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The Illusion of Inclusion: Geographies of the Lives of People with Developmental Disabilities in the United States

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Introduction

This article considers the historical and contemporary places of people with developmental disabilities

For people with developmental disabilities, as well as other disabilities and other minority status, space has been used to create and reinforce the prevalent social services mode that reflects the mixed and conflicting goals of those who fund services and supports. We will be addressing the spatial implications of two service designs: an initial design based on segregation and control by institutions which has dominated much of US history; and the more recently emerging community-based services design intended to redress the legacy of segregation and control.

Starting in the 1970s, Wolpert, Dear, Wolch and C. Smith, along with their many colleagues have greatly expanded the breadth and depth of geographical studies of mental health. In the 1980s Philo (later to be joined by Parr) began to describe the intricate historical geography of the "mad-business" in Great Britain. (Full citations to representative works by these authors can be found in the bibliography.) While the work of these geographers has relevance for people with developmental disabilities, it would be a mistake to simply generalize due to the "mental" adjective of developmental disabilities. In the 1980s, Radford, Park, Walker, and Metzel began to look more closely into various socio-spatial dimensions of the lives of people with developmental disabilities.

Now that most people in institutions have been re-located into communities, we are more concerned that this physical inclusion has not brought about social inclusion, full community membership and belonging, and valued roles for people with disabilities (e.g. Wolfensberger, 1972; Bogdan and Taylor, 1987; Schwartz, 1992) despite the claims that locations of services and supports are inclusionary. The first half of this paper examines the dubious inclusionary geographies of people with developmental disabilities from the colonial times through the mid-1900s. The second section addresses issues of contemporary service designs and their impact on people's lives.

A Brief Historical Geography of Lives in the Community

Our reading of early volumes of The Journal of Psycho-Asthenics (a publication of the American Association for the Study of the Feeble-Minded) and of a variety of overviews and histories of services for people with mental retardation and developmental disabilities (e.g., Davies, 1930; Best, 1965; Wolfensberger, 1972; Scheerenberger, 1983) reveals that the American history of treatment for persons with developmental disabilities can be broken down into a number of distinct historical phases. When the impairment of feeblemindedness was strongly differentiated from other dependent conditions (see Trent, 1994), the locations of services began to reflect the "new" classification. As a graphic overview, Table 1 summarizes the documented service ideologies of the time and their predominant locations. In this table, the term "community" is used to contrast with formal facilities such as asylums and institutions.

Table 1: Period, Policy and Place of Services for People with Developmental Disabilities

PERIOD	POLICY	PREDOMINANT PLACE
Colonial - 1820	• Indoor Relief	Families, relatives, other community households
1820s - 1850s	• Outdoor Relief	Almshouses
1850s - 1870s	• Education	Schools in the community, then expansion into rural locations
1870s -1880s	• Protection of people with developmental disabilities	Asylums in distant rural locations
1880s - 1920s	• Protection of people with developmental disabilities • Colonies and parole	Institutions in distant rural locations In communities
1920s - 1950s	• Custodial care	Institutions in distant rural locations
1950s - 1970s	• Custodial care • Initiation of Community-based services	Institutions in distant rural locations Schools, Day Activity & Residences in the Communities
1970s - 2000	• Deinstitutionalization • Continued growth of Community-based services	Schools, Day Activity & Residences in the Communities

In colonial times poverty and dependency were not unusual nor unexpected circumstances and communities were generally prepared to help those individuals or families who became needy. However, there were some criteria for receiving assistance. People who were part of the community received local aid; strangers were encouraged to move on. The condition of dependency, not the specific cause of dependency, was reason for communities to arrange relief, but only the worthy poor

- widows, orphans, and people with disabilities - were supported (Trent, 1994).

The colonial service design was either outdoor or indoor relief; both types were financed by the general community. Outdoor relief was intended to minimize disruption in the dependent people's lives while keeping them in the midst of the community (Rothman, 1971). This was accomplished by supporting them in local households which could be their own family, relatives, or neighbors (ibid.; Scheerenberger, 1983). Deutsch (1937) provided an example of John Deanne, an "Iddiot," who was "boarded out" to a Mr. Richard Henry in 1661. Not surprisingly, the household that offered the lowest fee for the service received the boarder. Yet while people who were considered feebleminded remained in their home communities, their social roles were not positively valued. While not feared, (Trent, 1994), village idiots were not highly valued community members.

