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ABSTRACT

This serial issue summarizes findings from a survey of 20 state mental retardation and developmental disabilities agencies and 93 community based providers on developing and financing community services. The survey queried respondents concerning: (1) which models or strategies for financing community services have been most effective; (2) what states' and providers' current and future community service priorities are; and (3) how particular actions or policies of federal, state, or local governments affect efforts to develop and finance community services. Stage agencies offered 10 recommendations of which the most important were funding flexibility, increased family support services, improved state government collaboration with local governments, and creative use of "traditional" models. Recommendations of community providers addressed the start-up of services and supports, the ongoing operation of services and supports, and missions and values of community organizations. Principles for developing and financing community services and supports were suggested by the surveys including improved collaboration between governmental agencies and private providers, the value of innovative examples, and a community employment system in transition. (26 references) (DB)

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Policy Research Brief

CENTER ON RESIDENTIAL SERVICES AND COMMUNITY LIVING
UNIVERSITY OF MINNESOTA

Financing Community Services for Persons with Disabilities: State Agency and Community Provider Perspectives

This issue of Policy Research Brief summarizes the findings from a survey of state mental retardation/developmental disabilities agencies and community based providers. The survey, conducted by the University Affiliated Program in Developmental Disabilities (UAP) at the University of Illinois at Chicago, sought agency and provider perspectives on developing and financing community services. This summary was prepared by Richard Hemp of the University of Illinois UAP.

Introduction

The population of the nation's state institutions serving persons with mental retardation/developmental disabilities (MR/DD) peaked at 194,650 in 1967. Since then it has steadily declined to slightly over 90,000 in 1989, and is projected to decline to 54,000 by the year 2000. Governmental spending in the nation for facilities of 15 beds or less and for other community services nearly doubled from 25% of total MR/DD spending in 1977 to 48% of the total in 1988. By 1988 there were 126,000 individuals served in fifteen-bed or smaller community residences, nearly triple the 45,000 served in small facilities in 1977 (Lakin, 1979; White, Lakin, Bruininks, & Li, 1991; Braddock et al., 1991; Braddock et al., 1990; Lakin, Hill, & Bruininks, 1985).

Although the U.S. has experienced more than two decades of deinstitutionalization and increases in community spending, there has been great variation across the states in rates of institutional depopulation, total resource commitments to community alternatives, and relative contributions by levels of government to the funding of community services (Braddock et al., 1990). For example, although the nation's institutional population declined between 1977 and 1988 by 39%, Michigan's population declined 79%, Arkansas and Tennessee saw declines of less than 5%, and Nevada experienced an increase of 51%.

"Fiscal effort" expressed in terms of 1988 community spending as a share of statewide personal income consisted of an expenditure of $1.46 per $1,000 of personal income in the nation as a whole. However, community fiscal effort levels ranged from $4.08 in North Dakota to $.40 in Mississippi. In addition, states' levels of support from federal, state or local governments and from individual federal programs varied greatly. Federal funding nationally constituted 25% of the $5.637 billion spent on community services. Yet state-by-state federal percentages ranged from 75% in South Dakota to 7% in Arizona. Local county and municipality funding contributed 12% of total spending nationally, with 6.2% in the form of required matches to Medicaid and other federal programs and the remaining 5.8% consisting of local government "over-match" funding. In the 22 states employing match and over-match dollars, Iowa received 48% from these local government sources compared to only 1% in North Carolina and in North Dakota.

States' and service providers' efforts at developing and maintaining community services have been impeded by limited funding (Gettings, 1977; PCMR, 1976; NARC, 1976), inferior wages and benefits and the resultant high turnover rates for community workers (Mitchell & Braddock, 1991), and by governmental restrictions and disincentives (Boggs, Hanley-Maxwell, Lakin, & Bradley, 1988; Conley, 1973; GAO, 1977). There is an institutional bias in federal ICF/MR reimbursements (Braddock, 1987). Furthermore, Lakin et al. (1989) reported that 38 of 51 state MR/DD agencies supported Medicaid reform even though such legislation would cap the federal institutional ICF/MR reimbursements on which most states relied heavily. State institutions are "closed-enterprises" benefiting from incremental federal, state and local funding, while community

A summary of research on policy issues affecting persons with developmental disabilities. Published by the Research and Training Center on Residential Services and Community Living, Institute on Community Integration (UAP), University of Minnesota.

based "open systems" must utilize generic services and a complex of public agencies (Smith & Ackerman, 1987). Community service providers must frequently employ creative strategies in order just to maintain adequate funding (e.g. Allard, 1988; Copeland & Iversen, 1981).

