

In Search of Meaningful Daytimes: Case Studies of Community-Based Nonwork Supports

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As of 2004, more than 114,000 individuals with intellectual/developmental disabilities in the United States were identified as receiving supports for community-based nonwork (CBNW), that is, activities that do not involve paid employment but do take place in the community rather than that in a facility (Institute for Community Inclusion, 2007). Little is known, however, about the nature of CBNW as implemented by provider agencies and experienced by people with intellectual/developmental disabilities. This manuscript reports the findings of case studies of CBNW in two states with well-established CBNW supports. Success of CBNW in meeting goals such as individualization, integration, choice, and independence varied from state to state and from site to site. This variability suggests a need for clearer standards and best practices for CBNW.

DESCRIPTORS: day services, community integration, case study research, intellectual, developmental disabilities

As of 2004, state intellectual/developmental disability (I/DD) agencies reported that more than 114,000 individuals with I/DD in the United States (22% of individuals receiving day or employment supports) received supports for community-based nonwork (CBNW). CBNW, also known as community integration or community participation, includes non-job-related activities that take place

in the community rather than that in a facility such as a day habilitation site (Institute for Community Inclusion, 2007). CBNW activities may include volunteer work, participation in community recreation or education programs, doing errands, going out to eat, and general community exploration. Supports for such activities are generally provided by local service providers and funded through the state I/DD agency. People with I/DD may participate in CBNW instead of, or in addition to, other day activities such as community employment, sheltered employment, or day habilitation.

Respondents to a national survey of all 51 state I/DD agencies (Sulewski, Butterworth, & Gilmore, 2008) and a survey of a random sample of U.S. community rehabilitation providers (CRPs; Sullivan, Boeltzig, Metzel, Butterworth, & Gilmore, 2004) have suggested that CBNW is a broadly defined service type without clear targeting toward specific requirements, goals, activities, or populations. Fewer than half (36.6%) of state agencies responding to the national survey of state I/DD agencies considered CBNW a distinct program or funding category (Sulewski et al., 2008), and both state agencies and CRPs indicated that they (a) had several different goals for CBNW, (b) included a wide variety of activities under the umbrella of CBNW, and (c) supported an array of individuals with disabilities in CBNW (including youth transitioning from school to work, retired people, people working part time, and people for whom work was not considered an option; Sulewski et al., 2008; Sullivan et al., 2004).

If properly implemented, CBNW has potential to enhance the quality of life for people with disabilities by supporting individuals to have a “full array of adult roles that comprise quality of life” (Halpern, 1993, p. 497). Specifically, CBNW supports can fill support needs for activities such as recreation (Draheim, Williams, & McCubbin, 2002; Stanish & Draheim, 2005), religious participation (Gaventa, 1994; McNair, 2005; McNair & Swartz, 1997; Minton & Dodder, 2003), and postsecondary education (Grigal, Neubert, & Moon, 2002; Hamill, 2003). However, little is currently known about CBNW support practices. Although there has been extensive research on policies, practices, and outcomes of community-based employment since the 1980s, there has been very little on CBNW.

There are, however, several existing studies that provide insight into the potential and challenges of CBNW.

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In the late 1990s, the Center on Human Policy at Syracuse University published several CBNW provider agency success stories (Hall & Walker, 1997; Hulin & Searle, 1996; Walker, 1998, 2000). For example, Hulin and Searle (1996) conducted a case study of CBNW services at Job Path, a supported employment service provider in New York City that had expanded beyond employment supports in an effort to better serve people with severe disabilities. Job Path had started out offering only supported employment services but saw that “as supported employment programs began developing, people with more severe disabilities were being left out of this revolution... and so we became interested in trying to begin to work with people with more severe disabilities” (Hulin & Searle, 1996, p. 2). CBNW activities at Job Path included going to the library, going to the gym, and doing volunteer work. Hall and Walker (1997) reported on a site visit to Common Ground, a New Hampshire provider that provided both employment and nonwork day supports one-on-one or in small groups. Examples of nonwork activities included volunteer work, outdoor activities such as walking or skiing, going out for lunch, joining a local community theater production, visiting with friends, and participating in a self-advocacy group. Using this model of supports, Common Ground was able to close its two sheltered workshops and convert to providing day supports in the community for all the individuals it supported. Walker (1998) conducted a case study at Options for Individuals, a provider in Markville, Kentucky, that was primarily facility based but had created community connections through a variety of CBNW activities. CBNW activities supported by Options included going out to eat, visiting the library, volunteering with Meals on Wheels, participating in a church choir, running errands, going to the gym, and simply spending time in the community to explore places and options. One-on-one and small group CBNW supports enabled Options to “get people out of the building,” to add variety to individuals’ lives, and to connect participants with their community better (Walker, 1998, p. 2). Walker (2000) also reported on a 1998 site visit to Katahdin Friends Inc. (KFI), a provider in Maine that had converted from a facility-based to a community-based approach in both its employment and nonwork supports. CBNW activities included going to the church, gym, and library; running errands; and joining community organizations such as a Singles Club or a bowling league. For KFI, CBNW supports served to fill a gap for those who were not working or were working part time. Walker (2007) later summarized in a book chapter key components and support strategies for meaningful leisure and social activities on the basis of these and other cases. In addition, Sowers, Dean, and Holsapple (1999) conducted site visits of 15 sites providing Alternatives to Employment (ATE) services, a CBNW option that at the time was the primary service type for 22% of recipients of day services in Oregon. The most common activities engaged in by the 87 ATE participants were going to the park,

going out for fast food, going for a walk, making store purchases, going to the mall/window shopping, going for a drive, and doing volunteer work. The ATE study found that levels of community integration for ATE users varied, with some individuals participating in community activities and others primarily or only in site-based activities. Moreover, most providers of ATE services were found to consider integration to mean “presence in the community,” not necessarily interaction and connection.