Indoor relief referred to larger and congregate settings that were initially based on a household model and were called "almshouses" (Rothman, 1971). Almshouses were constructed and used when people who needed intense supports could not be taken care of in a local household (ibid.). Discussing an almshouse in Boston in the mid-1700s, Rothman identified the elderly and people with disabilities as the majority of the residents therein. While this almshouse was located at the head of the Commons, a central area in the colonial town (Savage, 1884), the social exclusion of the residents was evident when Rothman (1971: 41) states, "Both were disqualified from taking a place in the community at large."

While there has been much written about the development of formal services in the mid-1800s for people, particularly children, with developmental disabilities, less is known about the home life of families and their members with developmental disabilities during that same time period. Recently Richards (Richards and Singer, 1998; Richards, 1999) has begun to address this gap by conducting archival studies of family experiences with members who had development disabilities. She provides meaningful context for these sources through an examination of the contemporary popular fiction. Some families were clearly supportive and loving and they valued their member with a developmental disability. But by the 1870s, the rise and growing dominance of professional expertise had changed these happy families to guilty families when children with disabilities were viewed as evidence of the sins and moral weaknesses of the parents.

In the United States, schools opened in the second half of the nineteenth century based on the belief that education would "cure" feeblemindedness and students would return to their families in a productive capacity. Physicians or teachers operated the small schools in their own homes located in the midst of the communities. As more students entered the schools, additions were built onto the homes or the schools relocated within the town or city (Journal of Psycho-Asthenics, 1940). Research on the geographical origins of the children and their social inclusion into the local community is lacking, but we can speculate that treated as a group such inclusion was unlikely.

Increased enrollments drove the relocation of these early training schools as children continued to be identified as feebleminded. Cheaper prices for land in the country undoubtedly contributed to the notion that the countryside was a preferable environment for schools for these children. Some students werefunded by the state in these private schools, thus laying the foundation for the creation of state departments responsible for schools for the feebleminded, and it was not long before this "new social problem" of feeblemindedness required capital construction to contain the burgeoning numbers of students.

But where to locate these schools? Edward Seguin, a respected leader in education for feebleminded children, advised that the locations of the schools "should be located where future inmates are born and raised" (Talbot, 1964, cited in Scheerenberger, 1975: 10).2 We can hope that this was to help maintain the students' local familial and social connections and to allow for their easier reintegration into their home community.

But this advice was blatantly disregarded. Capital cities, often themselves sited for geographical centrality, were a choice site for these facilities demonstrating the optimistic social policy of education as a cure for mental handicaps as well as showcasing the legislators' self-serving beneficence (Fernald, 1893 in Wolfensberger 1975; Braddock, 1998; Trent, 1994). In "Historical Notes on Institutions for the Mentally Defective," (Journal of Psycho-Asthenics, 1940: 188) the unidentified author observed:

> It is interesting to note that this first institution was located near Albany, the legislative seat of the State. The reason is found in the first report of the Trustees when they write, "As the enterprise was experimental there seemed great propriety in its being conducted so near the Capitol that the members of the Legislature might from time to time examine it and become acquainted with its success."

Since the institutions drew their residents from the entire state, children and youth were removed from their home communities, disrupted from their everyday lives, and thrust into an unknown and controlled environment.

Despite the great number of people who were institutionalized over time, the majority of children and adults with developmental disabilities were not. "The single overwhelming feature of the changes in policy toward retarded people between 1850 and 1875 is that they led to very little change in the daily lives of most of those individuals" (Ferguson, 1994).

In the 1870s, the training schools began to transform into asylums for the protection of the vulnerable children.3 Most of these children were the ones who had not been able to be cured by education. Their numbers increased as other severely disabled children were admitted. "By 1875 there were more than twenty-five State schools, almost universally spoken of as institutions" (Kuhlmann, 1940: 11). As feeblemindedness and delinquency began to be associated with the growing lower and immigrant class, institutions began to function to protect society from these potential troublemakers. The institutions expanded to meet the needs of "high-grade" and "low-grade" residents, designed to provide for every daily needs, thus there was little reason for a resident to enter the towns or cities.

