The Willowbrook Futures Project: A Longitudinal Analysis of Person-Centered Planning

Steve Holburn
New York State Institute for Basic Research in Developmental Disabilities
(Staten Island, NY)

John W. Jacobson and Allen A. Schwartz
New York State Office of Mental Retardation and Developmental Disabilities
(Albany, NY)

Michael J. Flory and Peter M. Vietze
New York State Institute for Basic Research in Developmental Disabilities

Abstract

We conducted a longitudinal comparative evaluation of person-centered planning processes and outcomes for 20 individuals with intellectual disabilities and problem behavior (former residents of Willowbrook) and a matched contrast group, who received traditional interdisciplinary service planning (ISP). At the inception of the study, all participants were living in one of four other developmental centers (institutions) in New York City. Process and outcome data obtained from questionnaires completed by team members approximately every 8 months at four time periods showed that the rate of improvement in both person-centered planning process and outcomes for the intervention group was significantly greater than that of the comparison group. Eighteen of 19 person-centered planning participants moved to community living arrangements, as did 5 of 18 in the contrast group.

As recently as 25 years ago, a large proportion of people with intellectual disabilities who received services in the United States lived at large institutional facilities, which provided few services promoting growth and development. Research, evaluation, and policy studies dating back to the 1960s and 1970s found that barren, minimally therapeutic, and often depriving institutional living conditions afforded few prospects for return to community living (Balla, Butterfield, & Zigler 1974; Farell, 1956; Goffman, 1961; Reppucci & Saunders, 1974; Rotegard, Hill, & Bruininks, 1983). Part of the legacy of institutionalization has been persistent concern, lasting until the present, about the quality of life for people with intellectual disabilities, regardless of where they live. An-

other recurrent concern has been whether the funded services are adequate, appropriate, or even beneficial for some or many individuals. Accordingly, for the last 40 years, efforts at many levels of the service system have been directed toward enhancing individualization in the development and provision of services.

Sweeping changes in philosophy and approach are not new to the intellectual disabilities service culture (see Bradley, 1994). Past system reforms have included such changes as the team approach to service delivery; the intermediate care facility (ICF/MR) model and its active treatment guidelines, the individual program plan, behavior modification, interdisciplinary rather than multi-disciplinary assessment, and mounting regulatory

guidance (S. Holburn & Jacobson, 1994). Yet, each of these reforms, in turn, has been found wanting. In general, reforms have been characterized as inconsistently producing desired levels of individualization, skill acquisition, maintenance, self-direction, and reductions in problem behavior (Baumeister, 1997; S. Holburn, 1997; Jacobson, 1987; Kincaid, 1996; Sturmey, 1992; Wehmeyer & Metzler, 1995).

The most recent reform in the intellectual disabilities field, especially prominent in the residential area, is the person-centered planning approach to achieving individualization of supports and improving quality of life. Based on the premise that people with disabilities should enjoy life in the community, person-centered planning seeks to reduce social isolation, promote friendships, and increase autonomy, competence, social contribution, and respect (Mount, 1994; J. O'Brien & Lovett, 1992). The principles of this approach now pervade agency policy, procedure manuals, and government regulations; in many states, the practice of person-centered planning is law (Schwartz, Jacobson, & Holburn, 2000). Significantly, person-centered planning requires service providers to facilitate a shift in power away from themselves in favor of those who receive the services. Ideally, the support needed by people with disabilities will be spread throughout the community, and agencies will provide services in a manner that makes consumers less dependent on those services (Bogdan & Taylor, 1987). The origin and development of various forms of person-centered planning have been described by C. O'Brien and O'Brien (2002).

It is clear that efforts to improve quality of life through person-centered planning abound in disabilities service systems today, but one wonders how effective these efforts have been. In the case of a complex intervention such as person-centered planning, it is important to evaluate both the achievement of the person-centered planning aspirations listed above and the performance of service agencies in faithfully conducting the planning (C. Holburn, 2001; Reid & Green, 2002). Person-centered planning is a long-term process consisting of multiple complex components, and misapplications are said be traceable to a variety of sources, including basic misunderstandings of the process (C. O'Brien, O'Brien, & Mount, 1997), a lack of sufficient ingredients or process components (Mount, 1994), inadequate facilitator training (Reid & Green, 2002), failure to integrate individualized planning into the existing service

culture (Sanderson, 2002), and failure of an agency to acknowledge and openly discuss the difficulties in adopting the approach (S. Holburn & Vietze, 1999).

It is reasonable to expect that person-centered planning will result in outcomes that differ among individuals, as has been the case with other outcomes such as quality of life (Dagnan, Jones, & Ruddick, 1994; Dagnan, Look, Ruddick, & Jones, 1995; Miner, Black, Sachs, & Smull, 1995; Simon, Rosen, Grossman, & Pratowski, 1995), engagement in choice-making (Kearney, Durand, & Mindell, 1995; Rawlings, Dowse, & Shaddock, 1995; Stancliffe, 1995, 1997), residential or life satisfaction (Hawkins, Kim, & Eklund, 1995; Hughes, Hwang, Kim, Eisenman, & Killian, 1995), and independence and self-determination (Heal, Rubin, & Rusch, 1998; Sowers & Powers, 1995; Tossebro, 1995; Wehmeyer, Kelchner, & Richards, 1996).

It is fair to ask whether person-centered planning produces better or different results than conventional individual service planning (ISP), also commonly referred to as individual habilitation planning (IHP). Conventional planning approaches typically entail an interdisciplinary group of professionals, mostly clinicians, who conduct assessments, devise habilitative objectives, and meet periodically to discuss progress and make adjustments to the service plan. In residential settings, the objectives constituting such plans have been found to be functional and technically adequate (Stancliffe, Hayden, & Lakin, 2000), but the objectives do not appear to be associated with targeted skill development (Stancliffe, Hayden, & Lakin, 1999b) or targeted reductions in challenging behavior (Stancliffe, Hayden, & Lakin, 1999a). Common criticisms of the ISP approach are that it is dominated by professionals, is too focused on the remediation of assessed deficits, and disregards more global quality of life and long-range lifestyle enhancement (Emerson & Hatton, 1996, and Stancliffe, Hayden, Larson, & Lakin, 2002, have presented findings consistent with some of these criticisms). Despite these concerns and the lack of correspondence between ISP objectives and outcomes, the ISP is the mainstay of habilitation programs for people with intellectual disabilities in the United States.

