Deinstitutionalization is a Double Edged Sword to Some

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3/25/2011
Deinstitutionalization is the practices of moving people with developmental disabilities from the mental institutions that they have been living for years, to community-based or family based environments. The policy was first used as a cost saving measure in the 1950s and 1960’s in various countries, as a sensible alternative to state hospitals which some called ‘snakepit’ institutions (Paige 1). To most deinstitutionalization and normalization seem like the best method of care for individuals with developmental disabilities, reducing the number of residents in public institutions, improving living conditions of these settings and reducing initial admissions to mental centers while making available to developmentally disabled persons the opportunity to experience a wide variety of culturally normative conditions and environments. However, deinstitutionalization and normalization are probably the most controversial and emotionally charged matters in the field of mental disabilities. Their merits and liabilities are debated passionately in courtrooms, legislative hearings, parent meetings, social and health service agencies, professional societies, and the media (Landesman & Butterfield 1).

The movements was largely based on two major concepts. These are the normalization principle and the least restrictive alternative (Cullari Salvatore S.). Normalization is basically described as making available to developmentally disabled persons the opportunity to experience a wide variety of culturally normative conditions and environments. The least restrictive alternative is a wide encompassing concept which has been defined by various court decisions for both education and treatment. The least restrictive alternative can be defined as providing interventions that are the least intrusive and restrictive, that meet the developmentally disabled persons’ needs (Willer, Intagliata, and Wicks).

Are the normalization principle and the least restrictive alternative principle really the best way to go? And have these principles really made their way to the main stream? Unfortunately, there has been some concern that deinstitutionalization and by itself does not necessarily insure that treatment is
less restrictive or normalizing in community settings. The shortcomings of some community placement options led to an increase emphasis toward other aspects of deinstitutionalization which have not received a great deal of attention in the past, such as returning the institutionalized person to their natural family. At the heart of the debate are the differences in the values and beliefs about to what extent the environment affects the functioning of those who have developmental disabilities and what kinds of environments are best for each individual. Proponents of deinstitutionalization and normalization recognize that community placement involves risk and raises complex questions about how to promote true social integration, but to most there are no doubts that living in the community provides a better quality of life (Landesman & Butterfield 2). Some individuals with developmental disabilities benefit from having caring and cheerful environments around them along with receiving sophisticated therapy, when placed back in their natural home those proponents may not be available.

What happens if the family cannot handle the individuals, sometimes violent behavior? The developmentally disabled, specifically those mentally incompetent from birth, are entitled to a full panoply of constitutional rights and protections. These rights include the right to terminate life-sustaining treatment, the right of procreative integrity and the right not to be involuntarily institutionalized. However, the mentally incompetent developmentally disabled are generally unable to exercise these rights. So what if the family members are unable to take care of the developmentally disabled person in the proper way, those rights go to the way side? There are really severely disabled people living in centers, and some argue they are not going to get the nursing care or their rehabilitative programs that they need in a group home let alone in their natural home. The assistants in group homes don’t always have the training or the capability to care for individuals with server disabilities and the chances of a natural family member being able to provide the required level of care for their family member is far less likely.
Yet, deinstitutionalization of people with developmental disabilities in the US has been embraced by the general community, viewing it as the most humane way for the individuals to live. The areas interesting some behaviorist are behavior patterns and the developmental outcomes of the deinstitutionalization. In their review of deinstitutionalization research in the United States, Emerson and associates found that adaptive behavior almost always improved following transfer to community settings and that such benefits consistently accrue to the people who leave institutions to live in small community homes. Emerson and associates reviewed studies in the United Kingdom and concluded that deinstitutionalization was often, but not always, accompanied by improvements in adaptive behavior. These researchers identified a reasonably consistent pattern of improvement in challenging behavior based on observational data. It was recently reported that most of the United States studies Emerson and associates reviewed showed significantly enhanced adaptive behavior following resettlement in the community and that many investigators reported improvement in challenging behavior, although only 24% of the studies reviewed showed a statistically significant improvement in challenging behavior (Emerson, Hatton, Robertson, Henderson, & Cooper 26). But is the decline of challenging behaviors exhibited a factor that can be objectively measured?