Soon after in the 1880s, restricted marriages, sterilization of both men and women with developmental disabilities, and institutionalization were implemented as social controls to prevent the reproduction of "degenerate" people (Weiner, 1993). Thus began the period during which the dominant professional perspective attributed all social problems to heredity and the solutions to eugenics. However, Lakin, Bruininks, and Sigford (1981) have noted that social policies for people with developmental disabilities were not a great concern for most of the American population during the eugenics period and that people with developmental disabilities living among them was not particularly unusual. We are regrettably uninformed about people's common daily lives and where they occurred.

From the 1870s through the 1920s, articles in The Journal of Psycho-Asthenics, a lead professional journal, focused primarily on issues concerning institutions and their residents. Yet professional interest in community services was growing hand-in-hand with the recognition that there would never be institutions big enough to contain all the "mental defectives" who allegedly needed their special services. Again, education for children who most likely had mild developmental disabilities was a primary community service. By 1930, fifteen states "enacted statutes making mandatory or permissive the establishment of special classes or schools for mentally handicapped children in connection with public schools" (Davies, 1930: 297). Articles reported on special education discussing competition among some major cities for the honor of being early innovators of exemplary programs. Special education classes, though physically in the communities and "connected to the public schools," were isolated from the regular classes in various ways that are still in use: in segregated classrooms in a regular school, in temporary buildings on shared school grounds, or in entirely separate buildings not on shared school grounds. In St. Louis, Missouri, classes for "subnormal children" were purposefully organized for complete segregation (Wiley, 1922: 231). He wrote:

The special schools were organized with the idea that not only should the children be segregated from normal children in their class instruction, but that they should also be segregated from the regular elementary school environment. Consequently nearly all of the schools have been established in locations set apart from regular elementary schools.

Such segregation was stoutly defended in St. Louis, despite the cost: $197.20/special class pupil compared to $59.70/regular class pupil.

Because of the high cost of maintaining these relatively small school centers there is occasionally questioning of the wisdom and necessity for the segregation of these classes for the feebleminded children from the environment of the regular elementary schools and it should be said that the experience had in recent years with the 3 schools conducted in connection with regular elementary schools has not been unsatisfactory. (Wiley, 1922: 232)

Despite the "not...unsatisfactory" experience, and the lower cost of being located "in connection with regular schools", the policy of segregation overrode experience and potential cost savings very likely signifying the preference of the professionals, thus the importance, of segregation. This service location, segregation within the community, foreshadows other service locations that would be chosen in the decades to come.

Two service designs were developed to meet the goals of productivity that the professionals of the times had for people in the institutions. Both colonies and parole were directed towards employment. The farm colony, an institutional satellite agricultural operation whose purpose was to "... provide suitable homes and employment to the boys, and secondly to supply the home institution with fresh food" began in the 1880s (Journal of Psycho-Asthenics, 1896: 69). The colony concept was greatly extended by Charles Bernstein, superintendent of the Rome (New York) Custodial Asylum from 1902 to 1942, to include industrial and domestic colonies that relocated people from the institutions into communities that needed labor. Not only did people from the institutions work in factories, mills, and homes in the communities, but they often lived in those same communities. Forerunners of group homes for women have been described to indicate that two "colonies" were located near work sites in town (Trent, 1994). Once again, more research is necessary to determine the degree of any social inclusion.

In the 1910s, the parole plan was recognized as a "successful experiment" presaging deinstitutionalization. Again, people from the institutions were placed in jobs and residences in the communities, and after having proved that they could live on their own without supervision from the institution, they were formally discharged. Not only did the parole plan demonstrate the success, and therefore the continuing necessity of the institutions, but it also minimally relieved the overcrowding, fueled by increased institutionalization during the eugenics period.

Despite the more physically integrated locations of some colonies and the people on parole, the institution continued to be the dominant service provider and its staff the experts on people with mental retardation and developmental disabilities.

Service design and locations did not remarkably change from World War I to World War II. People continued to be institutionalized with the number of people increasing from a little over 115,000 in 1946 to nearly 200,000 in 1967, "nearly twice the rate of increase in the general population" (Trent, 1994). In the mid- to late-1960s, federal legislation provided funds for new construction of institutions. Eventually these residents were the ones who constituted the great deinstitutionalizaton movement in the next two decades.