Collectively, these studies highlighted the emergence of CBNW as a way to augment employment services by providing other options for community involvement, especially for people with severe disabilities (Hall & Walker, 1997; Hulin & Searle, 1996; Sowers et al., 1999; Walker, 2000, 2007). Walker (2007) noted that because people with the most severe disabilities are not employed in the community, work limited hours, or do not work in jobs of their choosing, “it is important for many people to have various community connections and engagements, either in addition to or instead of work” (p. 76).

Some common issues also emerged across these case studies. One was the challenge of finding meaningful activities that foster community integration and relationships (Hall & Walker, 1997; Sowers et al., 1999). Another was figuring out when and to what extent the use of agency-owned sites is appropriate (Hall & Walker, 1997; Walker, 1998, 2000). For example, Hall and Walker (1997) found that closure of the day facility at Common Ground had had both advantages (forcing staff to be more creative about finding community-based options) and disadvantages (forcing individuals to deal with transportation issues and bad weather to be “in the community” at all times).

These similarities indicate that certain issues (such as the niche CBNW fills in the service system and the challenges of finding meaningful activities, determining the role of facilities, and helping people build relationships) appear to be present in multiple CBNW programs across the country. These same issues are reflected in Walker’s (2007) suggested key components for successful CBNW, which included pursuit of individual interests, the importance of place and being in social spaces, and having opportunities for social relationships and community connections.

An additional lens through which CBNW can be viewed is the Emerging Disability Policy Framework (Silverstein, 2000), a framework for determining if policies are consistent with the Americans with Disabilities Act and with the new paradigm of disability (Hahn, 1993; Oliver, 2000). The new paradigm or social model of disability (Hahn, 1993; Oliver, 2000) holds that disability is socially created and that public policy should focus on “eliminating the attitudinal and institutional barriers that preclude persons with disabilities from participating fully in society’s mainstream” (Silverstein, 2000, p. 1695). Silverstein’s framework “provides a benchmark for studying the extent to which generic and disability-specific policies and programs reflect the ‘new paradigm’ and achieve

its goals” (Silverstein, 2000, p. 1696). Those goals include equality of opportunity, full participation (empowerment), independent living, and economic self-sufficiency.

This manuscript describes a series of case studies of CBNW policies and practices conducted in two states in 2004–2005. The case studies are intended to shed some light on CBNW, including (a) how it is defined and implemented by state agencies and local service providers, (b) how it is experienced by individuals with disabilities, and (c) whether it is in keeping with current goals of disability policy as articulated in the Emerging Disability Policy Framework.

On the basis of previous survey research on state CBNW policies (Sulewski, Butterworth, & Gilmore, 2006), it was clear that the nature of CBNW was ultimately determined by a combination of the state’s policy, the local service providers’ and direct support workers’ implementation, and the interaction of individuals with disabilities and their support workers with the local community. Because the major strength of a case study is its ability to study phenomena in real-life context (Yin, 2003), case studies seemed the best approach for delving deeper into the implementation of CBNW on the ground level and its implications for people with I/DD.

Where previous case studies of CBNW focused primarily on local provider site visits (Hall & Walker, 1997; Hulgín & Searle, 1996; Sowers et al., 1999; Walker, 1998, 2000), this study investigated CBNW at multiple levels within each case (state, provider, and individual). It also addressed the current goals of disability policy by examining CBNW on the basis of four basic concepts, drawn from the four goals of the Emerging Disability Policy Framework, that are particularly relevant to I/DD supports and services. The four concepts investigated, which are explained further in the Data Analysis section, were *individualization* and *integration* (both of which relate to Silverstein’s first goal, *equality of opportunity*), *choice/empowerment* (which relates to Silverstein’s second goal, full participation), and *independence* (which relates to Silverstein’s third and fourth goals, independent living and economic self-sufficiency).

Methods

Participants

This study used an embedded case study design (Yin, 2003). Within each of two case study states, I examined policies and practices at the state level and at selected local service provider agencies as well as the experiences of selected individuals receiving CBNW supports from each provider agency. In total, between August 2004 and June 2005, I conducted semistructured interviews with 8 state agency contacts, 13 management-level provider staff (including agency directors and other managers), 8 individuals with disabilities, 3 family members, and 11 direct support staff. I also conducted observations of 16 individuals with disabilities (including seven of the

eight who were interviewed) and 13 direct support staff (including nine of the 11 who were interviewed). A more detailed depiction of the participants can be found in Table 1.

