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Policy
Research Brief

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Costs[*] and Outcomes of Community Services for Persons with Intellectual and Developmental Disabilities

This Policy Research Brief reviews available research on the costs and outcomes of community service provision for people with intellectual disabilities (or "mental retardation") and developmental disabilities, with a particular emphasis on residential services. It focuses on a number of key issues related not only to public expenditures, but also to funding systems, related policies and regulations, and their impact on service systems, on specific service types, and on service users. It was prepared by Roger J. Stancliffe and Charlie Lakin of the Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota, Minneapolis. Charlie Lakin may be reached at 612/624-5005 or lakin001@umn.edu, and Roger Stancliffe at rogers@localnet.com.au.

■ Introduction

In recent decades, formal paid support services for people with intellectual disabilities (or "mental retardation") and developmental disabilities (ID/DD) have shifted dramatically from institutional to community settings. Between 1967 and 2002, there was an 80.5% reduction in people with ID/DD living in state developmental disability (DD) and psychiatric institutions, from 228,500 to 44,610 (Prouty, Smith, & Lakin, 2003). Many factors have contributed to this rapid change, including costs that are consistently 5% to 27% higher in institutions for comparable intensities of service (Stancliffe et al., in press) to achieve consistently poorer outcomes (Kim, Larson, & Lakin, 2001). Equally important have been social and legal commitments to the "most integrated setting feasible" as conveyed in the Americans with Disabilities Act and defined in *Olmstead et al v. L.C. et al* (527 U.S. 581) and "with the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives and to fully participate in and contribute to their communities…" as conveyed in the Developmental Disabilities Assistance and Bill of Rights Act (42 USC 15001(101[a])). One essential outcome of deinstitutionalization was the growth of a comprehensive range of decentralized, flexible community services. It is the financing, cost, and outcomes of these community services that is the focus of this *Policy Research Brief*.

■ Method

This review examined research related to the financing, costs, and outcomes of community services for people with intellectual disabilities, especially residential services. The authors examined over 80 U.S. studies published from 1980 onwards, as well as a small number of policy-relevant studies from the United Kingdom (U.K.) and Australia.

A summary of research on policy issues affecting persons with developmental disabilities. Published by the Research and Training Center on Community Living, Institute on Community Integration (UCEDD), College of Education and Human Development, University of Minnesota.

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[*] The term "costs" is used throughout this review in many instances where the term "expenditure" might be more appropriate. "Cost" is often defined by economists to include contributions to supporting an individual to which a monetary value can be affixed (e.g., the actual fare plus the public services of the public bus ride an individual takes to work, or the income cost for the time a parent takes off work to accompany an adult child to the dentist). "Expenditures," on the other hand, are understood to mean money paid out. For the most part, this review is about what economists would call "expenditures," but in seeking to speak to non-technical readers the authors have also used the common term "costs" throughout.

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Research was selected primarily for its relevance to key policy issues such as a) the costs and outcomes of different types of residential services, b) the relation between funding level and service recipients' support needs, c) individual budgets, d) family support, and e) economies of scale. More detailed information on these and related issues may be found in Stancliffe and Lakin (in press*a*).

■ Findings

Challenges in Financing Long-Term Services and Supports (LTSS)

In the United States, federal, state, and local governments spent almost $35 billion in fiscal year (FY) 2002 on non-educational services for persons with ID/DD (Braddock, Rizzolo, Hemp, & Parish, in press; Rizzolo, Hemp, Braddock, & Pomeranz-Essley, 2004). Almost 80% of this amount was used to fund community services, with the remainder financing institutional services. In FY 2002, federal and state Medicaid ICF/MR and Home and Community Based Services (HCBS) programs exceeded $24 billion in total long-term care expenditures (Prouty et al., 2003). The recent budget crises faced by the majority of states in the U.S. have shown how important it is to have information on costs and outcomes and how rarely such information is available when needed. It is now better understood that there are undesirable consequences of not reforming ineffective, inappropriate or excessively costly services. These include limited (or nonexistent) access to needed services by those who are unserved, underserved or poorly served, and wholesale across-the-board funding cuts affecting efficient and effective services equally with inefficient and ineffective services. A focus on cost should not imply that lower cost is self-evidently better, or that cost outweighs other considerations. For example, Emerson, Robertson, Hatton, Knapp and Walsh (in press) found that institutional services in the UK, unlike the U.S., cost less than community services, but they concluded that the additional expenditure on community services was warranted in the light of the consistently better outcomes associated with community services.