Person-centered planning is often described as an alternative to conventional service planning, which has been called "system-centered" (Mount, 1994, p. 104). However, published studies in which researchers purport to evaluate the out-

comes of person-centered planning are scant, and, to date, research evaluating quality of life outcomes presumably produced through person-centered planning has been qualitative, with the exception of a single-case investigation by S. Holburn and Vietze (2002). Many quantitative studies on person-centered planning have been examinations of elements of the person-centered planning process or its outcomes; rather than an evaluation of the efficacy of person-centered planning per se. For example, Heller, Factor, Sterns, and Sutton (1996) reported improvement in quality of life variables, but the intervention was a group-oriented, person-centered training program for consumers rather than an individualized person-centered planning process. Conversely, Miner and Bates (1997) conducted a rigorous person-centered planning intervention, but they examined variables related to IEP planning meetings rather than the quality of life improvements typically targeted by person-centered planning (see C. O'Brien & O'Brien, 2002). Several investigators have focused on a single aspect of person-centered planning, such as those who examined the validity or utility of preference assessment and related changes in planning (Davis & Faw, 2002; Green, Middleton, & Reid, 2000; Reid, Everson, & Green, 1999). Another line of person-centered planning research has demonstrated reduction in challenging behavior following person-centered planning using applied behavior analytic designs, although these studies must be considered quasi-experimental because they lack true control phases (S. Holburn & Vietze, 2002; Klatt et al., 2002; Rea, Martin, & Wright, 2002).

In qualitative studies, which are typically based on information derived from sources such as participant observation and interviews, investigators have reported a myriad of favorable changes in quality of life following person-centered planning, including improvements in the areas of housing and decision-making (Malette, 2002); respect and opportunities for choice-making (Parley, 2001); community participation and relationships (Sanderson, 2002); and communication, job finding, and inclusive education (Dumas, De La Garza, Seay, & Becker, 2002; Hagner, Helm, & Butterworth, 1996). Qualitative researchers investigating person-centered planning invariably note the difficulties associated with carrying out person-centered planning within a service system and often point out unmet goals. For example, Hagner et al. (1996) noted that after 6 months of person-centered planning "only a few planned outcomes had been achieved, and several interviewees felt that 'not much had happened'" (p. 167).

In short, there are no quantitative group studies to date in which investigators have examined the relationship between a comprehensive person-centered planning intervention and a range of its purported outcomes or accomplishments as described by the founders of person-centered planning (see Mount, 1994; J. O'Brien & Lovett, 1992). Given the complexity of person-centered planning interventions, it is remarkable that there also are no studies in which researchers have systematically reported on the degree of adherence to the particular form of person-centered planning being employed. Recently, S. Holburn, Jacobson, Vietze, Schwartz, and Sersen (2000) reported a method to quantify the processes and commonly targeted outcomes of person-centered planning. Essentially, they combined three instruments, which permits formal evaluation of person-centered planning and can be used as a practical tool for managers and clinicians to self-monitor implementation and outcomes of person-centered planning within organizations.

In 1995, the opportunity arose to conduct person-centered planning with a group of individuals who had lived at Willowbrook State School on Staten Island and had been mandated by the Willowbrook Consent Decree in 1975 to live in the community (*N.Y. State ARC v. Carey*, 1975). At the outset of the study, these individuals were still living in developmental centers (i.e., state-operated congregate ICFs/MR) throughout New York City because of their challenging behavior. They represented the last remaining members of a legal class of over 5,000 individuals who had not yet achieved permanent community living arrangements. We were interested in ascertaining whether person-centered planning could hasten the transition to community living and produce improvements in quality of life for these people. Because of the anticipated challenges of this endeavor, including the extended nature of the person-centered planning process (Mount, 1994) when it involves transition to new living arrangements, we undertook a longitudinal analysis. This approach addressed another shortcoming of prior research, in that follow-up beyond 6 months permits detection of long-term effects of person-centered planning.

Method

Participants

Participants were 38 people residing at four developmental centers in New York City that were operated by the New York State Office of Mental Retardation and Developmental Disabilities. Twenty person-centered planning participants were contrasted with 20 matched peers who received conventional individual service planning (ISP); 2 ISP participants dropped out of the study. Matching was based on residence, age (± 5 years), gender, intellectual level (e.g., mild to severe mental retardation), presence of psychiatric diagnosis (yes/no), and overall severity or magnitude of maladaptive behavior. Table 1 shows the characteristics of the two samples, including scores on skills measures maintained in a data base by the state agency (see below).

The person-centered planning participants had not moved to the community because their challenging behavior required specialized or intensive services that were not generally available from community residential service providers. Two of them had lived briefly in the community but returned to developmental centers because of severe behavior problems. Salient problem behaviors among the person-centered planning group in order of descending prevalence included aggression, self-injury, destruction of property, pica, running away, and inappropriate sexual behaviors.

One person-centered planning participant died while her planning was in process at the developmental center, but her data were retained because questionnaires were completed for three of the four longitudinal administrations.

Instruments

Data were collected using four instruments. Personal characteristics (Table 1) were extracted from the data base for The Developmental Disabilities Profile 2 (Brown et al., 1986). The validity and reliability of this instrument have been established previously (Brown et al., 1996) and are comparable to those for adaptive behavior scales generally. Three instruments were used to assess person-centered planning processes and outcomes: the Personal Futures Planning Indicators (Mount & Holburn, 1996), the Indicators of Principles Scale (Schwartz, Jacobson, Rossi, & Warren, 1996), and the Person-Centered Planning Quality of Life Indicators (S. Holburn, Pfadt, Vietze, Schwartz, & Jacobson, 1996).

