

8

Evaluating Developmental Disabilities Services

JOHN W. JACOBSON[†]

This chapter focuses on contemporary program evaluation activities in adult developmental disabilities (DD) services. Program evaluation is best understood as a:

tool through which management seeks to understand the operational elements of a social program and the processes through which beneficial impacts are achieved. Critical issues confronting administrators involve (1) the degree to which an individual's needs and abilities mesh with the programmatic and social characteristics of his or her residential situation; (b) responsiveness to constituent demands and resource limitations related to changing care philosophies, new legislation, and regulation; and (c) the determination of relative program benefits and costs (Jacobson & Schwartz, 1991, pp. 35–36)

This definition is similar in its focus and overt parameters to services research (Jacobson & Holburn, in press, 2004, based on Newman, Howard, Windle, & Hohmann, 1994), which also similarly encompasses

epidemiology (including risk factors) and demographics of service and of services distribution . . . , the development of improved measures of disability . . . , the efficacy and effectiveness of treatment for specific disorders . . . , rehabilitative and habilitative features parameters of service delivery programs or classes of services, and assessment of outcomes of treatment with respect to alleviation of disorders, alleviations of symptoms

JOHN W. JACOBSON • Sage Colleges Center for Applied Behavior Analysis, Troy, New York 12180.

[†] Deceased.

of disorders, and social, family, and vocational functioning, as well as personal well-being and quality of life.

There are both critical and not-so-critical distinctions between program evaluation and services research. Some of the critical distinctions lie in considerations of breadth, application of findings, and generalizability of findings, whereas some of the less-critical distinctions involve focus of studies (where considerable overlap is apparent between these activities), and the initial goals of evaluative or research projects. While evaluative studies are generally intended to produce findings and services research often addresses administrative or systemic concerns, and hence are structured for application of findings at these differing areas of emphasis, the methods used in some evaluative studies may permit broad applicability of findings that transcend individual service organizations. Critically, depending on the breadth and clarity of definition of measured independent and dependent variables, and parameters such as single-site or multisite data collection and measurement, ensuing recommendations that are developed for management application may also demonstrate suitability for more pervasive generalization.

COMPLEMENTARY EVALUATION REVIEWS

The primary focus of this chapter is on considerations of individualization and implementation of specialized interventions in contemporary DD services. This focus was selected because substantive summaries of other aspects of past and present services have encompassed numerous other aspects of service operations (e.g., Jacobson & Holburn, in press, 2004; Jacobson & Schwartz, 1983, 1991), including foci on implementing evaluation activities (Jacobson & Regula, 1988) and training personnel or transferring technology (Jacobson & Holburn, 2004). Jacobson and Schwartz (1983), during a very active period of deinstitutionalization activity, focused their review on analysis of community residences and their impact on people served, and offered a general model for evaluation based on primary dimensions of developmental progress, quality of life, and home-like environments. Later, as community services had become well-developed, more diverse in form, and as barriers to effective coordination and cross-organizational collaboration had become more evident, Jacobson and Schwartz (1991) broadened their review of evaluative findings to include family living, supportive residential foster care, and medical and behavioral services, heightened emphasis on organizational and management issues such as staff turnover, and slightly increased attention to consumer and family. These reviews also identified instruments or measures suitable for application in evaluation of a range of settings.

Although it can be suggested that the primary concerns of program evaluation in developmental services have changed over the past 20 years (Schalock, 2000), in fact a substantive shift in the purposes of research is not so much apparent as a shift in the variables of interest. Whereas

20 years ago it was common to include measures used to assess the presence of noninstitutional and normalizing practices in evaluation efforts, today the types of measures used tend to be more narrowly focused on particular aspects of normalizing and noninstitutional practices, such as choice, self-determination, variation among individuals in lifestyle characteristics and routines, or receipt of clinical services. But individualization and responsiveness of services and supports (the latter referring to the activities of paraprofessionals in most instances, or to actions undertaken on behalf of, or to assist an individual) has remained a foundational aspect of evaluative activity throughout this period into the present.

EVALUATIVE METHODOLOGIES

Over the past decade or so it has become fashionable to distinguish between quantitative and qualitative approaches to program evaluation and services research. This distinction has emerged both as a consequence of reassessment of the parameters and purposes of program evaluation by evaluation specialists (Fishman, 1992) and as a manifestation of blending of ideology, constructs, and methodologies of special education research and evaluation into adult DD services research (Bogdan & Biklen, 1982). Whether the distinction between these methods is meaningful, and whether purely quantitative or qualitative methods are possible, can be challenged on rational grounds. Nonetheless, concerns for potential generalization of findings render purely qualitative methods and derivative findings impossible to assess for their utility, and it is reasonable to conclude that quantitative methods complemented by qualitative methods provide a reasonably sound basis for analysis, inference, and conclusions. Unfortunately, although purely qualitative studies can illuminate nuances of services and supports, and suggest valuable relationships among phenomena or events that merit further study and analysis, procedures recommended to reconcile and interpret the voluminous qualitative data collected in many studies and to enhance internal validity of conclusions, are fraught with potential shared researcher biases, and, unfortunately, the procedures used in many qualitative studies within special education and DD services research do not approach the rigor of kindred or model procedures for high-precision qualitative research, for example, as applied in anthropological research (Edgerton, 1993).

