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Get ICI Updates Reprint permission form Fill out this form if you are interested in photocopying, reprinting, and distributing this publication or portions thereof. Acrobat Reader may be downloaded from the Adobe Web site. 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. Roger Stancliffe may be reached at rogers localnet. Between and , there was an 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. 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. More detailed information on these and related issues may be found in Stancliffe and Lakin in press a. The recent budget crises faced by the majority of states in the U. 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. Several other financing challenges are influencing expenditures on long-term services and supports LTSS , such as: The proportion of the U. The result is a demand for services that is increasing more rapidly than would be expected based on general population growth alone. Nationally, between and , the number of persons receiving residential services grew by , During this period, the service utilization rate increased Despite growing financial commitments to services and increased utilization of those services, in there were almost 60, people waiting for residential services. By , more than 30 class action lawsuits that were related to issues of access to community supports had been filed Smith, 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. In another sense, however, they represent service models of substantial distinction. HCBS on the other hand, allows states great flexibility in the settings, rules, and types of services and supports financed. Available research on supported living in the U. 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. 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. 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. The WAS accounted for only 8. Importantly, Lakin et al. 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. This system is not restricted to a particular number of discrete funding levels. The different outcomes in Wyoming and Minnesota suggest that funding is most effectively needs based when: Funding arrangements based on individual assessment of support needs offer a rational and equitable basis for allocation of public money. 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. 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. Ideally, an individual budget is needs based, flexible, and portable i. 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 s to becoming a mainstream funding option in the early 21st century. In , Moseley et al. 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. 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. 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. 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. 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. 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. 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 s. 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, Participants had more control over many areas of their lives e. 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. Those with the highest initial costs in 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. 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. Herman , 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. 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 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. Caldwell and Heller 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. Economies of Scale Service policy and

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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. 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. Rhoades and Altman found that costs increase as residence size increases.

Chapter 2 : results in SearchWorks catalog

Chapters present established and emerging approaches to promoting communication and language abilities, academic skills, positive social relationships, and vocational and independent living skills. Current practices in positive behavior support are discussed, as are strategies for supporting family adaptation and resilience.

One third reported being lonely sometimes and one sixth said they were often lonely, but loneliness was not more common for people living alone or in very small settings. More loneliness was reported by residents of larger community living settings of 7 to 15 people. More social contact and liking where one lives were associated with less loneliness. By , some 29,, Amer- Loneliness is an important problem in itself icans lived alone, constituting Among people with in- consisted of people living by themselves Fields, tellectual disabilities and in the wider community, Likewise, Sheppard- erage was 5. Moreover, Lakin et al. Consequently, in addition to ments have drop-in support from staff for only a few residence size, we also examined a number of per- hours daily or even less often Perry et al. Under such circum- social climate factors that may be associated with stances, it seems possible that greater loneliness may loneliness. Apart from one previous small-scale cy, or duration of activities with friends, thereby study Stancliffe, a , we know of no previous reaffirming the subjective nature of loneliness. On the other hand, Duvdevany and Arar with intellectual disabilities. Denney, , showed that, in the general com- McVilly et al. Duvdevany and Arar and loneliness is essentially subjective, it is most appro- McVilly et al. Perry et from individuals themselves rather than from prox- al. For example, Chadsey-Rusch et al. A social relationships and is related to loneliness number of studies have shown that many but not Chadsey-Rusch et al. For example, McVilly all children and adults with intellectual disabilities et al. Personal characteristics have usually not been The subjective nature of loneliness means that associated with loneliness. For example, Stancliffe and their sample as a whole. Whaite found that some people experienced quite found no difference in self-reported loneli- serious loneliness even though they lived in group ness between adults with mild versus moderate in- homes with hour staffing. Therefore, it is also tellectual disabilities. Even so, some personal char- important to begin to identify factors associated acteristics may relate to factors affecting loneliness. In the pres- alone, we selected individuals who did not live ent study, our intent was to further explore and ex- with family or other people who did not have de- tend these preliminary findings using a much larger velopmental disabilities and without live-in paid sample of individuals from community living set- caregivers. The item on loneliness was answered by self- specific research questions addressed were: Substantial num- is the relationship between community residence bers of such individuals were unable to respond to size and self-reported loneliness? The National gave codeable responses to at least half the items, Core Indicators is an ongoing collaboration among including the loneliness item. State selection criteria for the ing in nonfamily community settings with 1 to 15 present study were a providing regional varia- residents who provided reliable self-report data on tion, b representing urban and rural states, c loneliness. Because we selected participants who including states with variations in ethnicity, d were judged to have given valid and consistent self- varying the mix of institutional and community report responses, we expected that the sample services, and e availability of data on residence would consist predominantly of people with mild or size for each participant. Selected states were In- moderate intellectual disabilities. State samples were sonal characteristics are summarized in Table 1. Data were collected using the National Core Residence size and living alone. We chose to ex- Indicators Consumer Survey. The person exhibits one of bers and Difference by Residence Size three types of behavior at least once per day: In this paper we focused on several Severe 9. The item about loneliness served as Challenging behavior our dependent variable. Psychiatric diagnosis Contact with friends and family. All tests are Like home. Core Indicators Consumer Survey protocol is sup- ported by a training program for interviewers, which includes training manuals, presentation slides, and Section II. In this study we used data from the training videos, scripts for scheduling interviews, Background section and Section I. These data are obtained from