The Personal Futures Planning Indicators consists of 12 dichotomous items that reflect the presence or absence of key factors or conditions associated with person-centered planning. The Indicators of Principles Scale, which contains 25 multiple-choice questions that refer to components or indicators of person-centered planning, reflects considerations such as whether the person

Table 1. Characteristics of People Served by Person-Centered (PCP) and Individual Service Planning (ISP) Teams

Characteristic	PCP teams (*n* = 20)			ISP teams (*n* = 18)			All participants (*N* = 38)		
	Mean[a]	*SD*	Range	Mean	*SD*	Range	Mean	*SD*	Range
Female (%)	30.0	—	—	15.7	—	—	23.1	—	—
Age (years)	41.4	6.4	28–52	35.6	10.9	19–61	38.6	9.1	19–61
Sev/Prof MR (%)	75.0	—	—	66.7	—	—	68.4	—	—
Psychiatric Dx (%)	55.0	—	—	44.4	—	—	52.6	—	—
Sensory Motor Index	77.5	21.2	30–100	77.2	21.1	20–100	77.4	20.9	20–100
Cognitive Index	22.8	32.2	0–100	28.4	37.3	0–89	25.4	34.3	0–100
Communication Index	47.2	27.1	22–100	53.7	28.7	22–100	50.2	27.7	22–100
Self-Care Index	68.1	26.7	9–100	69.9	23.1	27–100	68.9	24.7	9–100
Daily Living Index	20.4	32.5	0–93	23.7	31.0	0–90	21.9	31.4	0–93
Behavior Problems Index	71.1	20.0	36–96	72.9	20.9	34–100	71.9	20.2	34–100
Clinical services received daily[b]	0.70	0.57	—	1.17	0.92	—	0.92	0.78	—

Note. No between-group comparisons were significant.
[a]Means unless otherwise specified. [b]Maximum = 3.

and important others are involved in service and lifestyle planning. The Person-Centered Planning Quality of Life Indicators consists of 40 multiple-choice questions that tap eight dimensions of quality of life. S. Holburn et al. (2000) combined and analyzed data collected with these three measures to form process and outcome indices and reported psychometric properties for each index, including adequate validity and reliability. The Process Index incorporates subscales for Presence of Strategic Roles, Personal Relationship With the Focus Person, Desire for Change, Creation of a Personalized Vision, Commitment to Planning and Follow-Up, and Flexible Funding and Resources. The Outcome Index encompasses subscales for Autonomy and Choice Making, Home, Work and Day Activities, Health, Relationships, Community Places, Respect, Competence, and Satisfaction. More detailed information on the subscales and their interrelationships is presented in S. Holburn et al. (2000).

Procedure

Facilitator training. Each person-centered planning participant had their own team, which was headed by a facilitator. Facilitation was conducted by eight principal facilitators who received formal training in Personal Futures Planning, a type of person-centered planning developed by Mount (1992), and served as formal consultants throughout the project. Accordingly, facilitators attended a workshop conducted by Dr. Mount, observed or assisted her in conducting at least one personal futures planning session and received technical training and assistance from her throughout the project, both individually and during group process assessment sessions (see below). Most of the principal facilitators facilitated three person-centered planning teams (range = 1 to 4). By design, facilitators were not employees of the developmental center in which the person-centered planning recipient resided, but each mentored a co-facilitator, in "train-the-trainer" fashion, who was an employee of the respective center. The co-facilitator assisted the facilitator from the beginning of the person-centered planning process, assuming increasing responsibility, and eventually taking on the facilitator role as the principal facilitator withdrew, between the fourth and eighth meeting.

Interagency planning and coordination. To plan and organize the project, the principal investigators held meetings with developmental center directors and administrative staff, central office support staff, and members of the Commissioner's Willowbrook Task Force Subcommittee on Challenging Behavior, separately and in combination. These planning meetings resulted in a number of overarching interagency strategies and initiatives to support implementation of person-centered planning, including establishment of (a) a process assessment committee that met nine times over the course of the project to coordinate and facilitate implementation of project activities, (b) a roles clarification document that defined the roles of critical person-centered planning team members, and (c) an 11-step flowchart that specified a sequence of critical tasks that culminated in transition to community living. The flowchart consisted of essential components of the person-centered planning process and operationalized the agency relocation process (e.g., such elements as budget development, coordination of services with the receiving community agency, and residential certification requirements). During process assessment meetings, the group reviewed each person's progress and discussed problems and possible solutions. The defined roles were *facilitator* (the group leader), *contact person* (liaison to the ICF/MR interdisciplinary team), *agency coordinator* (overall coordinator of developmental center person-centered planning activities), and *champion* (lead advocate on the person-centered planning team). The champion role is subjective and emerges naturally during the planning process; not all teams had a member who functioned as a champion.

Early in the project, it became clear that for many of the individuals in the person-centered planning group, transition from institutional to community living, or even simply community exposure, would pose significant challenges. One team received special state funding to pay a person-centered planning team member to assist direct-support staff in accompanying the focus person during the initial introduction to community activities. Following the success of this endeavor, a community bridge-building fund was established by the central office, through which up to $5,000 was made available to each person-centered planning team to supplement community transition activities (a different team was assembled for each person). The fund was a mechanism to provide flexibility outside of the facility, because all participants were institutional residents, and access to such funds was consistent with the

process indicator Flexible Funding and Resources, which is one of the six subscales comprising the Process Index (see earlier discussion). Specifically, bridge-building funds were used to pay for extra costs associated with attending activities in the community, including costs of additional staff supervision, and incidental fees, such as event tickets, meals, and travel costs. Nine of the person-centered planning teams availed themselves of resources purchased through this fund. The bridge-building funding was not available to members of the contrast group. (Detailed descriptions of the process assessment committee, the flowchart, the roles, and bridge-building are available from the first author.)