Many qualitative studies in the special education and DD sectors focus on descriptive analysis of implementation methods for practice that may themselves have an uncertain foundation with respect to efficacy and effectiveness. Further limitations of qualitative research in DD services reflect ideological rather than theoretical grounds for interpretation of findings, selection of narrow samples, use of extreme or index cases as exemplars, and conclusions of cause and effect relationships based on methods that do not permit these types of inferences to be made (e.g., Biklen, 1993). Because of these limitations, the primary focus of this chapter is on recent findings that have emerged from studies that included use of quantitative

methods (see Jacobson & Schwartz, 1991, p. 50 for features of evaluative activities that permit and enhance generalization of findings).

CONTEMPORARY EVALUATION RESEARCH

Impacts of Progressive Practices

Contemporary research on semi-independent or group living includes some reports that are quite comprehensive in scope. Extensive evaluations in recent years, resulting in multiple reports of different aspects of the evaluations, have been reported by several groups in the past decade, mainly in the United Kingdom (e.g., Emerson et al., 2000; Smith, Felce, Jones, & Lowe, 2002) and in the United States (e.g., Burchard, 1999; Stancliffe, Hayden, & Lakin, 1999a,b,c). An example of this type of research is a study by Stancliffe and Keane (2000), who compared 27 matched pairs of adults in Australia living in group homes or semi-independent settings. They note that

Available research comparing outcomes for individuals living in group homes or semi-independently (i.e., with drop-in staff support) suggests better outcomes for semi-independent living services in a number of domains: quality of life, choice, self-determination, autonomy, satisfaction, self-esteem, independence, lifestyle normalisation, physical and social integration, compatibility with living companions, participation in preferred activities, and personal well being.... On the other hand, loneliness, self-care, domestic management, personal safety, money management and health can be areas of concern [in] semi-independent [living].... Problems may arise in these areas because of insufficient support... or inappropriate housing. (p. 282)

In their study they assessed social networks and use of mainstream community services, community participation, participation in domestic tasks, stability of place of residence, living companion turnover, and natural supports. They examined outcomes entailing quality of life, safety, aloneness, social dissatisfaction, personal care, domestic management, health care, money management, social network, use of mainstream community services, community participation, domestic participation, stability of place of residence, living companion turnover, and natural support. Outcomes tended not to differ between semi-independent and group-home settings, although better outcomes were found in semi-independent settings reflecting "less social dissatisfaction, more frequent and independent use of community facilities, more participation in domestic tasks, and greater empowerment" (p. 281).

Stancliffe and Keane suggested that the findings indicated that people living in semi-independent settings were provided sufficient support to enable them to attain outcomes similar to those for their peers in group homes, and that, because of differences in staff availability in these two

types of settings, “the semi-independent living environment not only provided *opportunities* for independent participation, it *demand*ed independent participation,” (p. 300), and that this, at least in part, accounted for some of the observed differences. Limitations to interpretation and generalization of findings included the considerations that comparisons were not made to nondisabled peers with respect to outcomes (e.g., findings did not indicate that outcomes were “satisfactory”; “they could have been equally poor,” pp. 299–300) and that data on services used or service processes were not gathered to place the findings in context. These are common limitations of studies that assess outcomes of settings or services like those addressed in this study (e.g., Holburn, Jacobson, Schwartz, Flori, & Vietze, 2004; Holburn, Jacobson, Vietze, Schwartz, & Sersen, 2000). Moreover, studies of service utilization in various settings seldom place their findings in context through measures of individualization or autonomy in the manner embodied by the Stancliffe and Keane study (e.g., Jacobson, 1987; Stancliffe & Lakin, 1999), despite the desirability of enhancing interpretation in this manner.

In a separate study of 74 adults living independently or in group residences operated by seven organizations, Stancliffe, Avery, and Smith (2000) investigated factors that were associated with increased personal control (of lifestyle and activity) by participants. Greater personal control was found in semi-independent settings, compared to group residences, and among living situations ranging from one to five persons in size. In a path analysis, greater adaptive behavior skills were associated with greater self-determination skills, policies, and practices that were more supportive of autonomy, greater individualization, and greater availability of money for discretionary use. In turn, these latter factors were associated with greater personal control. Given these findings, and as noted by the authors, unambiguous interpretation of differences in personal control among types of settings and those differing in size is compromised to some degree by the presence of differences in participant skills among the types of settings. Studies such as this one suggest possible factors for intervention that may support greater self-determination. However, as Algozzine, Browder, Karvonen, Test, & Wood (2001) have noted, few studies of instruction in choice-making and self-determination have focused on outcomes in terms of quality of life (including personal control, autonomy, or self-determination, which may be largely interchangeable constructs) and convincing demonstrations that self-determination can be taught, learned, and makes a difference in the lives of people with disabilities are still needed.