Several other financing challenges are influencing expenditures on long-term services and supports (LTSS), such as:

- **Utilization rate of ID/DD services is rising.** The proportion of the U.S. population receiving services has been increasing steadily. Substantially increased life expectancy among people with ID/DD (Janicki, Dalton, Henderson, & Davidson, 1999) means that people who receive services will receive them for more years than ever before. The result is a demand for services that is increasing more rapidly than would be expected based on general population growth alone. Nationally, between 1991 and 2002, the number of persons receiving residential services grew by 105,446 (36.7%). During this period, the service utilization rate increased 19.3% from 114 per 100,000 of total population in 1991 to 136.2 per 100,000 in 2002 (Prouty et al., 2003). Despite growing financial commitments to services and increased utilization of those services, in 2002 there were almost 60,000 people waiting for residential services.
- **Waiting lists.** People on waiting lists reflect an ongoing national crisis in equality and access to services (Hemp, Braddock, Parish, & Smith, 2001; Lakin, 1998). In June 2003, states reported an estimated 73,000 persons with ID/DD waiting for community residential supports (Prouty, Smith, & Lakin, 2004). By 2004, more than 30 class action lawsuits that were related to issues of access to community supports had been filed (Smith, 2004). *Boulet et al. v. Cellucci et al.* was one of the first of these lawsuits to be resolved. Its settlement agreement committed Massachusetts to spend $355.8 million between 2002-06 to expand community services (Smith, 2001).
- **Federal cost sharing.** Rizzolo et al. (2004) identified state expenditures on ID/DD services that are currently unmatched by programs offering federal cost sharing as one important but underutilized source of funding for states to draw on to meet the needs of people on waiting lists. Hemp et al. (2001) noted that $4.9 billion in unmatched state expenditure was applied to state ID/DD systems in 1998. Using unmatched state funds to match additional Medicaid HCBS funding represents one important avenue by which many states could expand their community ID/DD services.

Challenges to financing LTSS arise from current constraints on state revenues and expenditures, and from growing demand for services as indicated by rising utilization rates, waiting lists, and associated lawsuits. Ensuring that state expenditures are matched through federal cost sharing provides one means of financing an expansion of services. Careful examination of the costs and outcomes of existing services, and of current funding arrangements, is essential for effective use of public funding and to assure that LTSS recipients enjoy the greatest positive benefit.

Costs and Outcomes of Different Service Types

In a certain sense, Medicaid ICF/MR and HCBS programs are ways to finance services. In another sense, however, they represent service models of substantial distinction. ICFs/MR are highly regulated congregate settings in which no fewer than four and as many as several hundred people live according to rules established by the federal government. HCBS on the other hand, allows states great flexibility in the settings, rules, and types of services and supports

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financed. Medicaid expenditures are disproportionately higher for persons in ICFs/MR than for HCBS recipients. The 2002 average annual expenditure for ICF/MR residents was $85,746 as compared to $37,816 for each HCBS recipient (Prouty et al., 2003). Lakin, Hewitt, Larson, and Stancliffe (in press) and Hewitt, Larson, and Lakin (2000) reported that, in Minnesota, combined packages of health, social, and vocational supports for HCBS service recipients were about 78% of the service cost for ICF/MR residents. Conroy (1998) found that HCBS waiver service costs in California were 74% of the ICF/MR costs for groups with similar characteristics. Some of these comparisons were complicated by differences in characteristics of service recipients and/or the array of services provided. Even so, ICF/MR services are consistently reported, on average, to cost more.

Increased costs can be justified if significantly better outcomes are associated with additional expenditures in ICFs/MR. On the contrary, however, specific comparisons between community ICFs/MR (with 15 or fewer residents) and HCBS-funded residences have shown better self-determination, integration, quality of life, challenging behavior, and adaptive behavior outcomes in HCBS settings (Conroy, 1998; Stancliffe, Abery, & Smith, 2000; Stancliffe, Hayden, Larson, & Lakin, 2002).