Site and Participant Selection

Van Evera (1996) recommends choosing cases with extreme values on the dependent variable, which means if seeking to determine if an approach reaches certain goals, studying the most successful examples of that approach to see if it is possible to reach the goals under the best of circumstances. For this study, this meant attempting to identify the most successful cases of CBNW for each level: state, local service provider, and individual. This approach was not intended to provide a representative sample of programs or individuals and, consequently, the findings are not generalizable to the full population of either CBNW programs or individuals participating in CBNW in these states or otherwise. However, as described by Yin (2003), “case studies, like experiments, are generalizable to theoretical propositions and not to populations or universes.” Consistent with this definition, the current study was designed to be generalizable to the proposition that CBNW can be consistent with the goals of the ADA by choosing the best cases of CBNW to check against those goals.

The selection of states was based primarily on data from the 2001 National Survey of Day and Employment Programs for People with Developmental Disabilities (Sulewski et al., 2006). Because data on outcomes were not available, I chose the states on the basis of the assumption that states with the most established and clearly defined CBNW programs would be most likely to have outcomes consistent with the goals of the ADA. I first identified states that had high use of CBNW compared with other states (measured by percentage of service recipients in CBNW in 2001), early adoption of CBNW (determined by whether or not the state reported providing CBNW services in 1996, the first year this category was included in the survey), high rate of growth of CBNW compared with other states (measured by the change in percentage of individuals served in CBNW from 1996 to 2001), and/or clarity of definition of CBNW (based on four criteria: whether the agency provided a definition of CBNW in its response to the survey module, my and my colleagues’ assessment of whether the definition was clear, whether the agency reported that CBNW was a distinct funding category from other day services types, and whether the agency indicated that it had any specific guidelines for CBNW). On the basis of these criteria, I developed a list of eight top states that scored well in most or all of these categories. I then narrowed the list down to five states by soliciting input from colleagues who had performed extensive state systems research and were familiar with the states’ policies, programs, and cultures. I conducted preliminary telephone interviews with five states and eliminated three: two because CBNW was not considered

Table 1
Study Participants

Participant(s)	Data collection activity
State 2: Division of Developmental Services	
Two state agency central office staff	Individual interviews
State 2: Rural Area Associates (Provider 1)	
Agency director and two management-level staff	Group interview
Anne: a nonverbal, middle-aged woman who lived with her parents and had been coming to Rural Area Associates since she was in school. She had done some piecework in the past but at the time of the study was only participating in CBNW activities. Patty: Anne's direct support worker	Observation as a pair for a morning outing to the dollar store and the library and lunch at Burger King
Anne and her father	Interview as a pair
Emily: a middle-aged woman, who was one of the few verbal communicators in the study. Like Anne, Emily lived with her parents and received day supports from Rural Area Associates. Emily had worked in the past, but had been laid off and then switched to CBNW supports. Tiffany, Emily's support worker	Observation as a pair for one afternoon, during which time Emily volunteered at a nursing home playing Bingo with the residents and then met up with a friend at Dunkin' Donuts for hot chocolate and a card game
State 2: Small Town Counseling (Provider 2)	
Agency director	Individual interview
John: a young man just transitioning from school to adult life, who lived in a developmental home (an adult foster care type arrangement) on a farm and received day supports from Small Town Counseling every day. John, who was nonverbal and used a communication board, liked photography and had a 1-hour-per-week job at a local photography shop. Adam: John's support worker	Observation as a pair for 1 day, during which John went to the grocery store and the local food co-op, went for a short hike, and spent some time at the Small Town Counseling office doing some therapy, taking photographs, eating lunch, and using the computer.
Adam	Individual interview
Rachel: an older woman who lived with her sister and had worked a variety of jobs and lived in a variety of settings throughout her lifetime. At the time of the study, she had a retirement lifestyle, supported by both her family and her day supports from Small Town Counseling. Becky, Rachel's support worker	Observation as a pair during one of Rachel's three-times-a-week CBNW outings, which consisted of going to the pool to do her physical therapy exercises and then out to lunch afterward.
Rachel and her sister Tina	Interview as a pair
State 2: College Town Supports (Provider 3)	
Agency director and two managers	Group interview
Henry and Fred: brothers who were living on the family farm that they grew up on. Their mother had died a few years earlier and at the time of the study, they received both residential (supported living) supports and day supports through College Town Supports. Kathy: Henry and Fred's support worker	Observations of all three during time spent at the local gym, where Fred was playing basketball and Henry was walking around the gym; Group interview
Frank: an older gentleman who was living in developmental home after years of living first in an institution and then in a group home. Frank was blind and was very talkative but difficult to understand. Kelly, Frank's support worker	Observation as a pair for one morning, during which time they volunteered sorting donations at a homeless shelter, bought ice cream, went for a walk in a large store, then bought lunch and ate it at one of College Town Supports' day sites; Interview as a pair
Harold: a younger man who received "wrap around supports"—both developmental home and day supports—from one person (Matt). Harold also received 1 day a week of day supports with another support staff (Nora). Nora: Harold's day support staff person	Observation as a pair on a trip to the dollar store.