Social Networks

Robertson et al. (2001) studied the social networks of 500 adults with intellectual disabilities (ID) living in a variety of residential settings. From their literature review they concluded that the social networks of people with ID are often restricted in number of friendships, and involve few reciprocal relationships with others who do not have ID, or are not relatives

or staff. Further, relationships do not necessarily develop spontaneously or over the course of time as the result of community living or of deinstitutionalization, and do not necessarily entail frequent contacts with family members. Findings from prior research also suggested that living near family and in smaller residences, and personal characteristics such as being younger, having a disability that is not highly visible, and being more responsive socially were factors associated with increased contact with family.

Robertson et al. (2001) found that about 50% of participants had three or fewer people in their social networks, disregarding staff, and only 4% had a nondisabled neighbor in their social network. As in previous research, participants were seldom found to be engaged in reciprocal relationships with nondisabled people, although reciprocal relationships with other people with ID were far more common. Relationships with other people with ID tended to be lasting, with 75% of such relationships enduring more than 5 years. People living in smaller residences and supported housing had larger and more diverse networks, as did younger individuals. Those with autism or lower adaptive skills or with more severe problem behaviors tended to have smaller networks. The authors concluded that many of these individuals were socially isolated, at least with respect to the structure of social networks.

Another study that compared community use by people with ID and a staff control group (Baker, 2000) found that those with disabilities had a smaller range of activities, engaged in fewer frequent activities, and were less likely to use community resources alone with friends. Although tangible and meaningful differences in community use were identified, the extent that community access patterns "alone" reflected concerns for safeguarding and well-being, rather than restrictions upon access, were not addressed and are not well-addressed in most social network analyses.

Whether conclusions that social networks are coarsely deficient among people with ID is a broadly accurate characterization is less than certain. Exclusions of staff as legitimate members of social networks, and of peers or others with disabilities as members of networks are largely ideological exclusions, as such adjustments as to social network estimates are typically made in the absence of measures of individual preference for social engagement with particular staff or peers, or satisfaction with present social networks. Although such measures may be difficult or impossible to apply for people with few communication skills, they could be readily applied with those individuals with the requisite skills. Among people without disabilities, assortive formation of friendships reflecting educational levels and personal interests are common, as are social networks dominated by relatives, housemates or cohabitants, and longstanding coworkers. The question of possible relationships between satisfaction and social networks was investigated as part of a study by Gregory, Robertson, Kessissglou, Emerson, and Hatton (2001). In interviews of 95 people with ID living in "village communities" or community situations, those living in village communities expressed greater satisfaction with friendships and relationships. Extent of day services was associated with satisfaction with weekly hours of

scheduled activity, including those involving friendships and relationships, as was implementation of active support (see, e.g., Mansell, Elliott, Beadle-Brown, Ashman, & Macdonald, 2002). Relationships noted here between friendships and relationships and life satisfactions suggest that network size, at least, and possibly other aspects of networks merit improvement as a means to increase general life satisfactions.

In a few instances, community presence and participation of people with DD and of peers without disabilities has been assessed, without remarkable differences in some dimensions of networks being noted between disabled and nondisabled individuals in the extent of participation (Pretty, Rapley, & Bramston, 2002; Rosen & Burchard, 1990), although subjectively the extent of participation by those with disabilities might be characterized as low. Such findings underscore the importance of community norms for interpretation of findings regarding the lifestyle qualities of community living for people with DD.

Individualized Planning of Services

One enduring aspect of DD services is utilization of a process of individualized planning, usually embodied in a plan of services and supports. Planning processes have not been studied in adult or child DD services (e.g., Jacobson, 1987), to the extent that they have in special education, but as these processes have changed over the years from multidisciplinary or interdisciplinary in form to those characterized as person-centered, and public agencies have adopted policies encouraging or requiring these latter processes, efforts to evaluate the impact of planning on service and support delivery have increased (e.g., Holburn & Jacobson, 2004; Stancliffe et al., 1999).

In their study, Stancliffe et al. (1999) followed a cohort of 157 people with mild to profound ID in Minnesota who moved from institutional living to community settings over the course of 3 years. Individual plan objectives developed for these individuals were assessed on dimensions of quality (e.g., specification of community focus, teaching methods, and related data collection) and objectives were assessed further as predictors of outcomes such as social inclusion, community participation, or self-determination, as well as adaptive behavior change. Goals in individual plans focused, from most frequently to least frequently, on: self-care, household chores, communication, leisure and recreation, and community participation. Presence of leisure and recreation goals was applied as a predictor of social activities in the last 30 days. Neither the "five [goal] quality domain scores nor number of objectives were significant predictors" (p. 110) of social activities. Furthermore, from their analyses, the authors concluded:

This study provided no evidence to support expectations that the presence or quality of IHP objectives contributes to the increase of desired behaviors, skills, or participation among persons with mental retardation nor was there evidence that the

presence of IHP objectives is important in maintaining such outcomes. . . . These findings . . . cast significant doubt on the contribution of IHP objectives to developmental and lifestyle gains by adults with mental retardation in residential service settings (Stancliffe et al., 1999, p. 110).