Overall, the available cost and outcome studies are consistent in their findings that ICFs/MR are less cost-effective than HCBS-financed residential settings. Consistent with cost-effective use of public resources, the numbers of residents in community ICFs/MR were static (a 1% national decline) between 2001 and 2002, whereas persons living in non-family residential arrangements with HCBS financing grew rapidly (a 15% national increase) between 2001 and 2002 (Prouty et al., 2003).

Comparisons between group homes and semi-independent living have shown more favorable outcomes in semi-independent settings (Burchard, Hasazi, Gordon, & Yoe, 1991; Stancliffe, in press; Stancliffe, Abery, & Smith, 2000; Stancliffe & Keane, 2000). Not surprisingly, service costs were substantially lower for the semi-independent settings, which have part-time staffing as compared with the 24-hour paid staffing typical of group homes (Stancliffe & Keane, 2000). Available research on supported living in the U.S. (Howe, Horner, & Newton, 1998) and the UK (Emerson et al., 2001; Emerson et al., in press) has reported similar costs to traditional community living services. Supported living is, by definition, focused on assisting people to live out lifestyles of their own choice in homes of their own, so it is not surprising that these same studies have found better outcomes on resident choice and community participation than in traditional community congregate settings.

Overall, these findings suggest that more individualized services, such as semi-independent living and supported living, are more cost-effective than traditional community living services such as group homes.

Needs-Based Funding

Allocating funding in a manner that equitably meets the needs of service users is a basic value expected of effective service systems. Funding distribution is expected to be fair, consistent, and based on valid methods for determining who gets what levels of funding and support. To date, support needs have mostly been framed in terms of individual characteristics, so that persons with fewer self-care skills, more challenging behavior, or more serious health problems are considered to need, and are assumed to receive, more support. Such individuals are also assumed to require greater per-person expenditure when supports are provided by paid staff. Despite such assumptions, long-term service and support systems frequently have not been operated or financed on the basis of individual needs or preferences (see Stancliffe & Lakin, 1998). Financing of congregate facilities has often been based on rate schedules and facility operating costs, cost caps, local negotiation with service providers, and historical reimbursement rates, with little specific attention to the individual needs and characteristics of persons served.

Past research on different state service systems has reported varying findings concerning the association between expenditures and individual characteristics. Results ranged from a weak, inconsistent or non-existent association in Michigan, Nebraska, and New Hampshire (Ashbaugh & Nerney, 1990; Nerney, Conley, & Nisbet, 1990) as well as Minnesota (Stancliffe & Lakin, 1998), to a more moderate association in Pennsylvania (Jones, Conroy, Feinstein, & Lemanowicz, 1984), and a very strong association in South Dakota (Campbell & Heal, 1995). These mixed findings suggest that funding for services can be directly linked to individualized support needs, but that such practices are far from universal.

Current research on needs-based funding includes studies in Minnesota and Wyoming. In FY 1996, Minnesota implemented a four-level Waiver Allocation Structure (WAS) to assign funding for *new* entrants to the state's HCBS program in an attempt to make funding more needs based. Using assessed personal characteristics, the WAS assigns each individual to one of four levels of HCBS funding. This amount is provided by the state to the county, from which the county contracts with providers to deliver services to the person, but with no requirement that the amount of funding provided by the state to the county actually be budgeted for that particular person's services. That is, counties can spend more or less than they are allocated for an individual when purchasing that individual's support. Analysis of Minnesota's HCBS expenditures for FY 1998 revealed a relatively weak relation between the four WAS funding levels and actual expenditures for individual HCBS recipients (Lakin et al., in press). Minnesota's funding policy is needs based with regard to allocation to counties, but it has not resulted in a funding system that is needs based with regard to allocation to individuals. The WAS accounted for only 8.4% of variability in HCBS expenditures for individuals assessed under the WAS system. Importantly, Lakin et al. (in press) found that, when employed in addition to the WAS categories, recipients' personal characteristics accounted for an additional 15.3% of variability in individual HCBS expenditures. Adaptive behavior and challenging behavior were the strongest predictors. In other words, the same characteristics that were used to place people into one of the four WAS categories, when reemployed as *continuous* scales (rather than a few discrete levels), were much more predictive of individual HCBS expenditures in Minnesota than the assignment of people to one of four WAS categories.