Table 1
(continued)

Participant(s)	Data collection activity
Harold and Matt (Harold's developmental home provider)	Observation as a pair during one morning while going out to breakfast and to the general store.
Matt	Individual interview
State 1: Department of Mental Retardation	
Six state agency participants: two at the central office and four at regional offices	Individual interviews
State 1: Suburban Employment and Day Services (Provider 1)	
Two managers	Interview as a pair
Nancy: a quiet but verbally communicative woman who had been moved from the employment program to the CBNW program a few years earlier because she had said she did not like to work and had had behavioral problems at work. Mark: a younger man who communicated using sign language, used a wheelchair, and lived with his mother. Mark had been in the CBNW program since he was 21 years old. Elizabeth and Mary: direct support staff	Observation as a group for 1 day, in which they participated in group activities including an outing to clean the fire training school and time spent at the Suburban Employment and Day Services site
Nancy, Elizabeth, and one of the managers	Group interview
Mark, Mary, and one of the managers	Group interview
State 1: Coastal Day Center (Provider 2)	
Two managers	Interview as a pair
Three people with disabilities, all of whom lived in group homes and came to Coastal Day Center most days: Edward: a vocal (but not verbally communicating) man who used a communication board and a wheelchair. Rebecca: a middle-aged woman with severe mobility impairments who communicated by clicking her tongue or using a communication device. Mandy: a younger woman, who was also nonverbal. Tamara: Edward's support worker Kate: Rebecca's support worker Valerie: Mandy's support worker	Observation as a group for 1 day in which time was spent both on a field trip and at the Coastal Day Center site. During the field trip, different individuals got out of the van at different stops. Edward bought parsley at the grocery store. Rebecca and Mandy went to the crafts store for supplies for a project to be done later at the day program site.
Tamara, Kate, and Valerie	Individual interviews
State 1: Community Day and Employment (Provider 3)	
One manager	Individual interview
Sarah and Erin (direct support staff)	Interview as a pair
Three members of the "seniors group," all of whom lived in group homes and had been coming to Community Day and Employment since the 1980s: Kate: a middle-aged woman who had started out in employment and then moved to the seniors group when it was established. Kate talked a lot but did not communicate verbally. Thomas: Kate's housemate, who talked a lot, repeating a lot of what others said, but did not do much communicating verbally. Oliver: the oldest and quietest of the group and the only member of the seniors group who was older than 65 years at the time of observation. Sarah (direct support staff)	Observation as a group during a day-long outing. Activities included having coffee at McDonald's, attempting to visit a friend who turned out not to be home, going for a walk at the shopping mall, eating lunch at McDonald's, and delivering Meals on Wheels.

Table 1
(continued)

Participant(s)	Data collection activity
State 1: No site (individual support agreement)	
William: a young man with an individualized support agreement who lived at home and was seeking work as a chef. Beth: William's sister	Interview as a pair

Note. All names of local agencies and individual participants are pseudonyms.

a success by state agency contacts and one because the state was not interested in participating.

The two chosen states scored well on multiple measures. State 1 had 41% in CBNW (the seventh highest percentage among the 40 responding states), had had early adoption of CBNW (in the 1980s), had a distinct funding category for CBNW, and had specific requirements for how much time could be spent in work for someone to be considered to be in CBNW. State 2 had 59% in CBNW (the third highest) and had a distinct funding category for CBNW; State 2 also provided a clear definition of CBNW ("Provision of supports to assist people with developmental disabilities to build relationships and be participating members of their communities"). Moreover, telephone interviewees in both states presented a clear sense of priorities and policies for CBNW, seemed relatively satisfied with the implementation of CBNW to date, and were supportive of the research effort.

Within the states, I used snowball sampling (Bernard, 2000) both to identify key state agency informants and to identify three exemplary local providers in each state and two to four individuals with disabilities within each provider. Snowball sampling, in which each respondent is asked to identify other potential respondents, is an appropriate technique with small groups of people who are likely to know each other. Snowball sampling was particularly appropriate in this study because I wanted to use the expertise of existing contacts to identify the best cases at each level, consistent with the extreme cases approach used at the state level. For example, I asked state agency contacts to identify the best local providers of CBNW and asked provider management to identify the best individual cases. This approach was designed to ensure to the extent feasible that the provider and individual cases studied were the best of the best, enabling me to make conclusions about the status of CBNW in each state and in general.

In State 2, the snowball sampling technique resulted in interviewing two people at the state level (both in the central office of the state agency) and conducting site visits at three providers identified by the initial state contact (who was also one of the two state interviewees). In State 1, the state was divided into three regions, so I interviewed one or two state agency employees in each region (all on the basis of the recommendations of the original contact person, whom I did not interview for the study) and asked the key contact in each region

to identify one exemplary provider in that region. I also interviewed two state agency employees from the central office of the state developmental disabilities agency (also recommended by the original contact person). Finally, within each local provider, I asked the key provider contact (the person recommended by the state contact) to identify any other management-level staff that he or she wanted to include in the management-level interview as well as two to three individuals with disabilities who had successfully used CBNW supports.

To protect respondents' identities, all names of both agencies and individuals have been replaced with pseudonyms in this manuscript.

Data Collection

I conducted all interviews in person, at a place convenient for the interviewee. Most (89.3%) interview sessions were tape recorded and transcribed. Two individuals with disabilities objected to being recorded, and one staff member was interviewed in an informal discussion that was not recorded. In all three of these cases, I took detailed notes that I then used as the main source of data for analysis. Interviews lasted anywhere from 10 minutes to an hour, with most taking between 20 and 40 minutes. Some people were interviewed individually where others were interviewed in groups of up to four (see Table 1); whether the interviews were done individually or in groups was based on the preference of the interviewee(s).