The authors noted some potential restrictions on generalization of their findings: (1) the outcome measures may not have been sufficiently sensitive to detect changes associated with objectives; (2) the abbreviated adaptive behavior scale they used may not have been sufficiently sensitive (although their findings converge with comparable direct measures in other research, citing Felce, de Kock, Mansell, & Jenkins, 1984); and (3) they did not measure whether objectives were achieved (e.g., objectives were implemented and completed, but did not contribute to the broad outcomes assessed). It seems plausible that an abbreviated adaptive behavior measure might well be too insensitive to capture adaptive behavior changes in adults over the course of even 3 years. Of greater concern in this study, and a common limitation in large-scale DD sector evaluations, is that neither implementation of objectives nor outcomes assessed through completion of scales or report forms were confirmed by direct observation. Because this is a common limitation of large-scale evaluations, and the presence of close correspondence between scales and actual events is seldom confirmed during scale development, in this instance, and other studies relying principally on scaled measures (e.g., Holburn et al., 2004), whether findings of such studies should be regarded as relatively conclusive or suggestive in nature, warranting study using direct observation and measures, can be unclear.

DUAL DIAGNOSIS OR CO-OCCURRING BEHAVIOR PROBLEMS: AN INCREASING FOCUS

Developing and maintaining responsive community services for people with ID and either severe chronic health problems (including frailty) or persistent mental illness or severe and disruptive behavior problems have come to be one of the most difficult undertakings in operation of fully community based and highly individualized services. Adams and Allen (2001) conducted a retrospective study of aggressive behavior in a group of children referred for specialist services, and found that about 60% engaged in aggressive acts. Physical interventions were used in 56% of cases but were generally improvised by caregivers. Nottestad and Linaker (1999) followed 109 people with ID from institutions to community living and found persistence of psychiatric problems and a significant increase in behavior problems (including disruptive and aggressive acts), as well as reduced access to psychological and psychiatric services.

Joyce, Ditchfield, and Harris (2001) identified 482 people with ID and behavior problems in London and found that 24% had experienced a placement breakdown (moved from family or among community settings), 24% had come to the attention of the police, and 29% had been excluded from

day services at least once. Tonge and Einfeld (2000) followed a sample of children with ID ages 4–19 years over 4 years and found that 40% had psychiatric disorders that persisted over this period, in all likelihood because less than 10% of those in need received specialist services (see also Kiernan & Alborz, 1996). Varying and inconsistently available expertise in dual diagnosis and behavioral treatment, structural features of services, and difficulties in cross-sector collaboration and cooperation in service delivery have been identified broadly as barriers to effective services for people living in the community with ID and either mental or behavioral conditions (e.g., Alexander, Piachaud, & Singh, 2001; Davidson et al., 1994; Linhorst, McCutchen, & Bennett, 2003; Lohrer, Greene, Browning, & Lesser, 2002; Ward, Trigler, & Pfeiffer, 2001).

Recent Relevant Evaluations

Three recent evaluations (Emerson & Forrest, 1996; Stancliffe, Hayden, & Lakin, 1999a, 1999b) and one literature review (Ager & O'May, 2001) are especially relevant to appraisal of services for people with ID and either dual diagnosis or severe problem behavior. As a further aspect of the community living follow-along study conducted by Stancliffe and Keane (2000), Stancliffe et al. (1999a, 1999b) reported on the impact of IHP objectives entailing behavioral intervention (1999a) and their relationship to maladaptive behavior scores, and sought to predict the extent of behavioral intervention (1999b). Stancliffe et al. (1999a), found that, in this sample of predominantly people with severe to profound ID, 99 of 157 participants retained same status of having or not having a challenging behavior objective across three annual reviews. Moreover, there was no significant change in problem behavior across three annual assessments, or in the frequency of crisis intervention. Stancliffe et al. concluded that “These findings suggest that most challenging behavior IHP objectives are ineffective in reducing challenging behavior” (p. 482). They also suggested that the extant behavioral objectives may have been directed at behavior management rather than behavior change, as such.

However, the authors did note some possible reasons to qualify their findings: (1) the sample consisted primarily of people with severe or profound ID and long histories of institutionalization; and (2) although some data were collected on implementation, analyses were based on presence or absence of behavioral objectives rather than quality and implementation, and (3) discontinuation of an objective could reflect completion or discontinuation of an ineffective intervention. The use of maladaptive behavior scales rather than direct measures of behavior occurrence or magnitude might also have masked effects in this study, because it has not been established previously that the measures they used are sensitive to psychiatric or behavioral intervention effects. Overall, although such findings raise important questions regarding the quality and effectiveness of behavioral interventions in community living situations, because direct observational measures and records of intervention outcomes were not used, further evaluations of behavioral intervention in community settings should use

these methods in order to more exhaustively identify the consistency and parameters of implementation of these services.

