardless of where the services are provided. Clearly, as these individuals have moved from no-service institutional settings into full-service community residences, costs have risen commensurately. Yet, Ashbaugh and Nerney (1990) have concluded that it is the model of residential program and facility characteristics, rather than client needs, that increase costs. Some facility characteristics are linked to client characteristics (e.g., higher staff-to-client ratios), it is unfortunate that substantial public resources have been devoted to more expensive alternatives such as ICF/MRs and public sector programs with higher personnel salaries and fringe benefits.

The traditional view of community placement requires matching an individual's level of functioning to a hierarchy of facility types such as group homes, community training homes, supervised apartments, and independent living arrangements. These presumably reflect increasingly less restrictive environments that correspond to increasingly higher levels of individual functioning. When we describe a taxonomy of services based on the concept of the least restrictive environment, however, we fall into what Steve Taylor has termed a "continuum trap" (Taylor, 1987) and we confuse segregation and integration with the intensity of services that an individual needs (Taylor, 1988). We also create niches into which individuals with highly idiosyncratic needs seldom "fit."

By starting with a different premise, the policy and empirical question changes dramatically from "What type of person fits into this type of setting?" to "What services and supports does this person need to live in this home?" Parallel shifts in policy and research questions occur when we apply the same line of reasoning to day programs. Such a shift removes us as practitioners from what essentially has amounted to victim blaming but puts the onus back on professionals to be creative in assuring the success of community placement.

Thus, the critical issues in addressing problems associated with community living pertain to the quality of the community residences into which individuals have been placed and the level of support and services they received post-placement. For example, increases in adaptive behaviour are associated with greater individual control over the environment, more resident-oriented care practices, and participation in programs (MacEachron, 1983). Transition planning to facilitate the individual's adjustment and to assure that appropriate resources are available is critical (Gardner & Karan, 1984; Wilcox, 1988).

For community living to be optimally successful, several things need to be in place. A qualitative analysis of the impact of the closure of Pennhurst in Pennsylvania suggests the need for quality assurance, monitoring, advocacy, case management, individualized planning, and leadership in maintaining the momentum established initially by the American judicial system (Conroy & Bradley, 1985). To avoid isolation and depersonalization within the community, rigid administrative practices must be abandoned and vigorous community-building activities undertaken (Jacob & Taylor, 1990). Quality assurance efforts need to shift from assuring that minimal health and safety standards are met to addressing quality of life outcomes that are driven by consumer needs, wants, and desires (Knoll, 1990).

Administratively, staff-to-resident ratios can be increased by reassigning staff duties so that certain staff have more comprehensive responsibility for working with residents (Byrd, Sawyer, & Locke, 1983). Staff also must receive adequate pre- and in-service training in relevant topics such as designing and implementing appropriate resident training programs (Fiorelli, 1982; Fiorelli, Margolis, Heverly, Rothchild, & Keating, 1982; Gage, Fredericks, Johnson-Dorn, & Lindley-Southard, 1982).

Rejecting the "goodness of fit" between an individual and a particular environment as grounds for determining eligibility does not negate the importance of applying the model to identify support needs (Schalock & Jensen, 1986). For example, if an individual cannot perform a certain important skill, support is needed. Depending on the individual's unique needs, that support may take the form of either training to the necessary level of independence or personal care services to perform the skill totally or partially on behalf of the

individual (Falvey, Coots, Bishop, & Grenot-Scheyer, 1989). As Taylor (1988) also suggests, community living can involve a phase-out of supports as individuals become more autonomous rather than requiring the individual to change and make transitions from one facility to another (Rudrud & Vaudt, 1986).

Conclusion

Webster's New Word Dictionary, in its definition of "home" includes "... a place where one likes to be; a restful or congenial place . . . ; the members of a family or a unit; a household and its affairs." Home is more than an address, and when we discuss deinstitutionalization, we need to begin with the premise that everybody needs a home.

Deinstitutionalization in the past decade has been moving beyond the notion that individuals must be matched to pre-existing services (Cone, Bourland, & Wood-Shuman, 1986). More and more services today reflect a model of independent living which presumes that all community residences should be homes for the people who live in them (Knoll & Ford, 1987). Support for independent living requires that assistance with housing, transportation, personal care, finances, and employment is modified and provided according to individual need with a focus on individual self-help and self-control (Budde & Bachelder, 1986).

The commitment to deinstitutionalization is not universal among human service professionals (cf. Crissey & Rosen, 1986). Yet, the messages we are hearing from individuals with mental retardation themselves are loud and clear. The outcomes self-advocates want for themselves include being treated like everyone else, getting the supports they need regardless in which community they live, being empowered to choose where and with whom to live and associate, living in typical and integrated neighborhoods, having control over their daily lives and their futures, and getting the jobs they want and the training they require (Campbell *et al.*, 1985; Kennedy, 1990; Williams & Shoultz, 1982). Contrast this to Maryann Crowley's description of institutional life:

"It was just like a jail. You couldn't do nothing. You couldn't make conversation like I'm doing now

They can just push you around They don't let us go home, they move us farther away. . . . I hadda share a room with 200 people You couldn't keep your own stuff. . . ." (Schweir, 1990, p. 110)

The story about deinstitutionalization is about human beings, some of whom I don't know and some of whom I do. It is about respecting what they say they want and helping them to achieve it. It is building on a solid foundation

of empirical research that shows the benefits of community living in comparison to life in an institution and that enables us to overcome the problems we encounter along the way. It is mindful of the substantial investment of public resources in community-based programs and commitment to expending those resources to the greatest good of the people they are intended to help. Deinstitutionalization is about the lives of other human beings and helping to assure that their lives are meaningful.

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