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Extending the Independent Living Center Model to Rural Areas through State and Local Efforts

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Abstract

Independent living centers (ILCs) provide support services to adults with physical disabilities. Originally created through federal funding, most ILCs serve urban areas, leaving a large rural area and its population unreached by independent living ideas or services. Data on the expansion of the ILC service model to rural areas are presented. The need for further program development is discussed.

0ne third of the U.S. population lives outside of a Standard Metropolitan Statistical Area (Korte, 1983) and 26% live in towns with less than 2,500 inhabitants (Bureau of the Census, 1970 as cited in Photiadis & Simoni, 1983). Mathamatica Policy Research (1984) estimated that nearly 44 million persons have at least one chronic or permanent impairment. Thus, assuming disability is evenly distributed (although it is, in fact, more prevalent in rural areas) (Baker, O'Neil, & Karp, 1984; Matheson & Page, 1985), it is likely that 11 (26%) to 15 (33%) million persons living in rural areas have significant disabilities. This conclusion is further supported by the finding that of the 12,075,793 individuals between 18 and 64 years old reporting a work disability, 3,450,018 (29%) live outside metropolitan areas (U.S. Census, 1980). These data suggest there may be a great need for services, such as those provided by independent living centers (ILC), to address the needs of adults with disabilities living in rural America.

Title VII - Part B of the Rehabilitation Act of 1978 created a federally funded program of Independent Living Centers (ILCs) to actualize the independent living movement for adults with physical disabilities around the nation (P.L. 95-602). Part-B funds were originally three-year grants intended to assist in the development of ILCs. Ideally, these centers were to be community based, free-standing, non-profit corporations controlled significantly by their consumers (Frieden,

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1980). Their goal would be to enhance the ability of adults with severe physical disabilities (e.g., spinal cord injuries) to lead independent lives.

In addition to Part B, the 1978 amendments created Part A. Part A was planned as a way to help states provide independent living services; in part by contracting with the newly created Part-B ILCs. Theoretically, as Part-A funds came into use by states, they would support the operation of the ILCs. Then Part-B funds could be withdrawn and used to start more ILCs in unserved areas.

Approximately 175 ILCs were created by Title VII - Part-B funds from 1978 to 1989. The total budget of that program has reached approximately $25 million. The funding for Part A, originally planned to be as high as $200 million, has reached only $12.5 million, however. This funding discrepancy led to a Part A/B crisis in 1981 when the original 3-year Part-B initiation grants were completed. At that time, the Rehabilitation Services Administration stabilized the Part-B funded ILCs until an overall funding strategy could be worked out.

Unfortunately, no comprehensive funding strategy for ILC services has emerged. Since 1981, approximately 30 new ILCs were funded with new federal money. This plateau in the federal funding of I LCs has left a large population and many areas unreached by independent living services. Many of these are in rural areas (Richards, 1986).

To address this gap, several states have reported using Part A funds in an effort to create new ILCs directly (Bradford, personal communication 1988). In addition, a number of communities and states have created ILCs using resources other than those available from Title VII - Part B, including city and county funding, state funds and private funds. The extent of the growth in ILCs in this manner is not well understood, however. This study reports an effort to examine the creative efforts of people working at the state and local level to continue the expansion of the ILC model of service to adults with severe physical disabilities in rural areas.

Methods

State Independent Living Coordinators (usually located in a state's Vocational Rehabilitation department) were mailed a letter requesting information about ILCs within their jurisdiction. The letter asked Coordinators to identify ILCs which were funded solely by Part-A, state or private funds in the rural areas of their state. Four to six weeks following this mailing, nonrespondents were contacted by telephone and the same information was again requested. In addition, we cross-checked our list of programs with the Kansas list of Title VII, Part-B funded ILCs in order to eliminate any programs receiving Part-B funds from our non-B list.