Individualized, supported approaches to community living and work for people with disabilities are being developed in more and more states (Wright & King, 1991). These developments reflect a growing concern about established methods of service delivery, and established "models". Smull (1989) warned about a "crisis in the community" resulting from state agencies' and community provider organizations' preoccupation with funding services when a "support paradigm" involving relatives, neighbors, and friends would be more appropriate. Ferguson, Hibbard, Leinen, & Schaff (1990), outlined "a new social policy: disability services and supported community life," which included supported employment, community living, education, recreation, and services to families.

Together, community provider organizations and state governments plan for, establish, and maintain community services for persons with mental retardation/developmental disabilities within local communities. This shared responsibility must be carried out in the context of multiple governmental and private sector funding sources and other resources, each with special requirements and limitations.

Purpose and Method of the Study

In 1991, the University Affiliated Program in Developmental Disabilities (UAP) at the University of Illinois at Chicago completed a survey of state mental retardation/developmental disabilities agencies and community based provider organizations, seeking to better understand their perspectives and experiences in developing and financing community services. The following questions guided the development of two survey instruments:

- Which models or strategies for financing community services have been most effective?
- What were states' and providers' current and future community service priorities?
- How have particular actions or policies of the federal, state, or local governments affected states' and providers' efforts to develop and finance community services?

The Definition and Selection of Survey Respondents

"State MR/DD agencies" are the state government departments or divisions that have fiscal accountability for community service general fund appropriations and which are also responsible (directly or jointly with other state agencies) for managing federal and local government community service funds (Braddock et al., 1990). "Community service providers" contract with state MR/DD agencies through grants-in-aid or purchase-of-service arrangements, and are directly responsible for the establishment and operation of community programs, services and supports.

The first step in the selection of survey respondents was the identification of states that demonstrated substantial community resource commitments. A purposive sample of 20 states was selected on the basis of 1988 community fiscal effort rankings and the recommendations of a panel of experts in community service development. Four states (Arizona, California, Georgia and Illinois) were recommended by the panel because of their community living, employment, family support or other community initiatives (Hemp, Braddock, Bachelder, & Haasen, 1990). The other 16 states (Colorado, Connecticut, Iowa, Maine, Massachusetts, Michigan, Minnesota, Nebraska, New Hampshire, New York, North Dakota, Ohio, Pennsylvania, Rhode Island, Vermont, and Wisconsin) ranked in the nation's top 20 on the community fiscal effort index (Braddock et al., 1990).

The second step in survey respondent selection consisted of identification of the 20 states' MR/DD agency directors, and selection of community provider organizations in each of the 20 states. Developmental Disabilities Councils, state MR/DD agencies, and Associations for Retarded Citizens were statewide associations and agencies knowledgeable about community service development. They were asked to nominate providers that employed "creative strategies" in community financing. The DD Councils, state MR/DD agencies, and ARCs, respectively, nominated 57, 48, and 22 community providers. In addition, 29 community organizations received dual nominations and one was nominated by all three, resulting in 157 total nominations. In addition to private non-profit provider organizations, community respondents included state agencies with community service components, larger organizations operating MR/DD programs or supports, and for-profit business ventures employing people with disabilities (Hemp, Braddock, Haasen, & Bachelder, 1991).

Survey Administration

The 20 state directors identified constraints against community programs inherent in the fiscal or other practices of the federal, state or local governments, or of the private sector. They addressed recommendations for these levels of government and for the private sector and outlined successful strategies that they had employed in community service development along with their priorities for future development. For this first survey, structured telephone interviews were administered during October through December, 1989.

The second questionnaire for community provider organizations covered capital funding and other start-up issues, ongoing operations, and their recommendations for developing and financing community services. Between November,

1989, and January, 1991, 33 mailed survey instruments were returned and 60 telephone interviews completed. The total of 93 completed surveys represented a 59% response rate out of 157 requests.