The team planning process. Planning occurred in four phases: introduction, development of a personal profile, creation of a vision of the future, and follow-along. The intervention was a slight modification of Mount's (1992, 1994) Personal Futures Planning. Person-centered planning meetings were held approximately once per month at the residence of the focus person until the first three phases were complete; thereafter, they occurred less frequently, and the schedule depended on the intricacies of each team process. Team composition varied, but often consisted of a facilitator, co-facilitator, consumer, family member, behavior specialist, service coordinator or social worker, bridge-builder, direct-support staff, and unit or house manager. Team sizes ranged from 5 to 13 members; members occasionally missed meetings or dropped out altogether. As the planning proceeded, new team members were sometimes added, such as a representative of a community residential agency or a relative. Implementation of person-centered planning was staggered across participants, with the first meetings convened between November 1995 and July 1996.

Introduction. After the facilitator met the focus person and some of the people important to the focus person, he or she invited prospective person-centered planning members to a meeting to discuss (a) the project as a whole, including its historical significance in the context of the Willowbrook Consent Decree; (b) the philosophy and approach of person-centered planning; and (c) logistical details of the respective person-centered planning process, including team membership, roles, and coordination with the focus person's ISP team. Prospective members were told that participation was voluntary.

Personal profile. During the second meeting, which was designed to "put the pieces of a person's life together . . . [and] . . . evoke a new and deeper understanding of the person" (Mount 1992, p. 25), the facilitator solicited detailed information from team members about the focus person (when possible from the focus person as well) and recorded or mapped what people said on large pieces of paper, often with color-coded themes and graphic representations. The maps, which remained displayed throughout the meeting, contained information about the person's history, important people and places, preferences, dislikes, choices currently available, behavioral issues, and daily routine. Some individuals had additional maps addressing salient issues such as health or communication. Development of a personal profile took approximately 3 to 5 hours and sometimes required two meetings.

Vision of the future. In this phase, according to Mount (1992), team members "clarify a vision for the future, choose a focus for getting started, and organize to make it happen" (p. 29). Accordingly, the facilitator redisplayed the personal profile maps, reviewed each, then mapped out an ideal living, work, social, and recreational lifestyle based on group discussion. This ideal vision was consistent with information from the personal profile and reflected the team's consensus on balancing the preferences, choices, and needs of the focus person. Strategies for bringing the vision to fruition were brainstormed, priority actions were identified, and volunteers for various tasks were listed on another map that summarized the strategies and responsible persons. Maps of the personal profile, the vision, and the strategies were often redisplayed at subsequent meetings as prompts or as baseline comparison information. Developing the vision and initial strategies took approximately 2 to 4 hours to complete.

Follow-along. This phase consisted mostly of problem-solving discussions on implementation. During the follow-along meetings, the facilitator reviewed strategies and commitments, and team members reported on progress and obstacles to solutions. Goals were altered or added, and strategies were adjusted to accommodate new information or changing circumstances. New information was added to the personal profile if it was relevant to the vision. Formal person-centered planning meetings took place at least until the final administration of the questionnaires, and some continued after the person moved to a new home in the community (see *Discussion*).

Contrast group treatment. As noted, this group of matched peers living in the same developmental centers received the type of IHP typically provided to residents of large ICFs/MR. In New York's system, the plan that governs this process is the ISP. The ISP teams typically met quarterly in the developmental center. The teams are interdisciplinary, largely composed of professional staff (e.g., client coordinator, nurse, psychologist, speech therapist, teacher) who meet to discuss assessments, review progress toward service plan goals, and develop new written habilitative goals and methodologies to be pursued over the ensuing weeks and months. The contrast group received service planning through this more traditional ISP framework.

Data Collection

During the vision meeting, immediately after the initial strategies were developed, attendees anonymously completed the three instruments described above (at Time 1). Consumers were unable to complete questionnaires because of cognitive limitations. Within 10 days of a person-centered planning participant's questionnaire administration, the matched comparison's ISP team completed the same questionnaire in the course of a scheduled ISP meeting. Prior to the ISP Time 1 administrations, the primary author or the contact person, described above, met with the team, explained the purpose of the questionnaire, and remained to answer questions.

Team members who were absent at the time questionnaires were completed were asked to complete questionnaires as soon after the meeting as possible. About one fourth of the respondents completed questionnaires on more than one consumer. Because of the anonymity of respondents, we were unable to identify the exact numbers of respondents for all administrations; our estimate was about 300 team members. It is important to note that some respondents served on both person-centered planning and ISP teams. We did not assess the degree to which this kind of membership overlap occurred, and it was not determinable through questionnaire administrations because these were completed anonymously.

To accommodate the staggered implementation of person-centered planning, we scheduled the Time 1 administration between January 1996 and September 1996; the final administration, Time 4, occurred between March 1998 and February 1999. Administrations occurred, on average, approximately every 8 months.

Analysis

Participants were represented by multiple team members who completed questionnaires, and, therefore, item scores for each participant were obtained by averaging responses across respondents. Items were combined to form subscales, which were then combined to form process and outcome indices, as described in *Instruments* above. Thus, each participant had four process index scores and four outcome index scores (one for each administration). Trends in process and outcome for both groups were evaluated using stepwise generalized estimating equation models—GEE (Liang & Zeger 1986; Zeger & Liang 1986). This technique, as we applied it, resembles an ordinary least-squares (OLS) regression model with the effects of autocorrelation (the correlation of a subject's own scores over time) removed. It also compensates for the fact that the questionnaires were not administered at precisely equal intervals. The difference between the rates of improvement of the intervention and contrast groups was represented by the interaction of date of testing and group membership (coded 1 for the intervention group, 0 otherwise).

Results of the GEE analyses of process and outcome scores in the intervention and contrast groups are shown in Tables 2 and 3. The sample as a whole (both groups) showed significant improvement over time in both process and outcome measures. Including the group variable did not improve model fit (the model χ^2) in either model; as the intervention group began with lower scores, their average scores across all administrations did not differ greatly from those of the contrast group (see Figures 1 and 2). However, the strong interaction between time and group membership demonstrates that the rate of improvement in the intervention group was significantly better than that of the comparison group. This observation holds for both the process and the outcome measures.