As already noted, Stancliffe et al. (1999b) sought to predict behavioral intervention within the same study cohort (but including both those who stayed in an institutional setting and those who moved to communities). Presence of individual objectives and magnitude of maladaptive behavior was used to predict one-to-one crisis intervention during the past 30 days and services by behavior management professionals during the past 6 months. Less than 25% of participants received services from psychiatrists, psychologists, or behavior analysts, although as noted above, a majority had behavioral objectives in their plans. The researchers found that 68% of participants with behavioral objectives received professional services, as compared with 16% of those with no behavioral objectives. Participants were more likely to receive psychiatric or behavioral services if they evidenced more externalized behavior (see also, Rudolph, Lakin, Oslund, & Larson, 1998), were stayers (i.e., in an institution), and had greater adaptive behavior skills (i.e., because those with greater skills evidenced more difficult behavior).

Taken together with the findings from Stancliffe et al. (1999a) these findings suggest that presence of behavioral objectives did not effectively predict utilization of mental health or behavioral specialists, or referral to such practitioners; again, these findings suggest the need for service processes in community settings that entail behavioral intervention to be studied more closely.

Current research findings within the field of behavior analysis indicate that implementation fidelity and duration of behavioral interventions is improved by organizational provisions focused on maintaining interventions, as well as by ongoing involvement of a behavioral consultant (see Jacobson & Holburn, 2004).

Implementation of faithful and durable behavioral interventions within community living situations or day services requires sufficient training of staff in behavioral intervention competencies, supervisory practices that systematically encourage implementation. When staff and clinician competencies are not sufficient to conduct appropriate assessments, design corresponding interventions, and effectively monitor and alter interventions based on individual effects, efficient utilization of consultants and community practitioners (Ager & O'May, 2001; Jacobson & Holburn, 2004, in press, 2004; Parsons, Cash, & Reid, 1989; Reid, 1992). As noted by Stancliffe et al. (1999a), "specialist community behavior support teams are of limited effectiveness if nonspecialist ID services are ineffective in day-to-day management of challenging behavior" (p. 482). Research on the impact of specialist teams, which exist in the United Kingdom and to some (unknown) extent in the United States, has been mixed, variable across teams, and not entirely encouraging (Emerson & Forrest, 1996; Lowe, Felce, & Blackman, 1996).

Emerson and Forrest (1996) conducted a survey of community support teams for people with ID and problem behaviors in England and Wales, which they estimated to employ about 450 staff, at a cost of £10 million to

serve about 2000 people yearly. There were 65 of these teams in operation, 46 of which returned survey forms. Teams generally reported operating with a general behavioral orientation and allocating the greatest amount of consultation time to working with direct care staff. Only 1% of team members were reported to be psychiatrists and 24% were reported to be psychologists or assistant psychologists. Half (50%) of the team members were nurses.

Data collected on caseloads suggested that 48% of the estimated people with severe problem behavior in the localities served by teams were carried within current caseload. Other estimates indicated that annually case closures occurred for 19% of estimated local need, and successful closure for 13%. A majority of the teams required placement jeopardy as a specific criterion for consultative engagement.

Teams reported spending more time working with direct care staff on interventions for specific individuals than any other activity, followed by advice and consultation to caregivers (family members and staff) and direct intervention with specific individuals. People with less severe ID were less likely to receive direct intervention by specialist team members.

Many of the cases that were reported to be "successfully closed" were found to be considered successful by respondents based on acceptance of recommendations for referral to another service or the completion of assessments, not as the result of interventions that were effective in reducing problem behavior. This finding suggested that teams might not be effectively monitoring interventions, or following-up sufficiently.

Emerson and Forrest concluded from their findings that team engagement was often insufficient to achieve substantive impact on the treatment concerns for which assistance had been sought and posed the question of whether specialist teams not affiliated with programs or services "effectively influence their management and operation when this is needed" (p. 403). Conclusions offered by Ager and O'May (2001) as "best practices" in community behavioral intervention in DD services, based on review of the recent research base are compatible with the conclusions reached by Emerson and Forrest (1996) and Stancliffe et al. (1999a, 1999b) regarding the need for the development of more sufficient behavioral competencies among personnel in DD service and support settings, rather than primary reliance upon consultative involvement as a means to compensate for inadequate staff and clinician expertise within community agencies.

The conclusions reached by Ager and O'May (2001, pp. 253–254) merit consideration here, due to their foundation in empirical studies of implementation, and are closely paraphrased below:

Empirical evidence supports the effectiveness of interventions, particularly those that address socially disruptive and internally maladaptive behavior, involve manipulation of response contingencies, and are based upon prior functional analysis.

"Only one in four studies reports follow-up data to 12 months post-intervention; the general durability of change subsequent to intervention is thus uncertain.

Where details are given, researchers external to the service setting are responsible for assessment, analysis and design in about half of reported interventions . . . the recruitment of such external expertise, or the development of appropriate competences within existing staff, is a major challenge for services seeking to institute "best practice" in intervention.

In terms of developing such competence, Training to develop such competence has little impact on staff performance in service settings without additional emphasis on organizational processes.

Formalized procedures of feedback, supervision and support do have an established impact on staff behavior.

Staff training targeting reappraisal of assumptions and expectations may play an important role in shaping staff behavior . . . intervention protocols may be implemented with greater fidelity if they are coherent with staff attitudes and beliefs although this direct relationship has not been demonstrated.

Formal review mechanisms, where intervention strategies and protocols are explicitly defended on the basis of evidence of empirical support, may usefully foster accountability.