■ Results of the Study

State MR/DD Agencies: Experiences

The state MR/DD agencies discussed constraints against community programs. The principal *federal* constraints were the restrictions, adverse interpretations, and institutional incentives inherent in the federal Medicaid program. The *state government* problems that were identified consisted of insufficient funding, inappropriate or low reimbursement systems, and funding restrictions and interpretations. The primary constraints of *local governments* were insufficient funding, lack of community acceptance, and zoning. Finally, in addressing the *private sector*, state agencies identified community provider opposition to integrated services and lack of provider participation as major constraints.

State MR/DD Agencies: Recommendations

Ten major recommendations were provided by state directors and are presented here in priority order.

- **Funding flexibility.** State directors recommended flexible funding as a key component in community service development. For example, the director in the one state without a history of Medicaid funding (Arizona) stressed the importance of flexibility in establishing services and supports. "The primary reason for innovation and individualized services in Arizona is that state general fund dollars are flexible, with a family and individual focus." All twenty states recommended Medicaid reform in one form or another and six specifically recommended adoption of S. 384, the Medicaid Home and Community Quality Services Act of 1989.
- **Increased family support services.** The state agency respondents were unanimous in recommending more services for families. There needed to be a better recognition of families' competence in determining their own needs. In addition, government funding should more effectively comple ent families' natural supports from their extended families, their friends, and their neighbors.
- **Increased opportunities for employment.** There should be expanded supported employment and better "marketing" of peoples' abilities to the private sector. Respondents recognized the opportunity for government to modify its role of provider and funding agent, and to more aggressively promote to businesses the benefits of employing individuals with disabilities.
- **Improved state government collaboration with local governments.** This included training and technical assistance to keep officials at the local level in touch with state and federal initiatives and state-of-the-art practices. In states with strong county systems, respondents identified the need to obtain the participation of all counties in support of the state's philosophy and mission for community services.
- **Creative use of "traditional" models.** There was a need for group homes for individuals with special behavior or medical needs, for individuals involved with the criminal justice system, and for persons with dual psychiatric and developmental disabilities diagnoses. More creative approaches to traditional shift-staffing, such as intermittent supervision and support, were recommended.
- **Legislative mandates for community services.** This was emphasized by those states that had benefited from community mandates. Nebraska, Ohio, Pennsylvania, Rhode Island and Wisconsin described mandated community funding; Arizona, California, Colorado, Georgia, Michigan, Minnesota, and New Hampshire described community mandates without specific funding requirements.
- **Improved collaboration with community service providers.** Although state agencies had identified providers' "opposition to integrated services," and "lack of participation" as major private sector constraints, they were nearly unanimous in recognizing government's responsibility for improved funding and technical assistance. Government support was especially important when community organizations underwent transition from center-based models of service to providing individualized supported work and living opportunities.
- **Development of independent case management services.** The Nebraska director recommended improvement in the state's case management system. Case managers who independently established individualized program plans could "go outside the agency boundaries" and thereby help to develop the necessary services and supports. Several states were utilizing Medicaid "targeted case management" to provide more individually focused service coordination.
- **Advocacy and self-advocacy.** State agencies recommended actively involving persons with disabilities and their families in the development of services and supports. Especially in Maine and Michigan state directors highlighted the effectiveness of provider, state agency, and advocacy group coalitions whose statewide efforts improved and expanded community services and supports.
- **Federal/state collaboration with businesses and local communities.** Respondents commended the efforts and positive responses of businesses, industries, and neighborhoods. Reflecting on the limitations that many

government programs placed on developing and maintaining community services, state directors emphasized involving the private sector as a partner in community service development.

Community Providers: Experiences

Eighty-two of the ninety-three community respondents identified recently developed community services or supports as the focal points for their detailed descriptions of positive and negative experiences in the development and maintenance of community services. Many of the providers' descriptions were consistent with the experiences and recommendations of state directors discussed above. These included concerns about federal program restrictions, community acceptance, inadequate funding and wage parity, and the need for improved employment opportunities and individualization of services for persons with disabilities. Community providers expanded on other issues introduced by state directors, especially the need for improved governmental technical assistance, the problems of over-regulation and inadequate public and private interagency collaboration, and the importance of improved management techniques on the part of community provider organizations.