Emerson, Hatton, Robertson, Henderson, & Cooper identified a pattern of gains in adaptive behavior associated with moves to less institutional environments as the community settings with the most positive behavior changes. Transfers from institutions to hostels or to ordinary housing were both accompanied by adaptive behavior gains, but relocations from hostels to ordinary housing also consistently resulted in improvement, indicating that domestic-scale ordinary housing was associated with the best adaptive behavior outcomes (Emerson, Hatton, Robertson, Henderson, & Cooper 26). Although the environment is a major factor in the deinstitutionalization movement, other services such as delivery and living environment vary at each location, things such as staffing arrangements,
community participation, and social networks are also important factors to consider when looking at the changes in the behavior patterns and can be looked at as major predictors.

Changes in challenging behavior were unrelated to community residence type according to the Emerson, Hatton, Robertson, Henderson, & Cooper, 1999 study. There was some evidence of a significant initial decline in challenging behavior in the communities at the beginning but the last institution assessment and community levels of challenging behavior did not differ significantly once individuals had adjusted. Examination of the drop in challenging behavior showed that “behavior that is hurtful to self was rated as more frequent after individuals left the institution but was not more severe”. Some of this could be attributed to, community staff reporting mildly injurious behaviors that may have been overlooked and gone unreported in the institution. Community staff members sometimes have different expectations than institutional workers about residents’ behavior or may have more opportunities to notice such behaviors because there were fewer residents and more favorable staff ratios in community settings. Emerson and Hatton noted that observational data from deinstitutionalization studies consistently reveals less challenging behavior in community settings, whereas reports from informants using standardized behavior rating scales typically show no change or worse challenging behavior in the community. “However, observational studies of the duration of challenging behavior are influenced more by long-duration behaviors, such as stereotypy, than by briefer behaviors, such as aggression or SIB. Such findings may be due, at least in part, to greater material and social stimulation available in community settings and the consequent reduction in stereotypy “(Emerson, Hatton, Robertson, Henderson, & Cooper 26).

This leads researchers to the next question if these state run institutions being closed down through class action lawsuits and the remaining institutions being scrutinized because of the appalling conditions and the poor treatment of patients in these institutions were revealed, where do the
developmentally disabled individuals end up if they have to natural family to take them in and the community setting will not work for them? Institutions are being shut down everyday because of all the positive research findings like the ones found in Emerson’s study, so with the funding now going to community programs where does that leave the people who don’t fit the criteria for community placement? When individuals with developmental disabilities do not have a natural family to look out for their best interests they tend to fall through the cracks. While many individuals with developmental disabilities can be successfully integrated into the community, some will be at a higher risk of being unable to earn sufficient income to maintain independent housing; deinstitutionalization is thought to have caused widespread homelessness in the United States and some other countries. So what can be done now? While John A. Talbott, M.D. believe almost every error imaginable has been made in deinstitutionalization, he also believes it is unthinkable to suggest a return to pre-1955 days.” We have proceeded too far to turn back, and there is sufficient evidence that deinstitutionalization's failures were not due to ideological or philosophical deficiencies. Failures were due to implementation of the underlying ideas.” To learn from the mistakes there must be a tested method of implementation in place and the criteria may need to be readjusted (Talbott 1114). The quality of life was much better for the people in the group homes there is no doubt in that. Many of the individuals in the state run intuitions in the 1960’s never should have been institutionalized to begin with, but there are individuals in the large institution that were profoundly and severely developmentally disabled that still need the kind of care that institutions can provide that group homes cannot. While deinstitutionalization seems to work well for the majority of developmentally disabled individuals, there will always be a place for institutions as well.
Works Cited

Sean Paige. The devil in deinstitutionalizing, Insight on the News, Sept 14, 1998


