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Resource Networks for Community Settings: An alternative view of institutions

Abstract

Institutions, though declining in number and size, remain substantial components of services for people with mental retardation and other developmental disabilities despite rapid growth in community-based services. Vigorous debate has taken place between the institutional and community positions. This paper argues that an institutional capacity, envisioned as networks or regional resource centers, is still needed to support certain activities not readily available in the community. The term "institution" is explored and an alternative perspective is developed, suggesting that a softening of the strong anti-institutional position may be warranted. Examples of how regional centers can provide health care, specialized services, and research and professional training are presented to demonstrate the use of "institutional" components to support community-based services.

Résumé

Les établissements spécialisés, même si leur nombre et leur taille accusent un recul, demeurent une composante importante des services qui s'adressent aux personnes atteintes d'arriération mentale et d'autres troubles du développement, en dépit de l'essor rapide des services communautaires. La polémique est vive entre les partisans des établissements spécialisés et ceux des services communautaires. Les auteurs de cet article soutiennent que les établissements spécialisés, perçus comme des réseaux ou des centres de ressources régionaux, sont toujours nécessaires à l'appui de certaines activités qui sont difficilement accessibles au sein de la communauté. Ils analysent le terme «établissement spécialisé» et développent un autre point de vue qui préconise un assouplissement de l'opposition farouche à l'existence de ces établissements. Ils citent des exemples de la façon dont les centres régionaux peuvent offrir des soins de la santé, des services spécialisés en plus de mener des recherches et d'assurer la formation professionnelle afin de démontrer l'utilité des établissements spécialisés à l'appui des services communautaires.

During the last 20 years in the United States and Canada, remarkable growth has taken place in the development of community-based services for people with mental retardation and other developmental disabilities (Braddock, Hemp, Fujiura, Bachelder, & Mitchell, 1990). Recently New Hampshire announced the closure of its state-operated facility at Laconia, making it the first state in the United States with no public institutional facilities for people with mental retardation. While New Hampshire had only one public facility to close, the trend is being echoed in larger states in the United States and in Canada as well. For example, officials in New York State have recently announced their goal to close all state-operated institutions for people with mental retardation by the year 2000. Nevertheless, future historians of the field may still refer to the 20th century as the era of institutionalization since institutions flourished during most of the century, peaking in the mid-1970s (Scheerenberger, 1987). Despite some shrinkage since then, institutions continue to be a widespread service option as the century comes to a close.

Thus, as the ideology of the field shifts toward community-based, integrated services, many institutional facilities remain. This has given rise to vigorous, often acrimonious, debate on issues such as residential size and type, quality of life, inclusion, rights, advocacy, treatment, mainstreaming, and public policy. This article examines several of the issues and provides an alternative view of certain elements from the institutional era that may have utility in the future—in a community-based service era.

Institutions and the Community: A Brief Overview

The continued existence of institutions does not mean that the movement toward community-based, consumer-oriented services is not substantial; indeed, in the last 20 years it has spread across the continent. Service systems in both Canada and the United States are becoming increasingly community-based. For example, in the United States, Braddock and his colleagues (Braddock *et al.*, 1990) showed spending on community services increased steadily from \$.58 per \$1,000 of the nation's wealth in 1977 to \$1.44 per \$1,000 in wealth in 1988, a 150% increase. Further, they found that changes in state funding that was supportive of community services were related to "advocacy activities" and the "political climate of the state," and not necessarily to the availability of funds (Braddock & Fujiura, 1991). Thus, the communitization movement produced important changes in public policy, funding priorities, and the actual mix of service providers (e.g., Borthwick-Duffy, Eyman, & White, 1987).

Nonetheless, actual movement **into** the community may be occurring more slowly than many proponents would like. More resources are being devoted to community-based services than in the past, but spending for institutions still exceeds spending in the community (Braddock *et al.*, 1990). Also, more people with mental retardation still reside in institutional settings than in community settings (Braddock *et al.*, 1990; Cunningham & Mueller,

1991). And though fewer people presently reside in institutions, these facilities remain funded better than they ever have been.