SUMMARY

There is a rich and diverse research literature focusing on program evaluation in DD services and in this chapter it has been possible to indicate some exemplars and key concerns of contemporary studies. One of the most important concerns not addressed in this chapter include organizational factors that are associated with individualization and responsiveness of services and supports (e.g., Hatton et al., 1999; Hatton & Emerson, 1993; Holburn et al., 2000; Schwartz, Jacobson, & Holburn, 2000). As previously indicated, this literature is discussed in greater detail elsewhere (e.g., Jacobson & Holburn, in press, 2004).

Despite the wealth of applied research undertaken for evaluative and administrative purposes, there remain important research questions that have not been addressed with the needed precision of measurement and breadth of sampled settings needed to draw suitably compelling conclusions or to assure generalizability of findings. Medium to large-scale studies continue to rely, as in past decades, on rated indicators of key desirable features and outcomes of services, and to eschew more direct observation, even if limited to a subsample of programs with highly divergent ratings. Exemplars of substantive observational studies remain largely historical (e.g., Landesman-Dwyer, Sackett, & Kleinman, 1980; Romer & Berkson, 1980, 1981), with some very notable exceptions (e.g., Felce et al., 1999). Evaluation efforts that collect direct observational data tend to remain confined to approaches that focus on only one or several service settings. Finally, as evaluative efforts have continued to hone in on more

specific aspects of individualization of services or outcomes, such as self-determination, choice, autonomy, independence, lifestyle normalization, participation, and integration, because of the subtleties that differentiate many of these constructs, investigators need to further verify that the aspects of services they are measuring are (at least relatively) independent attributes of settings and services, and are not conflated by overlap of measures; as these distinctions become more subtle studies need to verify the suitability of planned analyses through such procedures as combined factor analyses of measures (e.g., Holburn et al., 2000).

Notwithstanding changes in the character of dominant rationales for services over time, some philosophical and others ideological, or even empirically founded, evaluators have continued to focus on factors that contribute to a varied lifestyle, individualization, and responsiveness of services, supports, and communities to people with developmental disabilities, although contemporary service systems remain largely unevaluated with respect to key concerns about the quality of services, or of impacts of often complex management and administrative procedures in unambiguous terms. These considerations point to the continued need to expand both the breadth and depth of medium to large-scale studies and to more effectively study key issues through independent replication of high-profile service issues that have been addressed by only one or two research groups.

REFERENCES

- Adams, D., & Allen, D. (2001). Assessing the need for reactive behaviour management strategies in children with intellectual disability and severe challenging behaviour. *Journal of Intellectual Disability Research, 45*, 335–343.
- Ager, A., & O'May, F. (2001). Issues in the definition and implementation of "best practice" for staff delivery of interventions for challenging behaviour. *Journal of Intellectual and Developmental Disability, 26*, 243–256.
- Alexander, R. T., Piachaud, J., & Singh, I. (2001). Two districts, two models: In-patient care in the psychiatry of learning disability. *The British Journal of Developmental Disabilities, 47*(93), 105–110.
- Algozzine, B., Browder, D., Karvonen, M., Test., D. W., & Wood, W. M. (2001). Effects of interventions to promote self-determination for individuals with disabilities. *Review of Educational Research, 71*, 219–277.
- Baker, P. A. (2000). Measurement of community participation and use of leisure by service users with intellectual disabilities: The Guernsey Community Participation and Leisure Assessment (GCPLA). *Journal of Applied Research in Intellectual Disabilities, 13*, 169–185.
- Biklen, D. (1993). *Communication unbound: How facilitated communication is challenging traditional views of autism and ability/disability*. New York: Teacher's College Press, Columbia University.
- Bogdan, R., & Biklen, S. K. (1982). *Qualitative research for education: An introduction to theory and methods*. Boston: Allyn and Bacon.
- Burchard, S. N. (1999). Normalization and residential services: The Vermont studies. In R. J. Flynn & R. A. Lemay (Eds.), *A quarter-century of normalization and social role valorization: Evolution and impact* (pp. 241–270). Ottawa, Canada: University of Ottawa.
- Davidson, P. W., Cain, N. N., Sloane-Reeves, J. E., Van Speybroech, A., Segel, J., Gutkin, J., Quijano, L. E., & Kramer, B. M. (1994). Characteristics of community-based individuals with mental retardation and aggressive behavioral disorders. *American Journal on Mental Retardation, 98*, 704–716.