Eleven categories of providers' recently developed services and supports are listed below. Six respondents did not identify one specific service or support. The five remaining respondents were one of the nation's first Centers for Independent Living, a comprehensive community mental health center involved in its state's aggressive deinstitutionalization effotts, a senior companion program matching elder citizens and people with disabilities, a dental program established in a rural area, and a statewide private residential association.

- **Case Management.** Two multi-county organizations and one respondent serving a single county emphasized the importance of life planning and of public and private inter-agency collaboration in the coordination of services and supports for individuals.
- **Family Support.** The four respondents included a small organization working with local hotels, restaurants, and theaters to provide "respitality" support to families; two larger multi-program respondents offered family supports and a state agency was managing cash subsidies for 3,500 families. Family support respondents stressed breaking down public and private turf issues. For example, the state PL 99-457 agency respondent described spending a one-time $10,000 to relocate a family nearer to a hospital and providing $18,000 worth of home support services annually in order to avoid spending $38,000 per year on hospitalization.
- **Early Intervention and Integrated Preschool.** Two respondents provided county-wide services, one representing a coalition of thirty provider organizations. A state agency was responsible for implementation of the mandates of PL 99-457, and an Hispanic agency developed a bi-lingual integrated preschool serving twenty-two "at risk" children and eight children with moderate or severe retardation. Early intervention respondents also stressed breaking down public and private agency turf issues. An early intervention network, for example, was able to consolidate its providers' 30 different intake forms into a single form for families to use. The integrated preschool respondent used a variety of funding sources to build a neighborhood center in the Hispanic community, and attracted education professional form the public schools by leasing preschool space for only one dollar per year.
- **Group Home.** The 15 group home respondents included those serving individuals with autism, mental illness, and dual psychiatric and mental retardation diagnoses. Respondents utilized a variety of strategies in program start-up and ongoing operation including combined private banking and state low-interest loan programs for capital financing, state waivers of institution-like standards, and individualized rate-setting. One group home organization planned for turnover through the employment of students from the local university. Another expressed concern that four-person group homes would have adverse effects on the surrounding communities, "not only with four unrelated adults living together, but also their staff."
- **Affordable Housing.** Four responding organizations utilized low interest tax-exempt bonds, state housing department loans, U.S. Department of Housing and Urban Development (HUD loans and rent subsidies, and other strategies to help individuals with disabilities benefit from lower monthly housing expenses.
- **Supported/Individualized Living.** Sixteen respondents developed options such as foster homes with natural supports, supported apartments, and supported living in family-scale houses. A supported/individualized living organization benefited from the experiences of a real estate attorney, a housing development expert, and a property management expert on its board.
- **Personal Care Assistant (PCA).** Organizations in Colorado, New York, and Wisconsin utilized Title XIX funding through the HCBS Waiver and a newly established "vendor unit" which allowed reimbursement via the state's Medicaid Management Information System (MMIS). A PCA respondent reported on the low overhead associated with having counselors or assistance live in an apartment building with people with disabilities; there was no "critical mass" of staff.
- **Consumer-Owned Housing.** Six respondents combined sources including state MR/DD agency funding, federal SSI monies, and HUD Section 8 rent subsidies to create

opportunities for apartment leases or home ownership on the part of individuals with disabilities or their families. One house leased by parents for their son was possible because of a joint process involving the Association for Retarded Citizens, another nonprofit organization, and state agencies. The respondent noted that "many parents and advocates look for 'models' and not outcomes; models tend to get in the way of an individual's options in the community."