Each interview was based on an open-ended interview protocol, with different protocols for state agency interviewees, provider management, individuals, and family or direct support staff. I did not always strictly follow the protocol in order but did make sure the conversation touched on each of the major questions. State and provider questions focused on CBNW goals, policies, and practices and included the following:

- What is your agency's name for CBNW? What is its definition?
- What are the goals of CBNW? How do these relate to overall agency goals?
- What criteria are local providers' CBNW programs required (or encouraged) to meet?
- What activities do people in CBNW participate in?
- What is the relationship of CBNW to other service types?

- What groups of people does the agency seek to serve in CBNW?
- What (if any) feedback have you had on CBNW from self-advocates, family members, or other advocates?

Individual, family member, and direct support staff questions primarily emphasized what people did during the day, how much they liked it, and the level of choice they had with respect to day supports and activities. Questions for these participants included the following:

- What do you/your family member/the person you support do in CBNW?
- How much time do you spend there each week?
- Do you/your family member/the person you support like it? What do you like about it? What don't you like?
- What other activities do you/your family member/the person you support do during the day?
- Do you belong to a self-advocacy group? Has that group had input or suggestions about CBNW?

Observations lasted anywhere from 2 hours to a full 8-hour day. The length and the timing of the observation as well as how many people were observed at once depended on the schedule and activities of the people being observed. Typically, the observation involved 1 day's worth of activities, but how many hours of supports each person received in a day varied. Moreover, with one exception (John and Adam at Small Town Counseling), the day-long observation periods involved those in group supports, who generally had more hours of supports. Consequently, the number of hours of observation was more consistent at two to three when considered on a per-person basis. Because the small size of the groups and the extent to which they moved around made it impossible to observe unobtrusively, I adopted a participant observation approach, joining the individuals and their support staff in whatever activities they had planned for the day. I typed up detailed field notes at the end of each day or visit.

One person with a disability was only interviewed and not observed at the request of him and his family member. Nine people with disabilities were observed but not interviewed because they were nonverbal (six people), declined to be interviewed (two people), or had already answered most of my questions during the observation (one person). Two direct support staff were interviewed but not observed in both cases because they had connections with the program or individuals in the case study but were not part of the group outing that I observed. Four direct support staff were observed but not interviewed: In three of the four cases, another direct support staff or family member was interviewed on behalf of that individual, and in the fourth case, a formal interview was not scheduled because I had the opportunity to discuss the person's supports during the observation. All participants had the opportunity to review a written summary of their case description for accuracy.

Finally, I reviewed a number of documents from state agencies and local providers, including regulations, policy manuals, annual reports, and guidelines for service providers, individuals with disabilities, and family members. The purpose of the document review was to obtain detailed information on CBNW goals, objectives, regulations, and policies; state quality assurance practices as related to CBNW; participation in CBNW; and satisfaction on the part of self-advocates and family members. For State 1, the following documents were reviewed:

- State DD agency annual reports (2001, 2004)
- Individual and Family Fact Sheet: Person-Centered Planning (2003)
- Individual and Family Fact Sheet: Home and Community-Based Services Waiver (2004)
- Review criteria for annual reviews of provider agencies (n.d.)
- State DD Agency Mission Statement (2004)
- Sample Service Contract with Provider Agency (2005)
- Supports and Services Descriptions (2004)
- State DD Agency Five Year Plan 2002–2007 (n.d.)
- Participant Handbooks for Senior Program and Community Program at one selected provider

For State 2, the following documents were reviewed:

- State DD Agency Annual Reports (2003–2005)
- State DD Agency Guidelines for Quality Services (1994)
- Regulations Implementing the Developmental Disabilities Act of 1996 (1998)
- Individual support agreement guidelines (2003)
- Selected provider review reports (2002–2004)
- Brochure for one selected provider

Triangulation of multiple data sources provided a more thorough understanding of CBNW. For example, although state- and provider-level interviewees tended to present the best-case scenarios in describing CBNW, the observations seemed closer to what a typical day might look like, providing a valuable sense of the day-to-day reality of CBNW. The observation sessions were also particularly important in that they provided insight into the lives of those individuals who were unable to complete an interview because of communication or cognitive barriers. In addition, information about state policies gathered through the state agency personnel interviews and the reviews of state agency documentation could be reinforced with provider-level interview and observation data to make conclusions about state-level policies and practices in each state and comparisons of policies and practices across the two states.

Data Analysis

Coding and memo writing (Miles & Huberman, 1994) were the primary tools for analysis of the field notes and interview transcripts. I conducted all coding myself using

Atlas.ti software. I derived my initial themes for coding from the four major concepts (as described in further detail later) and from the research questions and interview protocols and added new themes as they emerged from the data. Full qualitative coding was not used for the document review because the documents reviewed did not focus as extensively on CBNW as the other data sources; for these, I took notes and used those notes to inform the next stages (memo writing, developing case descriptions, and pattern matching, all described later). The notes from the document review were particularly useful in determining how providers' approaches reflected state-level policies and making conclusions about the states.

I further developed the themes through memo writing. As recommended by Miles and Huberman (1994), I wrote memos throughout the research process, starting with initial reflections and observations on the basis of each site visit. Later memos were more detailed and incorporated coded text from the interview transcripts as well as evidence from other documentation. I then sorted the memos according to the major overarching concepts, and they served as the basis for the findings. Throughout the process, I discussed emerging themes with colleagues as a check on researcher bias, as recommended by Yin (2003).