Fortune et al. (in press) have described the problems experienced in the 1990s in Wyoming with a system involving five payment levels, somewhat similar to Minnesota's WAS levels. Subsequently, Wyoming moved to an individualized funding model based on each person's objectively assessed individual characteristics and his or her service utilization – the DOORS model – which directly provides a *unique* Individual Budget Amount (IBA) to pay for that individual's services. This system is not restricted to a particular number of discrete funding levels. Compared to the situation prior to the introduction of DOORS, when the five-level system was used, the proportion of variability in individual funding associated with individual characteristics rose from 37% to 47%, and the proportion of variability explained by the total DOORS model increased from 52% to 75%. That is, there was a substantial increase in the association between individual service users' assessed support needs and the amounts of funding provided to meet those needs, indicating that the DOORS model successfully made Wyoming's HCBS funding system more needs based.

The different outcomes in Wyoming and Minnesota suggest that funding is most effectively needs based when: a) needs-based funding systems are applied to *all* recipients, not just those entering the system for the first time; b) continuous *individualized* funding amounts are provided (rather than a small number of discrete funding levels); c) a specified amount allocated to pay for services is received *by the individual* rather than infusing it into an overall pool to be managed by an intermediate agency for multiple service recipients; and d) variations in allocated amounts reflect different circumstances (e.g., people living with family members versus in residential settings; children who are enrolled in public schools). Funding arrangements based on individual assessment of support needs offer a rational and equitable basis for allocation of public money. However, in a national survey of individual budgeting methodology, the majority of states reported that they did not consider their current funding allocation methods to be data based (Moseley, Gettings, & Cooper, in press).

States participating in the Medicaid HCBS Independence Plus option for self-directed services purchased using individual budgets are required to use consistent, data-based methods to determine individual budgets. The further development, evaluation, and refinement of procedures to establish rational, reliable, and appropriate levels of funding for individuals needing support will continue to be an important task for researchers and policymakers. Existing systems, such as Wyoming's DOORS model, and existing instruments such as the American Association on Mental Retardation's *Supports Intensity Scale* (Thompson et al., 2004), may contribute to more universal and more effective approaches to individual need-based budget allocations.

Individual Budgets

A desire for more flexible, individualized, consumer-directed services, together with the move toward needs-based funding, has been reflected in the rapid increase in availability of "individual budgets" for use in purchasing services and supports. An *individual budget* is "A mechanism that establishes an amount of funding available for an individual with disabilities to direct and manage the delivery of services she or he is authorized to receive. The amount of the individual budget is derived from a data-based methodology, and is open to inspection and input from the individual receiving support" (Moseley et al., in press). Ideally, an individual budget is needs based, flexible, and portable (i.e., not tied to a particular service type or to a specific service provider), and is intended to provide service users and their families with significant control over services and supports as well as sufficient resources to purchase what they need (Moseley, 2001). Within the traditional facility-based, regulated long-term service and support systems, funding is often based on the costs of providing services to a certain size group of people in a particular setting. Such funding is rarely flexible or portable because it is not associated with specific individuals or their needs. The amount of the total funding required to support a particular person in the setting is rarely known, even though different people may receive very different amounts of assistance.