Reliability. Level of intellectual disability. Individuals with developmental disabilities but no labeled intellectual disabilities were grouped together with those labeled as having mild intellectual disabilities. Presence of challenging behavior often lonely. To identify more specifically where the highest percentage of residents are often lonely, we conducted a regression analysis with level of intellectual disability, difference between very small 1 to 2 residents and challenging behavior, and residence size as a continuous variable as the independent variables, and overall difference in loneliness by residence size as the dependent variable. Some previous research has reported a relation between gender and loneliness, but in our study, there was no significant difference between and loneliness. Level of intellectual disability, age, and gender were not significant predictors of loneliness, whereas residence size, such as personal characteristics, differences in personal characteristics by residence size approached significance. However, the amount of intellectual disability differed significantly, with a higher and gender were controlled statistically. We examined Spearman correlations among the variables to evaluate these variables in a multivariate correlation matrix. Level of intellectual disabilities, challenging behavior, gender, amount of paid support with those from settings with 3 to 6 residents. Importantly, loneliness among people living alone did not differ significantly from loneliness in two-person households, showing that loneliness in two-person households was associated with larger residence size. Most personal characteristics had a nonsignificant multivariate association with loneliness in expected choice, domestic participation, community participation, and loneliness. More contact with family and friends where one lives were significantly associated with less loneliness. Being afraid at home from larger settings. Experiencing such fear and social climate and social contact were much more important in accounting for variability in loneliness to overcome it may be experienced as loneliness. Evaluation of the effectiveness of these approaches to reducing Core Indicators program. Loneliness was an issue for loneliness awaits intervention studies or longitudinal research. These findings confirm previous research that loneliness is an important problem. For example, staff support for loneliness, with greater loneliness needs to be evaluated empirically. This was true for both our univariate and multivariate analyses in which differences in personal characteristics by residence size were controlled statistically. The strengths of the current study include the use of self-report data and the size and representativeness of the sample, which consisted of random participants from 5 states. This study is that they were afraid of other residents. Hewitt, also has limitations. Our data were derived from Larson, and Lakin found that of those who interviews with service users, so most participants were afraid of someone in a community living setting, had mild to moderate intellectual disabilities. This the majority were afraid of roommates. Whaite, Stancliffe, and Keane reported serious problems data Chadsey-Rusch et al. Another limitation is caused by resident-on-resident assault. In these circumstances, the victim likely would feel alienated that it was unclear how severe a problem loneliness from fellow residents and may well

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experience lone- was for participants, because the National Core In- liness. This explanation of the relation between dicators does not assess how strongly participants loneliness and feeling afraid at home was not eval- felt lonely. However, item on loneliness, but it appears to have good va- Margalit, Tur-Kaspa, and Most reported that lidity in that it was related to contact with friends students with learning disabilities who had an iden- and family in expected ways. These factors may help to explain why there was less loneliness in very small settings 1 to 2 Conclusions people than in larger 7 to 15 community settings. Someone living alone will not encounter compati- Loneliness was certainly an important issue for bility problems with roommates, and there are no substantial numbers of sample members, but lone- fellow residents of whom to be fearful. Indeed, more loneliness was reported in in larger settings it is more difficult for providers to larger community living settings of 7 to 15 people. Serious incompatibility small community settings, such as greater choice may well result in feelings of social dissatisfaction, a component of loneliness Chadsey-Rusch et al. As noted previously, Stancliffe and that fears about greater loneliness when living alone Stancliffe and Keane reported lower social are ill-founded and should not be used as a reason dissatisfaction among individuals in smaller settings to prevent someone from living alone if they wish living semi-independently as compared to group to. Instead, results of this study suggest that con- home residents. How free from fear at home, and to have regular contact do people who live alone ensure sufficient satisfy- with friends and family. Also available online at http: Effects and im- umn. Choice and without developmental disabilities pp. American Journal on Men- Gonzalez, P. Assessing the loneliness of workers with mental Lunsky, Y. Depressive symptoms in intellec- retardation. Mental Retardation, 30, 85â€” Does gender play a role? Services provided by state and nonstate Lunsky, Y. Suicidality in a clinical and com- agencies in

Chapter 3 : Policy Research Brief: Medicaid Home and Community-Based Services: The First 20 Years

Foreword Steven M. Eidelman Acknowledgments Context and Issues in Research on Expenditures and Outcomes of Community Supports Roger J. Stancliffe and K. Charlie Lakin.

Chapter 4 : Loneliness and Living Arrangements | Robert Doljanac and Giuseppina Chiri - www.nxgvision.com

www.nxgvision.com identified trends in the receipt of preventive health care by adults with intellectual and developmental disabilities by type of residential www.nxgvision.com used data from the collection round of the National Core Indicators (NCI) program.

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Roger J Stancliffe of The University of Sydney, Sydney with expertise in Abnormal Psychology. K. Charlie Lakin. Susan Balandin. Deakin University; increase independent living for.

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1. Author(s): Stancliffe,Roger; Lakin,K Charlie Title(s): Costs and outcomes of community services for people with intellectual disabilities/ edited by Roger J. Stancliffe and K. Charlie Lakin.

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