The first service design, a physically segregated unit (e.g. schools, asylums, and institutions), was the core component in all of the above service designs. A second service design emerged after World War II, resulting in a developmental disabilities community services landscape that is still visible based on the development of formal community services, has been well-documented elsewhere in the mental retardation/development literature (i.e. Wolfensberger, 1972; Scheerenberger, 1983; for a case study, see Metzel, 1983). Vacant and typically devalued spaces in the communities, often the archetypal church basements (Wolfensberger, 1972), became the sites for pre-schools and particularly for school classes for children with moderate and/or severe developmental disabilities who were excluded from public school special education classes.

As the children aged into adults, day activity programs, vocational training programs, and residences were sited in the communities. Though on a smaller scale, and much less physically isolated than the state institutions, this generation of expanded community and post-institutional services designs for people with developmental disabilities have clearly perpetuated the prevalent goal of serving society and promote isolation, exclusion and stereotypes with locations that emphasize congregation and segregation rather than individualization and inclusion.

The current generation of community services is struggling to increase community inclusion, membership and valued roles of people with developmental disabilities through the incorporation of person-centered planning, self-determination, and individualized supports. The next section of this paper reviews contemporary trends and issues in community services.

Current Issues in Community Living and Support Services for People with Developmental Disabilities

As a concept, deinstitutionalization was a corollary to the principle of normalization which emphasized integration and promotion of typical lifestyles (Scheerenberger, 1987; Wolfensberger, 1972). As a practice, deinstitutionalization began in the late 1960s spurred by lawsuits, exposes, and efforts by people with disabilities, parents, and professionals (Taylor, Racino & Walker, 1992). As of 1999, over 75,000 adults remain in institutions and other large facilities (16 people or more) for people labeled with mental retardation (Prouty, Lakin & Anderson, 2000). Also, as of 1997, 23,087 children and youth with developmental disabilities resided in out-of-home placements (Lakin, Anderson & Prouty, 1998).

While not everyone has moved out of institutions for people with developmental disabilities into community-based settings (e.g., some people moved into nursing homes and other types of congregate facilities), many more have moved into smaller residences located within typical neighborhoods and communities. This section first describes selected features of this community-based service system that developed and discusses some of its limitations and shortcomings.

As development of the community-based service system began, families who had children or adult members with disabilities were given limited respite and other supports. This was not adequate for those with severe disabilities. Instead, more intensive supports were offered in group homes and institutions forcing many children to miss the opportunities to grow up within their family, neighborhood and community.

Traditionally, community-based services were part of a designed "continuum of services" approach with the continuum ranging from most restrictive to least restrictive environments. The residential services continuum, for example, involves such components as: Intermediate Care Facilities for the Mentally Retarded (ICFs), group homes, supervised apartments, supported apartments, and independent living. The intensity of supports was linked to the type of setting. As people gained skills and competencies, thereby requiring less support, they would progress along the continuum. Educational and day/vocational services were designed in a similar fashion.

There have been, however, a number of problems with the continuum approach to services (Taylor, 1998). First, people who moved along the continuum experienced much dislocation as they often had to move away from neighborhoods, jobs, and social networks. Second, those who needed the most intensive services never "progressed" along the continuum thus remaining in the larger and more restrictive settings. Others, with less severe disabilities, attained independent living, but then were at risk for "failing" at independent living if they had a change or crisis in their lives which required more support.

Another shortcoming of the community-based system was the continued congregation of people with disabilities, albeit on a smaller scale than institutions. People with disabilities were moved into group homes with often at least eight or ten others. They spent their days at sheltered workshops or day habitation centers and recreated in specialized, segregated programs. Often they were transported as a group in private vehicles to and from these sites. Participation in community places consisted predominantly of those types of places that offer little possibility for interaction with others (Walker, 1999). Thus, the round of daily life for many individuals with disabilities was still highly segregated from the mainstream of community life and their social worlds were mainly composed of others with developmental disabilities and staff, both not necessarily of their own choosing. In the mid-1980s, in response to the dissatisfaction with this traditional community-based service system among increasing numbers of people with disabilities, families and professionals, a more individualized support approach evolved.