Individual budgets have moved from being a policy experiment in the 1990s to becoming a mainstream funding option in the early 21st century. In 2003, Moseley et al. (in press) conducted a national survey and received responses from 43 states. They found that an individual budget option was in place in 75% of these states. In some states, such as Wyoming, the individual budgeting approach is applied to *all* (HCBS) consumers, but in other states individual budgets are provided as an option or are only open to some service users (see Moseley et al., in press). One consequence of the latter approach is that individual budgets may be more accessible to some service users than others. For example, service users with strong advocates may obtain greater access to individual budgets. Stancliffe and Lakin (in press*b*) investigated whether personal characteristics, family involvement or living arrangements distinguished between service users with and without an individual budget. These investigators found that, for a sample of service users in Michigan, individual budget availability was equitable in that it was not related to service users' personal characteristics or family involvement. However, individual budgets were more frequently used by persons living in smaller residential service settings and in their own home. Given the cross-sectional nature of this study, it was not possible to determine whether this finding was the result of individual budget availability (i.e., consumers used their individual budget to *move* to such living arrangements) or whether individual budgets were made available more often to those *already* living in smaller settings or their own home. Future development of individual budget policy and practice will need to take into account equity of access to individual budgets for all service users.

The rapid increase in availability of individual budgets has confronted state officials with the need to develop methodologies for equitable allocation of funding. Need-based funding methodologies, such as the Wyoming DOORS model discussed previously, appear to provide a viable and equitable approach. Moseley et al. (in press) reported that, among the states offering individual budgets, about one-third used standardized tools to assess support needs and data-based procedures for calculating the amount of funding to be allocated to the individual. Once this amount is determined, individual planning approaches are employed to decide how these funds will be used to meet individual needs. In about two-thirds of states with an individual budgeting option, a more developmental approach is taken. Individual budget amounts are established within a planning process that includes identifying individual service and support needs and determining a budget needed to buy these service and supports (Moseley et al., in press). States may use individual budgets as a means to manage overall disability expenditures by establishing expenditure limits for individual recipients, sometimes at a notable "discount" on the estimated or previously experienced amounts that traditional services cost for the individual (e.g., Head & Conroy, in press; Moseley et al., in press). While Wyoming's system of Individual Budget Amounts (IBAs) is based substantially on each person's individual characteristics, other approaches have based the amount on the characteristics of service *providers* and/or costs of current services and supports. Campbell et al. (in press) argue that approaches focused on service providers result in undesirable outcomes, such as severely limiting portability of funding and constraining the ability to respond to an individual's specific needs. The individual and systemic consequences of different approaches to individual budgeting will assume growing importance as individual budgets become more widespread.

Evidence on Costs and Outcomes with Individual Budgets

Pilot projects on consumer-directed services (CDS) (often referred to as "self-determination") in various states were funded by the Robert Wood Johnson Foundation in the 1990s. A key feature of these projects was the provision of individual budgets with which to purchase services and supports, with the intent that control over the services and supports would rest with people receiving those services and their family and friends (Moseley, 1999). Conroy and Yuskauskas' (1996) study of the original Robert Wood Johnson Foundation funded self-determination project in New Hampshire found significant improvements in outcomes after 18 months of self-determination interventions. Participants had more control over many areas of their lives (e.g., spending own money, time use, choice of house), increased quality of life in numerous areas (e.g., health, relationships), more invited and unpaid people on planning teams, less challenging behavior, and more productive behavior. These positive outcomes were achieved at a significantly lower cost (a 12% to 15% lower inflation-adjusted expenditure) than before program participation. However, it was notable that, in New Hampshire, control over many service-related issues (such as choice of case manager, choice of people to live with, type of work or day program, choice of house or apartment, amount of time spent at work/day program) remained the least available choices to service users and their families and did not change significantly over time. This suggests that consumer control over services was not achieved to the extent expected in New Hampshire.

More recently, Head and Conroy (in press) found significant improvements in consumer choice and control, quality of life, satisfaction, and community participation following implementation of CDS in Michigan. The largest changes in choice and control were in major service-related areas such as hire and fire direct support staff, choice of agency support person, choice of people to live with, choice of house or apartment, and choice of case manager. In Michigan, a substantial transfer of control over services had taken place from staff and other professionals to individual consumers and their families after three years of CDS. In addition, Head and Conroy reported that, from 1998 to 2001, average public costs (adjusted for inflation) for study participants *decreased* by 16%, although not uniformly across all participants. Those with the highest initial costs in 1998 under traditional funding and service delivery arrangements tended to have the largest decreases in expenditures following introduction of an individual budget and consumer-directed services, but a number of individuals, who tended to have lower pre-CDS expenditures, had *increases* in expenditures during the three-year period.