Yin (2003) describes two general strategies for analysis of case study data: (a) relying on theoretical propositions and (b) developing case descriptions. I used both strategies in the analysis for this study. I developed case descriptions to address how CBNW is defined and implemented by state agencies and local service providers and how it is experienced by individuals with disabilities. To address whether CBNW is in keeping with current goals of disability policy as articulated in the Emerging Disability Policy Framework, I used pattern matching (Yin, 2003), an approach that involves comparing the actual data with the expected pattern on the basis of the theoretical proposition. I used pattern matching to compare the actual data with the ideal of meeting the goals of the ADA as expressed in the Emerging Disability Policy Framework.

As described earlier, both the ADA and the Emerging Disability Policy Framework focus on four goals: equality of opportunity, full participation (empowerment), independent living, and economic self-sufficiency (Silverstein, 2000). In this study, I examined four basic concepts, drawn from the four goals, that are particularly relevant to I/DD supports and services. The first goal described in the Framework, equality of opportunity, relates to the provision of *individualized* and *integrated* services and supports. The second goal, full participation, relates to *choice* (participation by individuals in decisions about the services and supports they receive) and *empowerment* (participation in the development of legislation and policy). The third and fourth goals in the Framework, independent living and economic self-sufficiency, both can be

considered part of *independence*. Therefore, this study investigates the effectiveness of CBNW supports in the areas of individualization, integration, choice/empowerment, and independence.

For coding and analysis, I expanded the four Emerging Disability Policy Framework concepts into more detailed codes related to actual practices. For individualization, I used two measures: (a) whether supports were primarily provided on an individual (1:1) basis and (b) whether person-centered planning or a comparable approach was used to design supports. For integration, I coded four levels of integration: (a) *presence* or physically being in community settings (rather than at a facility or site), (b) *interaction* with community members outside the developmental disability system, (c) *friendly acquaintanceship* with community members outside the developmental disability system, and (d) *friendship* with community members outside the developmental disability system. I considered friendship to be a relationship that extended beyond situational contact; for example, someone would only be considered friends with a worker from the local coffee shop if he or she interacted with that worker outside the context of purchasing coffee. I coded choice and empowerment as two distinct concepts, with choice denoting participation by individuals in decisions about their services, supports, and activities and empowerment denoting self-advocacy and participation in the development of legislation and policy. I measured the contribution of CBNW supports to independence in two ways: whether independent living skills were being gained and whether CBNW was helping the individual work toward an employment goal (as a proxy for increased financial independence).

Results

This manuscript presents findings from the pattern matching analysis for each of the four major concepts (individualization, integration, choice/empowerment, and independence).

Individualization

Individualization in State 2

Individualization was one area in which the findings differed across the two states. In State 2, one of the overarching principles guiding disability supports was individualization. Statutes and regulations limited the number of people in a residential setting and prohibited the use of state funds for congregate day programs such as day habilitation centers or sheltered workshops. The state's *Guidelines for Quality Services* included providing personalized services on the basis of individual planning. The two state agency interviewees, who had central roles in certification of providers, had basic expectations that providers would use person-centered planning and provide one-on-one supports. The state's philosophical emphasis on individualization carried through to provi-

ders' practices, with a clear pattern of individualization evident in both interviews and observations. Management and staff at all three providers in State 2 talked about the importance of person-centered plans to designing individuals' supports. As described by one provider director, "people go to programs in most places, and in State 2 they don't go to programs. They come to agencies that are organized to design programs around them." My observations in State 2 were consistent with this characterization of CBNW, with six of the eight individuals observed receiving 1:1 supports at the time of observation; the other two were brothers who lived together and received some day supports together. Activities observed in State 2 included (a) going to the grocery store or dollar store, (b) going out to eat, (c) volunteering (once at a nursing home and once at a homeless shelter), (d) meeting up with a friend and her support worker, (e) going hiking, and (f) going to the pool or gym.

Although supports were individualized in State 2, there were examples of people participating in activities and events that involved other people with I/DD. Three of the people I observed were involved in both Special Olympics and self-advocacy groups; two providers had day sites where people with disabilities and support staff congregated for lunch, and two providers offered classes or other group activities.

Individualization in State 1

In State 1, individualization and person-centered planning were embraced philosophically but the day-to-day provision of supports was more group based. Both state and provider-level interviewees in State 1 talked about using person-centered planning approaches. A state interviewee in one of State 1's three regional offices said that state quality monitors were attentive to "quality from the person's point of view. Like, does this person have a person-centered plan in the file? Are staff aware of it? Are they implementing it?" Provider management and staff interviewed in State 1, consistent with these state-level expectations, also emphasized the role of person-centered planning. A typical statement by a provider manager was that "Individuals have teams, and that helps out with that decision [whether to place them in employment or CBNW]."

Despite this focus on person-centered planning, the supports and services that I observed in State 1 (which were selected to be the best examples of CBNW) were almost always provided on a group basis. All three of the service providers I visited provided CBNW supports in groups, and two of the programs were primarily facility based. In contrast to what I saw in State 2, in State 1 I saw only group outings involving three or more people with disabilities and one or two direct support staff. Activities observed in State 1 included (a) going to the grocery store, (b) going to the craft store, (c) going to McDonald's for lunch or coffee, (d) going for a walk at the mall, (e) volunteer work (once delivering Meals on Wheels and once

cleaning at a fire training school), and (f) recycling cans. The staff took individuals' preferences into account in deciding on activities, but because of the need to accommodate a whole group, no one individual's supports could be tailored entirely to his or her interests.