In recent years, as an alternative to the continuum approach, innovative service providers began using an individualized supports approach. With respect to families, this is based on the principle that all children belong with families and that families should be offered "whatever it takes" to support the child and family (Taylor et al., 1987; Taylor, Knoll, Lehr & Walker, 1989). In terms of residential supports for adults, housing is separated from supports. The type of setting is not tied to the level of supports (Taylor et al., 1987; Racino, Walker, O'Connor &Taylor, 1993). Rather than having to "fit into" a group setting of four, six, eight, or more other individuals, not necessarily of their own choosing, this approach opened up many more options for people with severe disabilities. They now had the option of renting or owning a home or apartment on their own or with others; of living in the neighborhood and location of their choice; and living with the number of people, and the particular people of their choice. The supports that people need, whatever their intensity, are provided in the person's home. If the person's needs change, the level of support changes accordingly.

This support approach also requires more individualized support for community involvement and interaction. This includes providing support for participation in community places and activities based upon a person's choice and interests. This means promoting social interactions and relationships with a variety of community members deliberately beyond staff and others with developmental disabilities, again based on personal choice and interests.

Implications for Community Membership and Inclusion

Traditional community-based residential services have contributed to the community presence of people with developmental disabilities. These services have not necessarily facilitated community membership and in some ways have been an impediment (Bercovici, 1983; Calvez, 1993) giving the illusion of inclusion. While living in the community is a first step, that alone is not sufficient to promote community membership and inclusion (Bogdan and Taylor, 1987). Individualized approaches have increased opportunities for community inclusion compared to traditional service delivery approaches. At the same time, there remain some constraints to community inclusion and membership.

One is that people with developmental disabilities, who often rely on SSI and Medicaid, still typically have very limited financial resources which limits their housing options. In response to this, advocates have been working to help people with developmental disabilities gain access to funds that support low-income, nondisabled home owners or renters. A second is that Medicaid funds are still heavily invested in institutions and nursing homes with less allocated toward support for people with high levels of need to live in their own homes. Again, advocates have been working on legislation (MiCASSA) that would ensure home care options for people with disabilities, including those with developmental disability labels. Finally, there are limitations to the extent that any service design alone can promote community inclusion. Providing individualized supports that offer opportunities for participation in places of one's choosing does not necessarily guarantee that people will experience a sense of membership and belonging. Furthermore, neighbors, community members and society as a whole have an obligation to confront and dispel rejecting attitudes, stereotypes and practices. Continued efforts are needed to combat all of these constraints.

Conclusion

Our historical and contemporary discussions lead to the unsurprising conclusion that the dominance and designs of the service systems has, at every turn, unintentionally or intentionally prevented social inclusion when people with disabilities are treated as a group. Even if people with disabilities are supported in individualized ways that promote not only community presence, but participation, there still remain a number of constraints to the geography of their lives in the community. We are still learning how to provide support and services in places where people with developmental disabilities are that do not intentionally or unintentionally restrict them and devalue them.

Yet despite on-going constraints, an individualized approach support services design has made a significant contribution to expanding the social-spatial lives of people with developmental disabilities and to promoting increased control and spatial choice. In deliberate contrast to the traditional service models that perpetuated fear, stereotypes, and social exclusion, individualized approaches are designed to enhance social inclusion and community membership and to reduce fear and stereotypes.

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Notes

1. Examples of a developmental disability are: Down Syndrome, autism, cerebral palsy, epilepsy, and mental retardation. The Federal Developmental Disabilities Act (U. S. Public Law 101-496) defines a

developmental disability as a severe, chronic disability of a person five years of age or older which:

A) is attributable to a mental or physical impairment or combination of mental and physical impairments;

B) is manifested before the person attains age twenty-two;

C) is likely to continue indefinitely;

D) results in substantial functional limitations in three or more of the following areas of major life activity: self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; and economic self-sufficiency; and

E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are lifelong or extended duration and are individually planned and coordinated; except that such term when applied to infants and young children means individuals from birth to age five inclusive, who have a substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

The label, "developmental disabilities," is currently in use in the US though lately "cognitively disabled" has emerged. Other countries use "mentally handicapped" or "people with learning difficulties." In this paper, the terms "feebleminded" and "mentally defective" are used for historical accuracy.

2. For a similar recommendation by Edward Jarvis on the siting of lunatic asylums in North America in the nineteenth century see Philo (1995).

3. For an excellent and in-depth analysis of custodialism, see Ferguson, 1994.

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