An estimate of the magnitude of effect can be obtained by comparing degree of improvement of both groups. The person-centered planning group's Outcome Index scores increased, on average, 0.6 points (on a 5-point scale), which was approximately six times as much as the Outcome Index scores of the control group. The person-

Table 2. Results of GEE Regressions of Process Score on Time and Group (N = 38)

Measure	Coef.	SE	z	p>|z|	Coef.	SE	z	p>|z|	Coef.	SE	z	p>|z|
Time (T)	0.0003	0.0001	3.830	0.000	0.0003	0.0001	3.886	0.000	−0.0001	0.0001	−0.502	0.616
Intervention (I)					0.1002	0.0961	1.044	0.297	−9.1954	2.3787	−3.866	0.000
T × I									0.0007	0.0002	3.911	0.000
Model χ²	14.67 (1df)				15.69 (2df)				32.56 (3df)			
Change in χ²	—				1.02 (1df)*				16.87 (1df)**			

Note. GEE = generalized estimating equations.
*p < .69 **p < .001.

centered planning group's increase in process was as great as its outcome increment. The contrast group's process scores, on the contrary, showed a slight nonsignificant decline over the course of the study.

A more tangible comparison can be made between the two groups with respect to movement to community. As of January 2003, a greater proportion of the person-centered planning participants had moved from institutional living to a community living arrangement, $\chi^2(1, N = 37) = 4.34$, $p < .05$. Specifically, 18 of 19 person-centered planning participants (94.7%) moved to the community (one member of this group died while still living in the institution), whereas only 5 of 18 individuals in the contrast group (27.7%) moved out of the institution. Nine of the people who moved to the community had used community bridge-building funds, whereas 9 had not used such funds, suggesting that access to these additional funds did not predict movement.

Discussion

In this study, we investigated changes in person-centered processes, quality of life, and movement to the community when person-centered planning is added to the traditional ISP process for individuals with varying degrees of intellectual disabilities and challenging behavior. The results indicate that person-centered planning can produce an improvement (even as an adjunctive process) over more conventional interdisciplinary treatment team planning procedures typical of ICFs/MR serving people with developmental disabilities. These teams tend to be led by professional staff and focused, as required by federal regulations, on the development and implementation of habilitatively oriented goals and methodologies encompassed in an ISP (i.e., Centers for Medicare & Medicaid Services, 2002). In the present study, people who participated in person-centered planning were significantly more likely to leave the developmental center for a community living arrangement designed specifically for them than were matched peers who received conventional ISP interventions. The larger and more rapid improvement in process measures for the person-centered planning group also suggests that person-centered planning procedures enhanced team roles, commitment to a vision, and both identification and solution of barriers to community living as compared to changes within ISP

Table 3. Results of GEE Regressions of Outcome Score on Time and Group ($N = 38$)

Measure	Coef.	SE	z	P>|z|	Coef.	SE	z	P>|z|	Coef.	SE	z	P>|z|
Time (T)	0.0004	0.0001	3.945	0.000	0.0004	0.0001	3.949	0.000	−0.0000	0.0002	−0.126	0.900
Intervention (I)					0.0716	0.1793	0.399	0.690	−8.9148	2.7058	−3.295	0.001
T × I									0.0007	0.0002	3.328	0.001
Model χ^2	15.57 (1df)				15.67 (2df)				27.99 (3df)			
Change in χ^2	—				0.02 (1df)*				12.32 (1df)**			

Note. GEE = generalized estimating equations.
*$p < .89$ **$p < .001$.
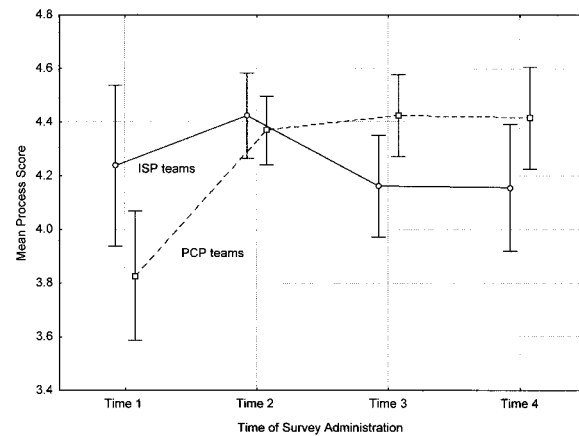
Figure 1. Person-centered planning process ratings for person-centered planning teams (PCP) and interdisciplinary service planning teams (ISP) at four time periods. Vertical bars denote 0.95 confidence intervals.

teams. Finally, the superiority of outcome measures for the person-centered planning teams demonstrates that many areas of quality of life (e.g., autonomy, choice-making, daily activities, relationships, and satisfaction) improved more for these participants than for the contrast group members.

Although the person-centered planning approach is radically different from the ISP approach in many respects (C. Holburn & Pfadt, 1998), the goals established through person-centered planning by the teams in our study were
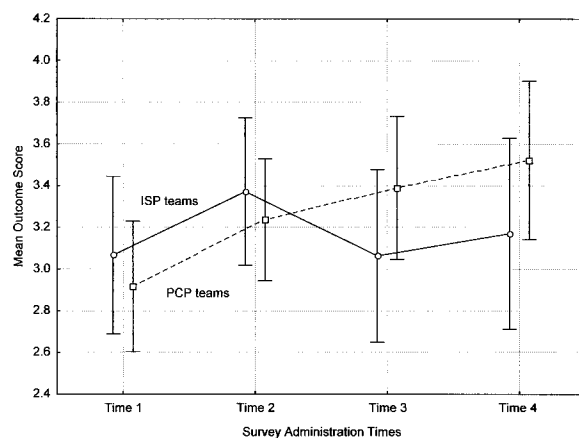
Figure 2. Person-centered planning quality of life outcome ratings for person-centered planning teams (PCP) and interdisciplinary service planning teams (ISP) at four time periods. Vertical bars denote 0.95 confidence intervals.

consistent with the missions of the developmental centers. Early on in the process, it became clear that the person-centered planning initiative and the developmental centers were working toward the same ends. It also became clear that many aspects of the existing structures and processes of the developmental centers were conducive to the aims of the person-centered planning teams and that person-centered planning provided an opportunity to accelerate the accomplishment of developmental center aims. These convergent conditions no doubt contributed to the superior performance of the person-centered planning teams within the developmental center framework. However, we also note that all staff members who participated in this study were aware that this was a comparison between how well person-centered planning worked compared to the traditional approach ISP process. Thus, it can be assumed that both groups of staff members were motivated to produce favorable outcomes.