Individualized Support Agreements, an emerging model of supports, provided an option for more individualized supports in State 1, and I did interview one individual who was receiving such supports through family members and had no connection with a program or site. Such cases were still relatively rare, however, accounting for only about 5% of funding, according to a state agency interviewee.

Integration

Integration in State 2

In State 2, it was clear from both interviews and observations that CBNW provided presence in the community (physically being in community settings, the first of the four levels of integration described in the Analysis section). State and provider interviewees emphasized being in the community as a goal, and my observations were consistent with that emphasis. Three of the people I observed never set foot in a provider site during the time I spent with them, three went to an agency site only for lunch, and one came to the provider site only to meet with me. It was revealed in interviews that some of these individuals did participate in on-site activities, but those were clearly a minority of their CBNW time. Only one person spent a considerable portion of his day (about half) at an agency site, and he was described by provider staff as an exception to the rule.

Being located in the community, CBNW activities in State 2 frequently involved opportunities for interaction with community members outside the developmental disability system (the second level of integration), both in formal activities such as classes or volunteer projects (which were described to me by state and provider interviewees) and (more commonly in my observations) in informal ways such as interacting with employees at a restaurant or shop. For example, five of the people I observed interacted with people like cashiers, food servers, and librarians.

I also personally witnessed a few examples of friendly acquaintanceships with people outside the developmental disability system (situations where people know and are friendly toward each other in a particular context, the third level), including one individual who was clearly known to the staff at Dunkin' Donuts and one who, with his support provider, visited with the owner of the local general store. Several more examples of friendly acquaintanceship were relayed to me in state and provider staff interviews.

Such relationships with people outside of the DD system did not, however, appear to frequently reach the level of what could be considered a friendship (a relationship that continues outside a particular context, the fourth level). I did not, in fact, observe any examples of

people interacting with friends outside the DD system. Instead, in interviews with individuals and family members, the relationships most often mentioned were with staff. One individual said her favorite thing to do was to “spend time with [her support worker].” Another individual’s father said that she and her support worker “get along good.” A third individual talked at length about a previous support staff person to whom she had been “very attached ... she invited me to go to her house many, many times,” and another who “was physically in the family.” I also observed interaction with friends who also had disabilities; for example, one woman met up with a friend with I/DD (with both women’s support workers present) to play cards at Dunkin Donuts.

Integration in State 1

In State 1, getting out in the community was a goal of CBNW according to state and provider interviewees. A state agency interviewee said that the goals of CBNW were “in keeping with our philosophy of community inclusion. That people are part of the community, that they belong in the community, that they have the right to participate in community activities,” and a provider manager said that “we want them to be able to go out, have a nice social time ... get them interactive and blend into the community.” The goal of making connections also stood out in the manual for CBNW support workers, titled *Community Connections*, which described itself as “a training guide that focuses largely on developing your skills as a support person to more effectively connect community members with their neighbors and coworkers with disabilities.”

In my observations, however, individuals in State 1 did not necessarily spend most their supported day in community settings, despite the fact that they had been chosen to represent successful examples of CBNW supports. Two of the three provider sites offered site-based programs; staff and managers informed me that individuals typically went out in the community on group trips two to three times a week, with each outing lasting anywhere from a couple of hours to most of a day. Consistent with that description, each group that I observed went on one outing during the 2 days I was at their site; one group for a couple of hours (although that outing was limited due to bad weather) and the other for most of a day. The third group did spend the whole day away from the agency site, but a considerable portion of the day was spent traveling from place to place in the agency’s van.

Because time in the community was limited, I observed fewer opportunities for interaction with community members in State 1 than I did in State 2. Even when people were out in the community, opportunities for making connections with community members seemed to be diminished by the dynamics of the group supports. For example, in one group, to keep supervision of the group manageable, staff brought one or two people in at each place they stopped while the others waited in the van. Another group spent much of the day volunteering cleaning a building, where

they did not see anyone else. The third group went out for coffee, for lunch, and for a walk in the mall, but during these activities the participants stayed together as a group and interacted only with each other; when this group later delivered Meals on Wheels, only one person got out at each drop-off site, and even then the interaction with the person receiving the meal was very brief.

Although some provider staff cited examples of friendly acquaintanceships in the community, such relationships were not apparent in my observations, suggesting that the friendly interactions described by staff may not be widespread. Real friendships appeared to be, if anything, even more rare in State 1 than that in State 2. I did not observe any examples of individuals having friends outside of the DD system. This observation was corroborated by a state agency interviewee’s statement that relationship building was a real challenge in this state:

We’ve got a lot to improve and a long ways to go in being creative, making sure people are participating as much as possible in their local communities, doing things that they really like to be doing, and always paying attention to, I think, valued roles ... to be creative, to be constantly pushing on the boundaries of ways to integrate people into their local communities, to have people making friends, making relationships.