- **Employment.** Seven respondents focusing on employment included an industry-based training program, a computer training program, contract work with the U.S. Department of Defense, private sector employment underwritten by foundation grants, and state vocational rehabilitation (VR) agency funding for mobile work crews. Six for-profit business ventures included a lumber mill, a kiln-dried lumber operation, and a bicycle shop. Three respondents focusing on services for traumatic head injury included a foundation begun with financial support from the friends of a young woman and her family. A multi-program agency was able to demonstrate to insurance companies that rehabilitation would save them money. The volunteer interview network of employers (VINE) was a strategy to introduce people with disabilities to the business community. One respondent was working to become the local resource for employers on understanding the Americans with Disabilities Act (ADA). Another saw the ADA's potential impact in helping businesses recognize that people with disabilities can be part of the solution to labor shortages. An organization discussing its for-profit business venture cautioned that non-profit providers should "not step on small businesses. Taxpayers don't want to pay for unfair competition." To address inadequate community funding, for-profit business ventures were looking beyond traditional government programs.

- **Conversion from Center-Based Services.** Seven respondents were re-directing resources from sheltered workshops, day training or day habilitation programs into support for integrated employment. One respondent was closing a five-person group home, and another was using the equity from a campus with 46 closed ICF/MR beds as collateral in the purchase of community housing.

- **Self-advocacy.** One respondent was an individual employed with state DD Council support; the other was a community provider organization which focused on it's self-advocacy initiative developed with funding from the state's UAP and from state agency and private foundation resources. Regarding a state MR/DD director's efforts, this respondent acknowledged that "fortunately, we did not have to sell the concepts of grassroots advocacy and educating people in systems to a stifled bureaucrat."

Community Providers: Recommendations

Recommendations by community providers were summarized and categorized according to the primary focus: a) the start-up of services and supports; b) the ongoing operation of these services and supports; and c) more general recommendations addressing the missions and values of community organizations.

- **The start-up of services and supports.** State DD Councils, the United Way, private foundations, and other private resources were instrumental in the initiation of services and supports that were not in the mold of established funding. Community respondents commended state MR/DD program development grants and "change-over" grants from the federal Office of Special Education and Rehabilitative Services (OSERS) for integrated employment. The Administration on Developmental Disabilities (ADD) provided family support start-up grants, and the National Institute on Disability and Rehabilitation Research (NIDRR) awarded grants for small business development. Without public or private funding dedicated to start-up, community organizations were forced to conduct general fundraising or to re-allocate funds for start-up from within their total budgets.

  Additional recommendations centered around capital funding strategies and methods to obtain community acceptance. Specific *capital funding* strategies included investment tax credits, no-interest or low-interest loan funds, and formation of a pool of agencies to allow access to the bond market. The capital funding and rent subsidies afforded by HUD received major complaints ("HUD would rather build a new building, and serve only people with mental retardation"), but also commendations. Specialized housing agencies viewed HUD positively and noted that the McKinney Homeless Act amendments offered a more "user friendly" housing development application process. A HUD and U.S. Department of Health and Human Services memorandum of understanding on the problems of persons who are homeless was cited as exemplary.

  Organizations addressing *community acceptance* described maintaining a low profile prior to opening a community residence as recommended by Seltzer (1984) and Sigelman (1976), and underscored the right of people with disabilities to live in regular community housing. However, community living options must be compatible with neighborhood housing patterns. Improved relationships with communities were seen in terms of education, and the provider becoming involved in the community's ongoing activities.

- **The ongoing operation of services and supports.** The first set of recommendations addressed organizations' *management expertise* and their use of *creative personnel practices.* There were benefits to having experts on

organizations' boards of directors, and keeping the experts in close touch with the objectives and ongoing needs of the organization. Community organizations' experiences with maximizing limited personnel resources were behind their recommendations about improved selection, orientation, training, and creative scheduling of staff. Community respondents emphasized the need for a clear mission and goals, the need to build strong internal systems, and the importance of developing leadership at all levels of the organization. "The line staff are closest to the customers and are the ambassadors to the business community."

In the second set of recommendations about ongoing operation providers addressed *over-regulation and the need for improved interagency collaboration*. Respondents saw regulatory redundancies and the burden of paperwork as symptoms of poor coordination and collaboration between providers and government agencies. Specific problems included cumbersome licensing, certification and oversight regulations; and the duplicated effort, contradictions, and excess paperwork resulting from numerous fiscal and program audits and other reviews. Several respondents saw the need for more effective quality assurance systems.