- Edgerton, R. B. (1993). *The cloak of competence* (2nd ed.). Berkeley, CA: University of California Press.
- Emerson, E., & Forrest, J. (1996). Community support teams for people with learning disabilities and challenging behaviours: Results of a national survey. *Journal of Mental Health, 5*, 395–404.
- Emerson, E., Robertson, J., Gregory, N., Hatton, C., & Kessissoglou, S., Hallam, A. (2000). Quality and costs of community-based residential supports, village communities, and residential campuses in the United Kingdom. *American Journal on Mental Retardation, 105*, 81–102.
- Felce, D., de Kock, U., Mansell, J., & Jenkins, J. (1984). Providing systematic individual teaching for severely disturbed and profoundly mentally-handicapped adults in residential care. *Behaviour Research and Therapy, 22*, 299–309.
- Felce, D., Lowe, K., Perry, J., Jones, E., & Baxter, H., Baxter, H. (1999). The quality of residential and day services for adults with intellectual disabilities in eight local authorities in England: Objective data gained in support of a social services inspectorate inspection. *Journal of Applied Research in Intellectual Disabilities, 12*, 273–293.
- Fishman, D. B. (1992). Postmodernism comes to program evaluation: A critical review of Guba and Lincoln's fourth generation evaluation. *Evaluation and Program Planning, 15*, 263–270.
- Gregory, N., Robertson, J., Kessissoglou, S., Emerson, E., & Hatton, C. (2001). Factors associated with expressed satisfaction among people with intellectual disability receiving residential supports. *Journal of Intellectual Disability Research, 45*, 279–291.
- Hatton, C., & Emerson, E. (1993). Organizational predictors of staff stress, satisfaction, and intended turnover in a service for people with multiple disabilities. *Mental Retardation, 31*, 388–395.
- Hatton, C., Rivers, M., Mason, H., Mason, L., & Emerson, E., Kiernan, C. (1999). Organizational culture and staff outcomes in services for people with intellectual disabilities. *Journal of Intellectual Disability Research, 43*, 206–218.
- Holburn, C. S., Jacobson, J. W., Schwartz, A., Flori, M., & Vietze, P. (2004). The Willowbrook Futures Project: A longitudinal analysis of person-centered planning. *American Journal of Mental Retardation, 109*, 63–76.
- Holburn, S., & Jacobson, J. W. (2004). Implementing and researching person-centered planning. In L. Williams (Ed.), *Developmental disabilities: Advances in scientific understanding, clinical treatments, and community integration* (pp. 315–330). Reno, NV: Context.
- Holburn, S., & Jacobson, J. W. (2004). Implementing and researching person-centered planning. In L. Williams (Ed.), *Developmental disabilities: Advances in scientific understanding, clinical treatments and community integration* (pp. 315–330). Reno, NV: Context press.
- Holburn, S., Jacobson, J. W., Schwartz, A. A., Flory, M. J., & Vietze, P. M. (in press). The Willowbrook Futures Project: A longitudinal analysis of person-centered planning. *American Journal on Mental Retardation*.
- Holburn, S., Jacobson, J. W., Vietze, P. M., Schwartz, A. A., & Sersen, E. (2000). Quantifying the process and outcomes of person-centered planning. *American Journal on Mental Retardation, 105*, 402–416.
- Jacobson, J., & Holburn, S. (2004). Research to practice: Management, staff training, and improvement of service in technology transfer. In L. Williams (Ed.), *Developmental disabilities: Advances in scientific understanding, clinical treatments, and community integration* (pp. 331–363). Reno, NV: Context.
- Jacobson, J. W. (1987). Individual program plan goal content in developmental disabilities programs. *Mental Retardation, 3*, 157–164.
- Jacobson, J. W., & Holburn, S. (in press). Residential services research in the developmental disabilities sector. In L. Glidden (Ed.), *International review of research in mental retardation*. San Diego, Academic Press.
- Jacobson, J. W., & Holburn, S. (2004). Research to practice: Management, staff training, and improvement of services. In W. L. Williams (Ed.), *Developmental disabilities: Advances in scientific understanding, clinical treatments and community integration* (pp. 331–363). Reno, NV: Context press.