These facts have not blunted the criticism of institutions. Despite richer funding, the view persists that institutional facilities are unfit places to live. Advocates armed with change strategies drawn from other rights struggles, philosophical concepts such as **normalization** and **social role valorization** (Wolfensberger, 1972; 1983), and accounts of institutional abuses have prompted substantial expansion in community-based services. Although concerns about possible negative effects of rapid deinstitutionalization have been voiced by parent and family groups (e.g., Louisiana Association for Retarded Citizens, 1984; Pennsylvania League of Concerned Families of Retarded Citizens, 1985), theoreticians and researchers (Crissey, 1975; Throne, 1979; Zigler, Hodapp, & Edison, 1990), and practitioners (Walsh & McCallion, 1987), it no longer seems reasonable to maintain that institutional facilities as we have known them in this century will continue far into the next. Many will close and the overall census in state-operated institutions will shrink (Braddock, Fujiura, Hemp, Mitchell, & Bachelder, 1991). In short, despite the present numerical predominance of "institutional beds", the beginning of the end for large, central, public institutional facilities is at hand—even if the last one doesn't close until well into the next century.

As this century closes, the field of mental retardation and developmental disabilities finds itself characterized by a dual system – the coexistence of institutional facilities and community-based services. Everyone associated with the field—people with developmental disabilities and their families; advocates; researchers; service providers; allied professionals; educators; and state administrators—is struggling to redefine their roles at the end of a century that began with the certainty of institutions, encompassed a diversity of opinion, and approaches its end struggling with a dual system. As such, it is an ideal time to examine ways in which institutions have been successful and which may bear renewal.

Elsewhere (Walsh & McCallion, 1987) these ideas were presented in the context of "fluid" institutions functioning as "regional resource centres." The present paper extends this reasoning to the consideration of institutions becoming centres or network bases able to support such things as specialized habilitative services, professional development and training, and health care coordination. Before examining some of these in detail, however, a fresh perspective on what constitutes an "institution" is needed.

Institutions: Beyond Brick and Mortar

Words become prisoners of their usage. In the field of mental retardation the term "institution" usually refers to a facility, a brick and mortar **place**, for the congregate care of as many as hundreds (in the past thousands) of people, or as few as 16. Other connotations beyond this "brick and mortar" view are

possible. For example, in institutional research, the term has also been used to characterize **practices** within facilities along a quality of care dimension (Balla, 1976; King, Raynes, & Tizard, 1971; Zigler & Balla, 1977). Sometimes the word is avoided altogether by the use of "intermediate care facility" or "residential treatment centre." In general, the word "institution" has come to carry negative connotations in that institutions are viewed as detrimental to human development and happiness.

Unfortunately, problems of humaneness, rights, and quality of services are not automatically avoided in community-living settings (Landesman, 1988). Reviews of the literature centered on the institutional *vs.* community debate (e.g., Biklen & Knoll, 1987; Walsh & McCallion, 1987; Zigler *et al.*, 1990) have often reached different conclusions. Some call for additional research, viewing the issues as largely empirical and requiring more refined concepts and study (Landesman & Butterfield, 1987). Others conceptualize the issues as only involving "values" and "freedom" and not subject to empirical scrutiny (Blatt, 1987).

A strong anti-institutional view, however, ignores certain important referents or meanings of the term "institution". Dictionaries provide several meanings, only one of which conveys the notion of a place or facility with buildings and property. The word also refers to elements of **social organization or custom**—rather different than the "brick and mortar" emphasis. This connotation suggests numerous "institutions" exist within our communities, including public and higher education; political structures ranging from city councils and school boards to Congresses and Parliaments; health care systems and facilities; private ownership of property; and elements of social structure.