These findings suggest that better outcomes can be achieved at slightly lower cost through provision of individual budgets and other elements of consumer-directed support. Still, there remains relatively little published research in this area and it will be important to continue to evaluate such initiatives to tease out those aspects of interventions that are causally related to changes in outcomes and costs. For example, at present there is little published information about how services and supports change following the availability of an individual budget and whether specific service changes are associated with changes in outcomes. Stancliffe and Lakin (in press*b*) found that small scale, individualized living arrangements were much more strongly related to the person's degree of choice and control than was their individual budget status (whether or not they had an individual budget). This suggests that the choices of services and supports made on the basis of control of one's budget may be particularly important. Such a finding does not diminish the importance of budgetary control, but reminds us that it is not opportunity that creates outcomes, it is what one does with opportunity. It will also be important to understand better the existing "market" for CDS – that is, which individuals and families are most interested in and able to benefit from such opportunities – so that potential use may be gauged and the preparation and support needed to make CDS more widely available can be designed and tested.

Family Support

Most people with ID/DD live in the family home and are supported by their immediate family. Fujiura (1998) estimated that in 1991, 61% of U.S. individuals with ID/DD lived with family members, with only 11% in the formal long-term ID/DD residential service system. For some time, there has been widespread agreement that children and youth with ID/DD should live with family (Roseneau, 1990; Taylor, Lakin, & Hill, 1989) and there is currently a major national commitment to "Support families as the most permanent unit of development, protection and assistance" (National Goals Conference, 2003. p. 4). The family home continues to be the place of residence for the majority of people with ID/DD, and immediate family members are the primary caregivers for these individuals. Despite this situation, in 2000, only 4% of expenditure of state ID/DD agencies was used for family support (Parish, Pomeranz-Essley, & Braddock, 2003). Although vastly fewer resources are available to families than to users of residential services, this disparity is diminishing, with an 85% real increase in family support expenditures between 1996 and 2000 associated with a rapid growth in both the number of families receiving support and the amount of support provided to each family (Parish et al.). In fact, in 2001 there were more recipients of family support (452,000) than of residential services (388,000) (Lakin, Prouty, Polister, & Coucouvanis, 2003).

Herman (1991, 1994) examined the impact of a family cash subsidy program in Michigan for families with a child with a developmental disability. Families reported satisfaction with the program and indicated that the subsidy helped to improve family life, ease financial worries, and reduce stress. Importantly, families used the subsidy for the types of services they said were needed.

Between 1977 and 1997, the number of children and youth 21 years and younger with ID/DD living in out-of-home residential settings for persons with ID/DD (excluding generic foster care) decreased from 91,189 to an estimated 25,841 (Lakin, Anderson, & Prouty, 1998). This is no doubt a result of family support in various forms including respite care, personal assistance, cash subsidies, and others. The much greater cost of out-of-home placements supports the argument that it is less expensive for taxpayers to invest in family support than to pay for costly out-of-home services. The challenge is, of course, the targeting of the benefits in type and cost to those who need them to maintain their children at home.

Formal family support services, such as respite care, personal assistance, and parent education have tended to be agency directed. Growing interest in consumer-directed services has also influenced a number of states to implement consumer-directed family support services. Caldwell and Heller (2003) examined a consumer-directed family support program in Illinois. They found that more control by families of respite and personal assistance services was linked to increased satisfaction with services, more community participation by the person with a developmental disability, less staff turnover, and more hours per week of employment for mothers. This last finding represents an important outcome in the context of the substantial economic costs and reduced employment opportunities experienced by families with a member with a disability (Anderson, Larson, Lakin, & Kwak, 2002; Lewis & Johnson, in press). Caldwell and Heller (2003) also reported that families tended to hire people they knew (friends, neighbors, other relatives living outside the immediate home) to provide respite and personal assistance. Hiring relatives was associated with increased community participation by the person with ID/DD. In short, consumer-directed family support was shown to have benefits for both families and people with ID/DD.