Third, there was a series of issues and recommendations in the areas of *federal Medicaid reform, funding flexibility, and better government incentives*. There was a problem utilizing the Medicaid Waiver to "do what it was intended to do," and concern that the Waiver, unless revamped, could not effectively meet the needs of people in the community. The ICF/MR "active treatment" requirements prohibited integrated community living and employment. Four respondents specifically recommended Medicaid reform as outlined in S. 384, the Chafee Bill; seven others had more general recommendations about reform which would allow more flexible community financing. Several organizations discussed the need for a stronger message of incentive from the federal government.

Fourth, there was concern about the related issues of *wage parity and the need for adequate funding*. Community respondents addressed the imbalance between funding for institutions and for the vastly larger system of community services, and the critical problem of community staff turnover. "There must be parity between community and institutional salaries. In our state, the community staff turnover rate is 45%."

Finally, *government leadership and technical assistance* affected both start-up and the ongoing operation of services and supports. Community respondents frequently commended state agency management and funding flexibility. State government leadership was implicit in the more complicated housing finance programs, in which state MR/DD agencies' policies and procedures had to be coordinated with those of other public and private organizations.

- **The missions and values of community organizations.** A dominant theme in providers' recommendations was emphasis on independence and productivity for persons with disabilities through *employment and regular work*. Respondents recommended improved collaboration with, and more integrated employment funding from, state vocational rehabilitation agencies. Businesses, through Employee Assistance Programs (EAPs), were becoming more like human service agencies and there were recommendations about blending human service and business best practices.

The other major theme was recommendations on shifting the focus from the service system to the *needs of the individual*. Family support would benefit from the use of volunteers, improved funding, and the creative redirection of funding. Several respondents called for tax incentives to families and to individuals with disabilities. "It is important to let families know that family support is a service that they have long deserved."

Conclusion

Many of the state agency and community provider respondents emphasized how best to create systems of *individual support* for community living and employment, and for families. In response to a survey question about "models" in community services, state agencies discussed abandoning past program models, and striving for individualized approaches in the financing of housing or employment. As expressed by one state director, "the best are those support systems that are the most invisible."

The surveys suggested important *principles* for developing and financing community services and supports:

- Besides acquiring funding, the initiation and maintenance of community services requires improved collaboration and coordination between governmental agencies and private providers, and working within the larger system of neighborhoods, private businesses, and county and local services such as the public schools. Community service financing should be understood in terms of *community development* in which local needs and resources are carefully assessed. Business and other local community leaders should participate in the conceptualization and development of opportunities for employment and community living.

- Financing community services and supports can be described through innovative examples. Personal care assistant services in Colorado, New York, and Wisconsin represented individualized adaptations to Medicaid. Case management organizations worked across agency boundaries in order to more effectively direct resources and energy toward the individual and the family. Early intervention and case management respondents outlined

both promise and current problems inherent in the 1986 "Part H" amendments (PL 99-457) to the Individuals with Disabilities Education Act. Part H was seen as a model for inter-agency collaboration, yet there needed to be more funding and more of the right incentives and for a true family focus.

- Community employment respondents provided a snapshot of a system in transition. The needs of businesses to maintain a stable work-force, and the spirit of the ADA offer an opportunity for human service organizations to become consultants to private businesses. Employment respondents were concerned about adopting more business-like techniques, working to become members of local industry or business associations, and not competing unfairly with a community's businesses. Respondents converting from center-based programs noted the importance of public and private "bridge" financing during the transition. However, to benefit from such transitional funding, providers and their boards of directors must commit to planned organizational change and must carefully assess the needs of local businesses and of the surrounding community.

Community organizations consistently faced bureaucratic inefficiencies, the institutional bias inherent in major government funding programs, and other government policies frustrating individuals' efforts to live and work in the community. Nevertheless, community survey respondents frequently commended federal and state government leadership, policy direction, technical assistance, and financing designed to complement the strengths and abilities of individuals and their families. The two groups of respondents illustrated how they could be effective partners in developing individualized funding approaches, family supports, consumer-ownership of housing, and self-advocacy initiatives. Yet in many examples presented during the course of the two surveys, people with disabilities and their families clearly were partners as well. A community organization closing its ICFs/MR in favor of individualized living alternatives explained what was perhaps the most important principle for community financing. "We receive dollars for individuals. It is their money. Consumers must drive the system."

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