Next, as part of a larger study of rural services (Seekins, Ravesloot, Jackson, & Dingman, 1990), we surveyed the identified rural programs not supported by Part B federal funds. Questionnaires were mailed to the directors of ILCs serving rural areas. These questionnaires asked directors to report on a variety of program features, including: number of consumers served annually, number of counties served, total annual budgets, budget sources, disabilities of clients served, services offered, and number of staff and volunteers.

Results

A total of 48 (96%) state coordinators responded to our mailing and telephone follow-ups. Twenty-four states (50% of respondents) reported having ILCs serving rural areas that were not supported by Title VI 1, Part -13 funds. The state coordinators reported a total of 76 ILC programs supported by Title VII, Part-A funds, state general revenue, local government, private sources, or a combination of these. They reported that thirty of these programs were supported solely by state and local government funds. One program reported receiving significant support from private sources. The remaining programs (45) received a combination of all these sources or their funding could not be determined.

The directors of twenty-nine (38% of the 76 non-B centers) of these rural I LCs responded to a survey of rural ILCs. Survey respondents

not supported by Part-B funds reported serving a total of 143 counties and 10,298 consumers annually; an average of 4.9 counties and 368 consumers. These consumers fell into several categories of primary disabilities, including: progressive degenerative diseases (17% of consumers), spinal cord injuries (114%), cerebral palsy (13%), head injury (8%), traumatic brain injury (7%), stroke (4%), visual impairments (4%), mental retardation (4%), amputations (3%), mental illness (3%), arthritis (3%), polio (3%), cardiopulmonary problems (3%), and other disabilities (13%).

Table 1 presents the percentage of ILCs reporting the provision of various services. These services were provided by an average of 9.5 staff and 15 volunteers. Of staff, 60.4% were reported to have a disability.

Table 1. Percentage of Rural Independent Living Centers Reporting Provision of Various Services

Service	Percent
Information Referral	96
Individual Advocacy	93
Peer Counseling	89
Systems Advocacy	86
IL Skills Training	86
Public Education	86
Housing Assistance	82
Home Visits	79
Case Management	71
Support Groups	64
PCA Referral	54
Transportation	50
Social & Recreational	46
PCA Management Training	29
Family Counseling	36
PCA Training	29
Health Education	21
Housing	18
Vocational Services	18
Home Health Care	14
Housekeeping	14
Transitional Housing	11
Other	18

Twenty-two (76%) programs were reported to be independent, community-based, non-profit agencies; three (10%) were units of larger community agencies; and two (7%) were reported as units of a state agency. Twenty five (86%) reported having a board of directors.

These boards averaged 10.3 members of which seven (62%) had a disability.

Table 2 presents the percentage of programs reporting budgets in five major categories from $0 to more than $500,000 annually.

Table 2. Annual Budget Ranges for Rural Independent Living Centers

Budget Ranges	Number of Centers	Percent of Centers
$0 - $50,000	3	11
$50,001 - $100,000	7	26
$100,001 - $250,000	12	44
$250,001 - $500,000	3	11
Over $500,000	2	7

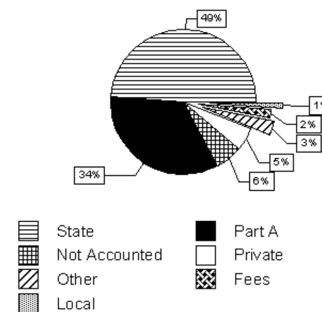
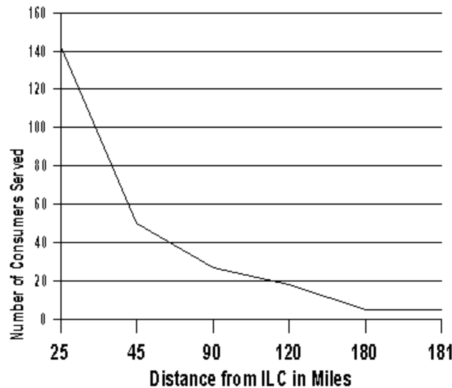


Figure 1 - Rural Independent Living Centers Budget Sources

Finally, Figure 2 presents the average number and percent of consumers served at various distances from the ILCs. Seventy-nine percent of consumers lived within about 45 miles of their ILC.