Economies of Scale

Service policy and planning have been influenced by the widespread assumption that economies of scale operate in human services, and that the congregation of greater numbers of service recipients in a setting will tend to yield lower per-person costs. Larger scale public institutions and community ICFs/MR has been defended as responsible fiscal policy because of presumed economies of scale (Erb, 1995). Similarly, small individualized living arrangements have, until recently, tended to be limited largely to individuals requiring relatively low levels of support, partly because high levels of support were believed to be too costly to provide in small service settings.

Intellectual disability services are staff intensive. As a result, human services do not behave like manufacturing industries with regard to “economies of scale.” Actual evidence for economies of scale in ID/DD services has been equivocal and has frequently contradicted the expectation that smaller-scale services will be more costly. The recurring U.S. finding that institutional services have higher per-person costs than much smaller scale community services directly contradicts the notion of economies of scale (Campbell & Heal, 1995; Stancliffe, Lakin, Shea, Prouty, & Coucouvanis, in press). Rhoades and Altman (2001) found that costs *increase* as residence size increases. In Minnesota, Stancliffe and Lakin (1998) found medium-sized community residential settings (with 5-6 people) to be more costly than either smaller or larger community settings in the 1-15 person size range. Howe, Horner, and Newton (1998) found no difference in the costs of supported living and traditional community living in Oregon, even though the number of residents per setting averaged 1.6 and 6.9 respectively.

Nerney et al. (1990) reported some U.S. evidence of diseconomies of very small scale, but their findings appear to be model dependent and only evident among very small group homes with 24-hour paid staffing. Felce and Emerson (in press) concluded that, in UK residential services, except for very small settings with continuous staff presence, no economies of scale were evident. They observed that increased per-resident costs for staffing arise only when the staff ratio can no longer be held constant as resident numbers fall. When resident numbers are such that only *one* staff member at a time is required on duty, a further reduction of staff (below one) is not possible when continuous staffing is needed, so if resident numbers drop still further, staffing cannot be reduced proportionally and staffing ratios and per-resident staff costs usually rise (Felce & Emerson, in press; Felce et al., 2003; Stancliffe, in press). Such diseconomies of very small scale apply only in settings requiring continuous paid staffing. For settings that do not involve full-time staff (such as semi-independent living), staffing ratios (and costs) can be held constant as resident numbers fall (see Emerson et al., in press; Stancliffe, in press). Similarly, in support arrangements that do not involve 24-hour payment even if 24-hour support is provided – as in adult foster/host-family support, companion models, and supported living with some unpaid natural support – economies of small scale likely do not affect staff costs.

The available evidence suggests that economies of scale play little or no role in the cost of many community residential services and only have a significant influence in very small settings with continuous paid staffing. These findings, taken together with the trend toward more individualized services and provision of individual budgets, indicate that substantially more individualized supports can be provided without necessarily increasing average per-person costs, but that this is unlikely to be accomplished exclusively through smaller and smaller residences with full-time staffing.

■ Conclusion

Growing demands for services and supports, in an economic climate that seeks to limit the growth of public expenditures, create increased pressure for accountability for both costs and outcomes in community supports. Increasingly, support systems will be explicitly challenged to increase cost-effectiveness (i.e., obtain better outcomes at lower or equal cost, or equal outcomes at lower cost). Although there is much left to learn in increasing cost-effectiveness, there is a promising foundation of research and experience to guide these efforts. The challenge will be to adopt these promising practices in systems that have, in the past, been slow to change.

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■ Additional Information

All stakeholders require up-to-date information on current ID/DD expenditures, enrollment patterns, trends, and Medicaid program variations. Greater detail on the topic of this *Policy Research Brief* may be found in *Costs and Outcomes of Community Services for People with Intellectual Disabilities,* by R.J. Stancliffe and K.C. Lakin, with a projected release date of September 2004, published by Paul H. Brookes Publishing. In addition, two other useful sources of expenditure data are the University of Minnesota and the University of Colorado:

- **University of Minnesota**. For several decades, the University of Minnesota's Research and Training Center on Community Living has gathered and reported national data that document and analyze status and trends in service use and expenditures for Medicaid HCBS and ICF/MR programs nationally and for individual states (e.g., Prouty et al., 2003). In addition, the center undertakes specific-purpose national surveys of important issues, such as waiting lists (Polister, 2002) and staff wages (Polister, Lakin, & Prouty, 2003). To access research findings, as well as other information from and about the center, visit its Web site at http://rtc.umn.edu or call 612/624-6328.
- **University of Colorado.** The University of Colorado's State of the States project collects data on the programmatic structure and financing of ID/DD services nationally and for each state (Braddock, 2002; Rizzolo et al., 2004). This project identifies emerging trends and issues, as well as undertaking more focused surveys such as Status and Trends in Family Support Services in the U.S. to provide comprehensive data on family support spending and numbers of families served in each state and the U.S. (Parish et al., 2003). For further information about the State of the States project, its data collection, and findings visit its Web site at http://www.cusys.edu/ColemanInstitute/stateofthestates or call 303/735-3096.

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■ Related RTC/Institute Resources

The following are resources from the Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota. Publications may be found online at the Web address noted for each item, or in print through the Institute's Publications Office. For information and costs on print copies call 612/624-4512 or e-mail publications@icimail.umn.edu.

- ***Impact: Feature Issue on Consumer-Controlled Budgets.*** (June 2004). This issue of the quarterly publication *Impact* includes articles on the impact of self-determination on supports and services; individual budgeting, control, and support – what systems need to tell people; pointers for families and individuals who want to manage their own services; finding, keeping and training staff when individuals and families control the budget; individual and family success stories as well as program profiles from around the country; and resources for additional information. Available online at http://ici.umn.edu/products/newsletters.html#various.
- ***Service Use By and Needs of Adults with Functional Limitations or ID/DD in the NHIS-D: Differences by Age, Gender and Disability*** (issue in *DD Data Brief* series). (December 2003). This publication summarizes findings from the National Health Interview Survey on Disability conducted by the U.S. Bureau of the Census, National Center on Health Statistics in 1994 and 1995. It examines employment services and status, personal supports used and needed, professional and mental health services, previous long-term care services, transportation services, preventative health care, and waiting for services. It focuses specifically on how service use and needs vary by age, gender, and disability group. Available online at http://rtc.umn.edu/nhis/pubs.html.
- ***Characteristics of and Service Use By Persons with MR/DD Living in Their Own Homes or With Family Members*** (issue in *MR/DD Data Brief* series). (April 2001). This publication uses the data from the National Health Interview Survey Disability Supplement to describe people with MR/DD living in the community in terms of basic demographic characteristics, functional and other limitations, residential services history, medical services received, social activities, transportation used, and waiting list status, and compares people with and without MR/DD in regard to health status and service, functional limitations, major activity status, and school status. Available online at http://rtc.umn.edu/nhis/pubs.html.
- ***Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2003.*** (July 2004). A report providing statistics on persons with developmental disabilities in state, non-state, and Medicaid-funded residential programs in the U.S. for the fiscal year ending June 30, 2003. Available online at http://rtc.umn.edu/risp/index.html.
- ***Policies and Resources Related to Waiting Lists of Persons with Mental Retardation and Related Developmental Disabilities.*** (2002). A report detailing the findings of a national survey of state directors of developmental disabilities services conducted in 1998. The survey covered four areas: type and content of statewide waiting lists, state laws and regulations addressing waiting lists, policies and initiatives to reduce or eliminate waiting lists, and assistance and access to services for persons on waiting lists. Available online at http://rtc.umn.edu/pub#reports.
- ***Qualitymall.org (http://qualitymall.org).*** This Web site has compiled resources and information available from organizations nationwide related to delivery of person-centered supports. The section titled Systems Change Shop includes 14 resources on cost effectiveness of services, including information about expenditures on various types of services for people with developmental disabilities and the outcomes enjoyed by service users. Implications for systems change are often explored, and products focus on specific initiatives, as well as information at a state and national level.

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This and other issues of *Policy Research Brief* are also published online at http://ici.umn.edu/products/newsletters.html#policy. Recent issues include:

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- **Health Status, Health Care Utilization Patterns, and Health Care Outcomes of Persons with Intellectual Disabilities: A Review of the Literature (2002)**
- **Family Support for Families of Persons with Developmental Disabilities in the U.S.: Status and Trends (2001)**

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