Two factors may have militated against findings of larger quality of life differences favoring the person-centered planning group. Some of the developmental center staff members served on both types of teams during the project. No attempt was made to prevent adoption of the person-centered planning philosophy or procedures by the ISP teams, and, thus, diffusion effects were possible. Another possibly mitigating factor is inherent in the person-centered planning process itself. A central role of the facilitator is to elucidate disparities between what the person wants and what the person is experiencing (J. O'Brien & Lovett, 1992), and this can motivate team members to reduce the disparity. Thus, person-centered planning team members might have been more sensitized than ISP team members to such rifts, which might explain why ISP teams reported higher process and outcome scores at Time 1.

One possible concern with our measurement of process and outcome was that proxy data were used (staff responded on behalf of the consumer). The validity of proxy responding has been questioned, mainly because the proxy respondent has no direct access to information for which there are few behavioral indicators that can be observed by others (Cummins, 2002). Nonetheless, some investigators have reported high concurrence between proxy and participant ratings of quality of life (e.g., McVilly, Burton-Smith, & Davidson, 2000), and recommend their use.

One question that might be raised is whether the person-centered planning participants would have moved into community settings anyway because the mandate of the Willowbrook Consent Decree to achieve movement to the community of these remaining people was concurrently being addressed as a renewed priority. We think not, or at least not at the pace that they did. The Willowbrook advocates actively represented 8 person-centered planning participants and 3 contrast group members. Removing these 11 from the analysis, 3 of 15 individuals in the contrast group (20%) moved, whereas 10 of 11 individuals (91%) in the person-centered planning group moved. This finding suggests that Willowbrook advocacy was not a determining factor for community movement outcomes.

One might also contend that it was movement to the community, rather than person-centered planning, that was responsible for the differences in process and outcome scores. If true, this finding would not be especially problematic because person-centered planning appears to be responsible for the greater degree of movement in the person-centered planning group. However, movement dates indicate that 13 of the 23 individuals who left did so after the final administration of evaluation instruments, leaving only 10 participants whose data could have been affected by their moving to the community. These 10 participants moved between Times 3 and 4, and, as the figures show, the slopes between these evaluation times were essentially the same for both groups on the process measure and on the outcome measure. Thus, it appears that movement to the community was not responsible for the differences in process and outcome scores between the two groups.

A possible confound in the study was the bridge-building funds because they were available only to the person-centered planning participants, and only 9 of these 20 person-centered planning participants used such resources. It appears that this fund did not create an advantage favoring community placement because even though about one half of person-centered planning participants received some bridge-building assistance, all but one person in the person-centered planning group moved to the community. We did not assess possible group differences in community activities that might have been influenced by bridge-building funds or differences in the ease with which participants were accessed such activities.

Managers and clinical service providers should be rightfully concerned with the effectiveness of their organizations in individualizing services and achieving the personal goals that are central to the promise of person-centered planning. They need information about the effectiveness of various planning strategies to provide management support and policy direction for programs, services, and personnel. Implementation of person-centered processes requires extensive modifications of organizational processes, including relationships among personnel, relationships between personnel and the people they serve, and changes in staff training and oversight practices (S. Holburn, 1997). Managers need effective means to measure both faithful implementation of person-centered processes and attainment of desired outcomes. The scales and monitoring practices used in the present study offer a methodology that permits managers to fulfill these obligations readily.

References

Balla, D. A., Butterfield, E. C., & Zigler, E. (1974). Effects of institutionalization on retarded children: A longitudinal cross-institutional investigation. *American Journal of Mental Deficiency, 78,* 530–549.

Baumeister, A. A. (1997). Behavioral research: Boom or bust? In W. E. MacLean, Jr. (Ed.), *Ellis' handbook of mental deficiency, psychological theory and research* (3rd ed., pp. 3–45). Mahwah, NJ: Erlbaum.

Bogdan, R., & Taylor, S. J. (1987). The next wave. In S. J. Taylor, D. Biklen, & J. Knoll (Eds.), *Community integration for people with severe disabilities* (pp. 209–213). New York: Teachers College Press.

Bradley, V. J. (1994). Evolution of a new service paradigm. In V. Bradley, J. W. Ashbaugh, & B. C. Blaney (Eds.), *Creating individual supports for people with developmental disabilities: A mandate for change at many levels* (pp. 11–32). Baltimore: Brookes.

Brown, M. C., Hanley, A. T., Nemeth, C., Epple, W., Bird, W., & Bontempo, A. (1986). *The Developmental Disabilities Profile: Final report—The design, development & testing of the core instrument.* Albany: New York State Office of Mental Retardation and Developmental Disabilities.

Cummins, R. A. (2002). Proxy responding for subjective well-being: A review. In L. Glidden (Ed.), *International review of research in mental retardation* (pp. 183–207). San Diego: Academic Press.

Dagnan, D., Jones, J., & Ruddick, L. (1994). The psychometric properties of a scale for assessing quality of life of people with learning disabilities in residential care. *British Journal of Developmental Disabilities, 40,* 98–103.

Dagnan, D., Look, R., Ruddick, L., & Jones, J. (1995). Changes in the quality of life of people with learning disabilities who moved from hospital to live in community-based homes. *International Journal of Rehabilitation Research, 18,* 115–122.