Institutions viewed as elements of social organization are known to change, being modified by the conditions of a particular historical period. For example, marriage and family life, as social institutions, have changed dramatically in the past half century. While the traditional nuclear family survives, numerous other arrangements flourish as well. This malleability, examined in the field of developmental disabilities, dramatically softens the dichotomy between institutions and the community, one that has fueled debate for two decades. Zigler, Hodapp, and Edison (1990) conceptualized strong anti-institutional sentiment as representing a fallacy of according too much importance to a social address. They argue, as have others, that **what** is done is more important than **where** it is done. For example, group homes, employing similar physical and programmatic regulations as institutional facilities and responding to traditional political, administrative, and fiscal pressures, may be quite similar to institutional units. This is not to argue for the continuance of large congregate facilities or to deprecate community residential services. Rather, the intent is to highlight the notion that services should be matched to the needs of individuals, regardless of setting (Zigler *et al.*, 1990).

In this way, too, it becomes clear that large bureaucratic systems designed to provide community-based services are, by nature, institutional systems – fraught with many of the perils of brick and mortar institutional facilities. In this context the words of Throne (1979) are unambiguous:

The distinction between institutions and communities is a false one. A human community is composed of people and their institutions. It is impossible to imagine a community of people without institutions. (p. 171)

Providing for Individual Needs: Regional Resource Networks

Institutional facilities are centralized systems—resources are located in one central place; community-based services, on the other hand, represent dispersed systems with resources flowing to several locations. Centralized facilities tend to provide all services required by a person, often in a less individualized manner; community systems tend to individualize more and access existing resources in the community. Thus, the efficiency (economy of scale) of the institutional model may be offset by its inability to individualize services. Similarly, although community-based systems tend to be more individualized, needed services are often inaccessible, incomplete, or simply unavailable. For example, at least in the United States, access to health care services has often been difficult for a variety of reasons (Crocker, 1989; Garrard, 1983).

Future service systems must be developed that avoid the drawbacks of both systems while preserving their benefits. Community-based services are here to stay (Janicki, Krauss, & Seltzer, 1988) and will be refined as we enter the next century (Braddock & Fujiura, 1991). The remainder of this article will focus on a few elements of the institutional model that should be preserved. Unlike previous efforts in this vein (e.g., Zigler *et al.*, 1990), however, the recommendations here do not argue for the maintenance of large institutional facilities. Rather a case is made for an **institutionalized capacity** able to (1) provide quality services in a variety of settings; (2) completely and adequately address the training and development of professionals and other practitioners; and (3) maintain adequate facilities to conduct discipline and policy-oriented research (Bruininks, 1990).

The task then becomes to determine ways of addressing problems in the field that bridge the gap between institutions and the community, and by extension between social policy advocates and researchers (Landesman-Ramey, 1990; Menolascino & Stark, 1990). "Institutions" of the future, then, might be thought of as organized systems of specialized resources, perhaps housed in regional centres but not necessarily, through which public policy can

be implemented. Sites for such centres could include universities, hospitals, established service providers, or sections of institutions that have closed or been reduced in size. In this perspective, an institution is best viewed as a network or a system rather than as a piece of real estate with residential buildings, classrooms, workshops, and administrative offices. In the haste to close centralized institutions, their potential, in altered form and reduced in size, as community support systems, resource banks, specialized service sites, and training and research centres has been neglected. While institutions gave rise to abuses, they also provided the foci for a "critical mass" of professionals who developed specialized treatment and service knowledge, conducted research, and developed additional specialists. Coordinated service networks will be able to continue certain of these functions as the following examples demonstrate.