Discussion

Seventy-six ILCs serving rural areas in twenty-four states were identified by IL Coordinators in 48 states. All of these programs were supported by funds from Title VII - Part A, state or local general funds, or private sources. None were funded by Title VII, Part B; the federal source originally intended to create such programs.

Despite not receiving support from Part B, these programs appear to meet the spirit of ILC standards for Part B centers. Seventy-six percent of survey respondents were independent, community-based, non-profit agencies. Eighty-six percent had boards of directors with an average of 62% members having a disability. Finally, they appear to make services available to all disability groups.

At the same time, these programs appear to have relatively small budgets; most (81 %) under $250,000. They also appear to serve geographically large areas with sparse populations.

Interestingly, the number of individuals receiving services from these rural programs drops off sharply after their distance from a center exceeds about 45 miles. This may be due to a decline in the actual population of people with disabilities as the total population grows sparse. It may also be due to the imposition of service boundaries that impose restrictions on services outside a given area. Alternately, this decline in service may be a product of rural obstacles that reduce access. Further study is needed to clarify such issues.

These state and locally supported programs represent an expansion of nearly twice again as many ILCs as were created with new Part B funds. This growth in rural ILCs suggests a high level of both demand and commitment to the IL service model. It also reflects an effort to distribute those needed services to rural areas.

The center model of IL service delivery in rural areas poses a number of challenges (Richards, 1986). Among these are distances, sparse populations, low prevalence of many different disabilities, limited staff time for services because of travel, and cultural differences (e.g., Native American reservations). Yet, currently, no adequate rural IL models exist.

While urban models of I L services are relatively well established, they may not easily generalize to rural areas. For example, programs may have to serve areas significantly larger than one contiguous community (i.e., city and surrounding suburbs) because of the sparse population and great distances. This poses obstacles to developing local community identity and support. Similarly, it may be extremely difficult for consumers to come together to manage programs or participate in peer groups.

Using Part-A, state, and local funds to initiate and support ILC programs in rural areas has proven to be a workable option. But such uses of Part-A funds have their limitations. For instance, each state must use its Part-A funds to deliver services to the entire state. In addition, there are a number of regulations and procedures (e.g., eligibility determination) that impose restrictions that often obstruct efficient service delivery.

Using state and local general revenue funds, or private funds may, on the one hand, reduce restrictions such as those imposed by Federal Part A regulations. It also may reduce assurances of consumer control, however.

Of course, blending Federal, state, local, and private funding would seem an effective compromise for extending ILC models to rural areas. Multiple funding sources might give programs needed flexibility by increasing the types of disability groups that can be served, the types of services that can be offered, and the range of individuals eligible for services. Multiple funding agencies might also improve the quality of programs by applying a broader variety of service delivery standards (e.g., consumer control) than any one agency would use.

In those programs where funding came exclusively from state resources, staff reported both advantages and disadvantages to being state as opposed to federally funded. The foremost advantage they described was being in close personal touch with their funding source. The disadvantage cited most frequently was that they were less well funded than programs receiving federal monies.

Summary

The original ILC strategy, if funded at planned levels, would have provided a healthier growth pattern for the development of community based ILCs. Unfortunately, the lack of funding has left the expectation of services without their availability. The good news appears to be that half of the states have made commitments to expand I LC service models into rural areas using local resources. The bad news appears to be that many of these states may lack sufficient resources to meet the I L goals of people with disabilities in rural areas. Many consumers still do not have access to the important ideas and services offered by IL programs.

The expectations of people with disabilities living everywhere have been raised by the IL movement. More resources from all levels of society - Federal, state, local, and private-need to be allocated to meet these expectations.

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