Davis, P., & Faw, G. (2002). Residential preferences in person-centered planning: Empowerment through self-identification of preferences and their availability. In S. Holburn & P. M. Vietze (Eds.), *Person-centered planning: Research, practice, and future directions* (pp. 203–221). Baltimore: Brookes.

Dumas, S., De La Garza, D., Seay, P., & Becker, H. (2002). "I don't know how they made it happen, but they did": Efficacy perceptions in using a person-centered planning process. In S. Holburn & P. M. Vietze (Eds.), *Person-centered planning: Research, practice, and future directions* (pp. 223–246). Baltimore: Brookes.

Emerson, E., & Hatton, C. (1996). Deinstitutionalization in the UK and Ireland: Outcomes for service users. *Journal of Intellectual and Developmental Disability, 21,* 17–37.

Farell, M. J. (1956). The adverse affects of early institutionalization of mentally subnormal children. *Journal of Diseases of Childhood, 91,* 278–281.

Goffman, E. (1961). *Asylums.* Garden City, NY: Doubleday.

Green, C. W., Middleton, S. G., & Reid, D. R. (2000). Embedded evaluation of preferences sampled from person-centered plans for people with profound multiple disabilities. *Journal of Applied Behavior Analysis, 33,* 639–642.

Hagner, D., Helm, D. T., & Butterworth, J. (1996). This is your meeting: A qualitative study of person-centered planning. *Mental Retardation, 34,* 159–171.

Hawkins, B. A., Kim, K., & Eklund, S. (1995). Validity and reliability of a five dimensional life satisfaction index. *Mental Retardation, 33,* 295–303.

Heal, L. W., Rubin, S. S., & Rusch, F. R. (1998).

Residential independence of former special education high school students: A second look. *Research in Developmental Disabilities, 19,* 1–26.

Heller, T., Factor, A., Sterns, H., & Sutton, E. (1996). Impact of person-centered later life planning training program for older adults with mental retardation. *Journal of Rehabilitation, 62,* 77–83.

Holburn, C. S. (2001). Compatibility of person-centered planning and applied behavior analysis. *Behavior Analyst, 34,* 271–281.

Holburn, C. S., & Pfadt, A. (1998). Clinicians on person-centered planning teams: New roles, fidelity of planning, and outcome assessment. *Mental Health Aspects of Developmental Disabilities, 1,* 82–86.

Holburn, S. (1997). A renaissance in residential behavior analysis? An historical perspective and a better way to help people with challenging behavior. *Behavior Analyst, 20,* 61–85.

Holburn, S., & Jacobson, J. W. (1994). Impact of federal regulations on desired processes and outcomes in public residential facilities: National perspectives. *Journal of Developmental and Physical Disabilities, 5,* 109–120.

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.

Holburn, S., Pfadt, A., Vietze, P. M., Schwartz, A. A., & Jacobson, J. W. (1996). *Person-centered planning quality of life indicators.* Albany: New York State Office of Mental Retardation and Developmental Disabilities.

Holburn, S., & Vietze, P. (1999). Acknowledging barriers in adopting person-centered planning. *Mental Retardation, 37,* 117–124.

Holburn, S., & Vietze, P. (2002). A better life for Hal: Five years of person-centered planning and applied behavior analysis. In S. Holburn & P. M. Vietze (Eds.), *Person-centered planning: Research, practice, and future directions* (pp. 291–314). Baltimore: Brookes.

Hughes, C., Hwang, B., Kim, J. H., Eisenman, L. T., & Killian, D. J. (1995). Quality of life in applied research: A review and analysis of empirical measures. *American Journal on Mental Retardation, 99,* 623–641.

Jacobson, J. W. (1987). Individual program plan goal content in developmental disabilities programs. *Mental Retardation, 25,* 157–164.

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 Press.

Kearney, C. A., Durand, V. M., & Mindell, J. A. (1995). Choice assessment in residential settings. *Journal of Developmental and Physical Disabilities, 7,* 203–213.

Kincaid, D. (1996). Person-centered planning. In L. K. Koegel, R. L. Koegel, & G. Dunlap (Eds.), *Community, school family, and social inclusion through positive behavioral support* (pp. 439–465). Baltimore: Brookes.

Klatt, K. P., Bannerman-Juracek, D., Norman, K. R., McAdam, D. B., Sherman, J. A., & Sheldon, J. B. (2002). Evaluating preferred activities and challenging behavior through person-centered planning. In S. Holburn & P. M. Vietze (Eds.), *Person-centered planning: Research, practice, and future directions* (pp. 315–332). Baltimore: Brookes.

Liang, K. Y., & Zeger, S. L. (1986). Longitudinal data analysis using generalized linear models. *Biometrika, 73,* 13–22.

Malette, P. (2002). Lifestyle quality and person-centered support: Jeff, Janet, Stephanie, and the Microboard Project. In S. Holburn & P. M. Vietze (Eds.), *Person-centered planning: Research, practice, and future directions* (pp. 291–314). Baltimore: Brookes.

McVilly, K. R., Burton-Smith, R. M., & Davidson, J. A. (2000). Concurrence between subject and proxy ratings of quality of life for people with and without intellectual disabilities. *Journal of Intellectual Disabilities, 25,* 19–39.

Miner, C. A., & Bates, P. E. (1997). The effect of person centered planning activities on the IEP/Transition planning process. *Education and Training in Mental Retardation and Developmental Disabilities, 32,* 105–112.

Miner, V. A., Black, M. M., Sachs, M. L., & Smull, M. W. (1995). Services for adult family members with mental retardation: Perceptions of accessibility and satisfaction. *Mental Retardation, 33,* 181–185.

Mount, B. (1992). *Person-centered planning: Finding directions for change. A sourcebook of values, ideals, and methods to encourage person-centered development.* New York: Graphic Futures.

Mount, B. (1994). Benefits and limitations of personal futures planning. In V. J. Bradley, J. W.

Ashbaugh, & B. C. Blaney (Eds.), *Creating individual supports for people with developmental disabilities: A mandate for change at many levels* (pp. 97–108). Baltimore: Brookes.