Health care

As more people with developmental disabilities return to the community, problems arise in the provision of basic health care (Garrard, 1983; Luckhardt, Rupp, & Stevens, 1989), especially in meeting their specialized needs (Rubin, 1987). Consider a regional community medical centre that provides primary medical care to people living in the community, using staff of the centre (Ziring, Kastner, Friedman, Pond, Barnett, Sonnenberg, & Strassburger, 1988). While not an institution in the traditional "brick and mortar" sense, it is a centralized site providing quality services. Services are not rendered by the local community physician, but rather by professionals whose primary practice consists of people with developmental disabilities. While many health care issues of people with developmental disabilities are not unique and can be readily treated by community practitioners, certain problems require specialized services or, at least, specialized knowledge (e.g., Friedman, Kastner, Pond, & O'Brien, 1989). Further, such specialized systems or networks operating in the community have been seen as desirable in the provision of health care services (Crocker, Yankauer *et al.*, 1987; Kastner, 1991). Not only do such systems constitute essential health care services, they also serve an important coordination function among disparate members of the service provision scene. Although the primary goal of such systems in the future may be to support the delivery of primary care by local health care professionals, there may always be a need for regional centres as secondary and tertiary care providers based on the specialized needs of people with developmental disabilities.

Specialized services

The community movement rests on the assumption that the needs of people with developmental disabilities are best served in integrated settings. While this position does not deny the existence of individual differences among

people with developmental disabilities, the effect in practice is to minimize their differences from nondisabled people. However, a specialized field and specific body of knowledge has existed for well over 150 years (Scheerenberger, 1983). Although many of their needs are not different, some people with developmental disabilities do require special services. Controversial issues are encountered when considering specialized services. One is diagnostic labeling; another is segregated services; and sometimes congregate living becomes an issue. In the simplest model, specialized services begin by identifying specific needs in people (diagnostic labelling), and then bringing people with similar needs together for service (segregation). If the services require residential placement, some form of congregate living is arranged. Advocates have spurned the use of diagnostic labels (cf. Lilly, 1992) as inherently demeaning and too easily employed as a basis for devaluation of the person. However, from a scientific perspective, classification is essential before work can be carried out to explicate a phenomenon. Blurring aspects of the definition of mental retardation and disavowing diagnostic classification may well impede scientific advances (Burack, Hodapp, & Zigler, 1988; Zigler, Balla, & Hodapp, 1984; Zigler & Hodapp, 1986). From a clinical or treatment perspective, this may also not be in the best interests of people with specific disabilities (Hodapp & Dykens, 1992).

Specialized services and treatment are sometimes provided best in segregated, congregate living settings. For example, the author participated in a project that established a very structured group home treatment program for adults diagnosed with Prader-Willi syndrome, a syndrome that, among other problems, involves disordered eating patterns and, sometimes, associated behavioural problems (Omrod, Rose, & Walsh, 1985; Walsh & McCallion, 1987). In this program, adults with the syndrome lived in a group home and worked in the community. The program was designed to teach, among other things, appropriate eating and meal preparation behaviours. Individual choice was promoted within the structure (e.g., by allowing choice among dietary equivalents); routine tasks and daily discussion and therapy sessions afforded the mutual support of others who shared this rare disorder. It can be argued that the congregate life in this structured home of a small group of individuals with a similar genetic disorder, actually empowered them to succeed, in most cases, for the first time in their lives. In addition, a related benefit of this program has been the facilitation of a research program designed to systematically examine aspects of this syndrome (Dykens, Hodapp, Walsh, & Nash, in press). Most important, perhaps, is that anecdotal reports of the individuals themselves are generally positive; individuals appreciated the need for the structure employed. Indeed, the group dynamics of the program shifted such that the consumers themselves assumed control over the maintenance of structure. In short, they viewed the structure as "house rules" that applied equitably to everyone and had the advantage of helping everyone overcome the effects of their common syndrome.

Further, segregated residential treatment settings are not uncommon in other areas such as mental health, substance abuse, or cancer. Beyond treatment settings, cultural history is replete with examples of subgroups who share common needs, religious preferences, cultural background, or simply lifestyles affiliating in either existing neighborhoods or in specifically designed communities (Fitzgerald, 1981). Thus, if "congregate settings" refer to small home-like specialized living facilities, designed for specific therapeutic purposes related to developmental disabilities, offering individualized state-of-the-art treatment by knowledgeable staff, then in certain circumstances they may be quite appropriate. Given fiscal reality, it may also be that such settings could profitably employ the best small units of some larger, institutional facilities that are being reduced in size or closed.