- Jacobson, J. W., & Regula, C. R. (1988). Evaluation issues and resources for community living situations. In M. P. Janicki, M. W. Krauss, & M. M. Seltzer (Eds.), *Community residences for people with developmental disabilities: Here to stay* (pp. 85–101). Baltimore: Brookes.
- Jacobson, J. W., & Schwartz, A. A. (1983). Evaluation of community living alternatives. In J. L. Matson & J. A. Mulick (Eds.), *Handbook of mental retardation* (pp. 39–66). Elmsford, NY: Pergamon.
- Jacobson, J. W., & Schwartz, A. A. (1991). Evaluating the living situations of persons with developmental disabilities. In J. L. Matson & J. A. Mulick (Eds.), *Handbook of mental retardation* (2nd ed., pp. 35–62). Elmsford, NY: Pergamon.
- Joyce, T., Ditchfield, H., & Harris, P. (2001). Challenging behaviour in community services. *Journal of Intellectual Disability Research, 45*, 130–138.
- Kiernan, C., & Alborz, A. (1996). Persistence and change in challenging and problem behaviours of young adults with intellectual disability living in the family home. *Journal of Applied Research in Intellectual Disabilities, 9*, 181–193.
- Landesman-Dwyer, S., Sackett, G. P., & Kleinman, J. S. (1980). Relationship of size to resident and staff behavior in small community residences. *American Journal of Mental Deficiency, 85*, 6–17.
- Linhorst, D. M., McCutchen, T. A., & Bennett, L. (2003). Recidivism among offenders with developmental disabilities participating in a case management program. *Research in Developmental Disabilities, 24*, 210–230.
- Lohrer, S. P., Greene, E., Browning, C. J., & Lesser, M. S. (2002). Dual diagnosis: Examination of service use and length of stay during psychiatric hospitalization. *Journal of Developmental and Physical Disabilities, 14*, 143–158.
- Lowe, K., Felce, D., & Blackman, D. (1996). Challenging behaviour: The effectiveness of specialist support teams. *Journal of Intellectual Disability Research, 40*, 336–347.
- Mansell, J., Elliott, T., Beadle-Brown, J., Ashman, B., & Macdonald, S. (2002). Engagement in meaningful activity and “active support” of people with intellectual disabilities in residential care. *Research in Developmental Disabilities, 23*, 342–352.
- Newman, F. L., Howard, K. I., Windle, C. D., & Hohmann, A. A. (1994). Introduction to the special section on seeking new methods in mental health services research. *Journal of Consulting and Clinical Psychology, 62*, 667–669.
- Nottestad, J. A., & Linaker, O. M. (1999). Psychiatric health needs and services before and after complete deinstitutionalization of people with intellectual disability. *Journal of Intellectual Disability Research, 43*, 523–530.
- Parsons, M. B., Cash, V. B., & Reid, D. H. (1989). Improving residential treatment services: Implementation and norm-referenced evaluation of a comprehensive management system. *Journal of Applied Behavior Analysis, 22*, 143–156.
- Pretty, G., Rapley, M., & Bramston, P. (2002). Neighbourhood and community experience, and the quality of life of rural adolescents with and without an intellectual disability. *Journal of Intellectual and Developmental Disability, 27*, 106–116.
- Reid, D. H. (1992). Recent developments in treating severe behavior disorders: Advances or impediments for residential services? *Behavioral Residential Treatment, 7*, 181–197.
- Robertson, J., Emerson, E., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., et al. (2001). Social networks of people with mental retardation in residential settings. *Mental Retardation, 39*, 201–214.
- Romer, D., & Berkson, G. (1980). Social ecology of supervised communal facilities for mentally disabled adults: III. Predictors of social choice. *American Journal of Mental Deficiency, 85*, 243–252.
- Romer, D., & Berkson, G. (1981). Social ecology of supervised communal facilities for mentally disabled adults: IV. Characteristics of social behavior. *American Journal of Mental Deficiency, 86*, 28–38.
- Rosen, J. W., & Burchard, S. N. (1990). Community activities and social support networks: A social comparison of adults with and adults without mental retardation. *Education and Training in Mental Retardation, 25*, 193–204.
- Rudolph, C., Lakin, K. C., Oslund, J. M., & Larson, W. (1998). Evaluation of outcomes and cost effectiveness of a community behavioral support and crisis response demonstration project. *Mental Retardation, 36*, 187–197.

- Schallock, R. L. (2000). Three decades of quality of life. *Focus on Autism and Other Developmental Disabilities*, 15, 116–127.
- Schwartz, A. A., Jacobson, J. W., & Holburn, S. C. (2000). Defining person centeredness: Results of two consensus methods. *Education and Training in Mental Retardation and Developmental Disabilities*, 35, 235–249.
- Smith, C., Felce, D., Jones, E., & Lowe, K. (2002). Responsiveness to staff support: Evaluating the impact of individual characteristics on the effectiveness of active support training using a conditional probability approach. *Journal of Intellectual Disability Research*, 46, 594–604.
- Stancliffe, R. J., Avery, B. H., & Smith, J. (2000). Personal control and the ecology of community living settings: Beyond living-unit size and type. *American Journal on Mental Retardation*, 105, 431–454.
- Stancliffe, R. J., Hayden, M. F., & Lakin, K. C. (1999a). Effectiveness and quality of individual planning in residential settings: An analysis of outcomes. *Mental Retardation*, 37, 104–116.
- Stancliffe, R. J., Hayden, M. F., & Lakin, K. C. (1999b). Effectiveness of challenging behavior IHP objectives in residential settings: A longitudinal study. *Mental Retardation*, 37, 482–493.
- Stancliffe, R. J., Hayden, M. F., & Lakin, K. C. (1999c). Interventions for challenging behavior in residential settings. *American Journal on Mental Retardation*, 104, 364–375.
- Stancliffe, R. J., & Keane, S. (2000). Outcomes and costs of community living: A matched comparison of group homes and semi-independent living. *Journal of Intellectual and Developmental Disability*, 25, 281–305.
- Stancliffe, R. J., & Lakin, K. C. (1999). A longitudinal comparison of day services and outcomes of people who left institutions and those who stayed. *The Journal of the Association for Persons with Severe Handicaps*, 24, 44–57.
- Tonge, B., & Einfeld, S. (2000). The trajectory of psychiatric disorders in young people with intellectual disabilities. *Australia and New Zealand Journal of Psychiatry*, 34, 80–84.
- Ward, K. M., Trigler, J. S., & Pfeiffer, K. T. (2001). Community services, issues, and service gaps for individuals with developmental disabilities who exhibit inappropriate sexual behaviors. *Mental Retardation*, 39, 11–19.