Mount, B., & Holburn, C. S. (1996). *Personal futures planning indicators*. Staten Island: New York State Institute for Basic Research in Developmental Disabilities.

New York State ARC v. Carey, 393 F. Supp. 715, 718–19 (E.D.N.Y. 1975) and New York State ARC v. Carey, No. 72-C-356/357 (E.D.N.Y., 1975)

O'Brien, C. L., O'Brien, J., & Mount, B. (1997). Person-centered planning has arrived . . . or has it? *Mental Retardation, 35,* 480–483.

O'Brien, C. L., & O'Brien, J. (2002). The origins of person-centered planning: A community practice perspective. In S. Holburn & P. M. Vietze (Eds.), *Person-centered planning: Research, practice, and future directions* (pp. 2–27). Baltimore: Brookes.

O'Brien, J., & Lovett, H. (1992). *Finding a way toward everyday lives: The contribution of person centered planning*. Harrisburg: Pennsylvania Office of Mental Retardation. (Available from the Research and Training Center on Community Living, Center on Human Policy, Syracuse University, 805 S. Crouse Ave., Syracuse, NY 13244-2340.)

Parley, F. F. (2001). Person-centered outcomes. *Journal of Learning Disabilities, 5,* 299–308.

Rapley, M., & Beyer, S. (1996). Daily activity, community participation and quality of life in an ordinary housing network. *Journal of Applied Research in Intellectual Disabilities, 9,* 31–39.

Rawlings, M., Dowse, L., & Shaddock, A. (1995). Increasing the involvement of people with an intellectual disability in choice making situations: A practical approach. *International Journal of Disability, 42,* 137–153.

Reid, D. H., Everson, J. M., & Green, C. W. (1999). A systematic evaluation of preferences identified through person-centered planning for people with profound multiple disabilities. *Journal of Applied Behavior Analysis, 32,* 467–477.

Rea, J. A., Martin, M., & Wright, K. (2002). Using person-centered supports to change the culture of large intermediate care facilities. In S. Holburn & P. M. Vietze (Eds.), *Person-centered planning: Research, practice, and future directions* (pp. 73–96). Baltimore: Brookes.

Reid, D. H., & Green, C. W. (2002). Person-centered planning with people who have severe multiple disabilities: Validated practices and misapplications. In S. Holburn & P. M. Vietze (Eds.), *Person-centered planning: Research, practice, and future directions* (pp. 97–126). Baltimore: Brookes.

Reppucci, N. D., & Saunders, J. T. (1974). The social psychology of behavior modification: Problems of implementation in natural settings. *American Psychologist, 29,* 649–660.

Risley, T. (1996). Get a life! Positive behavioral intervention for challenging behavior through life arrangement and life coaching. In L. K. Koegel, R. L. Koegel, & G. Dunlap (Eds.), *Community, school family, and social inclusion through positive behavioral support* (pp. 425–437). Baltimore: Brookes.

Rotegard, L. L., Hill, B. K., & Bruininks, R. H. (1983). Environmental characteristics of residential facilities for mentally retarded persons in the United States. *American Journal of Mental Deficiency, 88,* 49–56.

Sanderson, H. (2002). A plan is not enough. In S. Holburn & P. M. Vietze (Eds.), *Person-centered planning: Research, practice, and future directions* (pp. 97–126). Baltimore: Brookes.

Schwartz, A. A., Jacobson, J. W., & Holburn, S. (2000). Defining person centeredness: Results of two consensus methods. *Education and Training in Mental Retardation and Developmental Disabilities, 35,* 235–249.

Schwartz, A. A., Jacobson, J. W., Rossi, L., & Warren, B. (1996). *Indicators of Principles scale*. Albany: New York Office of Mental Retardation and Developmental Disabilities.

Simon, E. W., Rosen, M., Grossman, E., & Pratowski, E. (1995). The relationship among facial emotion recognition, social skills, and quality of life. *Research in Developmental Disabilities, 16,* 383–391.

Sowers, J., & Powers, L. (1995). Enhancing the participation and independence of students with severe physical and multiple disabilities in performing community activities. *Mental Retardation, 33,* 209–220.

Stancliffe, R. J. (1995). Assessing opportunities for choice-making: A comparison of self and staff reports. *American Journal on Mental Retardation, 99,* 418–429.

Stancliffe, R. J. (1997). Community living-unit size, staff presence, and residents' choice-making. *Mental Retardation, 35,* 1–9.

Stancliffe, R. J., Hayden, M. F., & Lakin, K. C. (1999a). 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. (1999b). Effectiveness and quality of individual outcomes in residential settings: An analysis of outcomes. *Mental Retardation, 37,* 104–116.

Stancliffe, R. J., Hayden, M. F., & Lakin, K. C. (2000). Quality and content of individualized habilitation plan objectives in residential settings. *Education and Training in Mental Retardation and Developmental Disabilities, 35,* 191–207.

Stancliffe, R. J., Hayden, M. F., Larson, S. A., & Lakin, K. C. (2002). Longitudinal study on the adaptive and challenging behaviors of deinstitutionalized adults with mental retardation. *American Journal on Mental Retardation, 107,* 302–320.

Sturmey, P. (1992). Goal planning for adults with a mental handicap: Outcome research, staff training and management. *Mental Handicap Research, 5,* 92–108.

Tössebro, J. (1995). Impact of size revisited: Relation of number of residents to self-determination and deprivitization. *American Journal on Mental Retardation, 100,* 59–67.

Wehmeyer, M. L., Kelchner, K., & Richards, S. (1996). Essential characteristics of self-determined behavior of individuals with mental retardation. *Mental Retardation, 100,* 632–642.

Wehmeyer, M. L., & Metzler, C. A. (1995). How self-determined are people with mental retardation? The national consumer survey. *Mental Retardation, 33,* 111–119.

Zeger, S. L., & Liang, K. Y. (1986). Longitudinal data analysis for discrete and continuous outcomes. *Biometrics, 4,* 121–130.