Specialized services, of course, do not always imply residential living. Specialized community clinics are possible as are specialty treatment services within existing facilities. For example, although rarely encountered in the community, comprehensive physical management programs for multiply handicapped individuals can be efficiently arranged in more centralized settings (Smith & McFarland, 1991). A similar perspective has been articulated in relation to education (Gottleib, 1990; 1981). Further, an argument can be made that special educators possess specialized skills quite applicable beyond the classroom (Rosen, Rice, Walsh, Hartman, & McCallion, 1991).

Research and professional training

As institutional facilities close and their resources are dispersed into the community, it is important not to lose the ability to conduct applied research in the area of mental retardation and developmental disabilities. While some community advocates have suggested that research into practical and service issues is less important than simply applying appropriate values (e.g., Blatt, 1987), others have recognized the need for continuing applied research efforts (Landesman & Butterfield, 1987; Robinson, 1987). Indeed, Brooks and Baumeister (1977) early on called for more ecologically valid research. Community research, however, has often lacked focus or been too narrowly defined. Allen (1987), for example, has described the identity crises that have plagued community-based research efforts, including lack of clarity in definitions and methodological problems. Research in this area has been reviewed extensively (see Landesman & Butterfield, 1987; Landesman & Vietze, 1987, for extensive discussions of these issues).

Institutional facilities have been good sites in which to conduct research. The community-based services that replace institutions often do not include the same "critical mass" of professionals specializing in the field. This fact remains a concern in the provision of quality services (e.g., health care), and represents a significant problem in the conduct of applied research. As institutions are

phased down, steps need to be taken to preserve the "critical masses" of professionals these facilities have traditionally maintained. In the past, professional departments in institutions provided a base for numbers of practitioners in a multitude of professions to work together, often with collaborations resulting in important research findings or the development of formal internship programs. Although the field is not totally devoid of opportunities, they are clearly more limited and dispersed. Nevertheless, the importance of a "critical mass" should not be underemphasized; professionals often are attracted to fields or subspecialties when opportunities exist to work closely with colleagues.

Such groups of professionals will also usually spawn training programs and opportunities for students and younger professionals. As generic community services (those used by people who are not developmentally disabled) are increasingly utilized by people with such disabilities, it is imperative that professional training opportunities remain available. Indeed, the need for specialized training in the area of developmental disabilities will be heightened as more community practitioners from all disciplines begin to provide services to people who have developmental disabilities.

Conclusion

In this article I have presented the view that as large, centralized institutional facilities are replaced by services in the community, a specialized institutionalized capacity – conceptualized as systems, networks, or regional centres—is still needed. Such regional centres can continue to support professionals who provide specialized services, conduct research, serve as resource and consultation banks, and train young professionals. Zigler *et al.* (1990), Crissey (1986), and Walsh and McCallion (1987) have all suggested that these types of centres will be needed in the future. However, ardent proponents of community services have often espoused such a strong anti-institutional position that first, the institutional nature of many community services has not been recognized, and second, discussion of networks or regional centres such as those described herein has been precluded.

It may be that the foundations of such regional resource networks already exist in the form of large public institutional facilities that are shrinking and being closed. Service networks and resource centres as those described herein could support, supplement, and help coordinate community providers; they could also serve to organize knowledge, provide consultant assistance, and develop research and training programs. Without such centres, knowledge of developmental disabilities may become difficult to acquire as research activities disappear from service sites.

Without such centres, for example, a community physician, treating an individual with developmental disabilities living in the community, may have nowhere to turn for information about unfamiliar diagnostic or treatment

issues; or a psychologist working in the community, asked by parents to help them gain control over their child's behaviour, may not know how to design an individualized behavioural plan. Finally, without such centres, a young professional, of any discipline, seeking research opportunities or an internship or practicum site offering a broad range of experience with all levels and ages of people with disabilities, may search in vain for an opportunity.

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