Choice and Empowerment

Choice and empowerment in State 2

Choice (of each individual’s supports and activities) was clearly valued in state policy in State 2, with one of the state’s *Guidelines for Quality Services* being that “People and their families and guardians have opportunities to make meaningful choices about services.” In keeping with that guideline, the decision to be involved in CBNW was described by state and provider agency personnel as the individual’s choice. One of the State 2 state employees described the choice of day supports as open ended: “You generally get 20 to 25 hours of support. If you want to work, you can work. If you want to have more community, social nonwork stuff, you can do that too.” Once someone was receiving CBNW supports, providing a choice of activities also came through as a goal in State 2 both in interviews and in observations. Both management and staff of local providers talked about supporting choice. Provider staff who were interviewed frequently said they wanted to support choice, although it was sometimes challenging to do so given individuals’ communication barriers, their lack of experience with community activities, or the lack of options.

Because I was not often able to directly interview the individuals I observed, it was difficult to verify the extent to which CBNW was actually their choice as opposed to what parents, guardians, or staff thought was best for them. However, findings from the consumer survey of State 2 indicated that 94% of individuals said that they were “listened to at their support plan meetings,” 89%

said “people at their agency listen to them,” and 82% said they felt they had enough control over their life. In addition, during my observations, there was a clear effort on the part of the provider staff to discern individuals’ preferences, and that effort was reflected in the statements of individuals and family members regarding their satisfaction with CBNW. For example, one woman, Emily, had worked in the past and had switched to CBNW because of concerns about losing her Social Security payments. The Social Security issue seemed to be more her parents’ concern than hers, but she did say that there was not anything else she wished she were doing during the day. Another participant, John, was just transitioning out of school and receiving CBNW while also exploring employment options. Although Adam, his support worker, said that he “couldn’t see [a job] as a goal as far as something he could do,” his father and support team were trying to figure out a way for him to be self-employed as a photographer on the basis of his clear interest in taking pictures. His enjoyment of photography was apparent in my observations of him as well. Rachel, one of the more articulate people, was 60 years old and had health issues, so she was being supported in CBNW although she had worked in the past. She was, however, clear about what she wanted out of CBNW and had even, with her family’s help, laid off a past support worker who did not listen to her. Another older participant, Frank, had never worked, and Kelly, his support staff member, thought CBNW was best for him because of his age; it was difficult to determine what Frank thought. Henry and Fred, two brothers interviewed together, both had worked (at the family farm and elsewhere) when they were younger; Fred said that he did not like working, whereas Henry did not have much to say on the matter. Harold, an individual whom I observed in State 2, was working a few hours a week and spent most of his remaining time with his support worker, Matt; although Harold did not articulate verbally whether this was his choice, he did seem content spending time with Matt, and the staff who worked with him reported that a number of adverse and even violent behavioral problems that he had when living in a group home and receiving more formal day supports had disappeared when he had gone to live with Matt.

Regarding empowerment (opportunities for input on policies and supports more generally), provider interviewees described using a variety of feedback mechanisms, including advisory councils or committees and open-door policies to give people with disabilities a voice in their services. In addition, interviewees at all three provider agencies as well as the state agency reported using satisfaction surveys to gain feedback from individuals and families. Participation in self-advocacy was also encouraged; according to state interviewees and documents reviewed, 15 self-advocacy groups were operating in the state. Provider-level interviewees also stated that their agencies supported self-advocacy groups. Responses to the state’s consumer survey reinforced the idea that

self-advocacy was indeed widespread, with 82% of respondents saying they saw themselves as self-advocates. Consistent with this emphasis on self-advocacy, two of the three providers I studied had self-advocacy groups that they supported and at least three of the individuals I observed had been involved in self-advocacy groups and traveled to state or regional conferences and events.

Choice and empowerment in State 1

Where in State 2, choice was conceptualized as a person-by-person decision of what an individual wanted to do with his or her supports, in State 1 choice was described by state and provider interviewees more as a way for people to pick a day program or a provider. Portable funding, which had recently been made the standard for all residential and day supports, meant that people could take their money to any provider they chose. As a provider manager put it, “The participants go around and pick where they want to work, where they want to live. It’s up to them, it’s not up to us.” This characterization was consistent with how the system was described by state agency interviewees as well. People also had the option to take their funding and develop an Individual Support Agreement, but with only 5% of individuals choosing that option (according to a state agency interviewee), most simply used portable funding to choose among a set of program-based options.

As far as choice of activities within CBNW is concerned, it was clear in my observations that providing such choices in State 1 was difficult because of the grouped nature of supports. Despite the good intentions of the provider staff, the need to juggle a variety of needs and interests constrained choice. For example, if some people in the group had behavioral issues, needed a lot of personal care assistance, and/or were wheelchair users, those needs limited where the group could go, for how long, and how many of them could participate in the activity. In addition, two of the three sites I visited had a limited number of vans available for outings. Because of these limitations, both my observations and the interviews with provider staff and management indicated that choice in State 1 was offered on a more limited basis. For example, an individual might have a choice between participating in one activity or another or between going on an outing and staying at the facility.

It was even more difficult in State 1 than in State 2 to discern the extent to which individuals had had the opportunity to choose their setting or were satisfied with CBNW, both because of the communication barriers and because I observed them in groups. On the basis of the limited evidence I had, however, there seemed to be less individual choice in State 1 than that in State 2. Rebecca, Mandy, and Edward, the three participants at Coastal Day Center, all had always been in CBNW, and the staff there did not believe they were capable of work, suggesting that they had not been exposed to other alternatives; none of the three was interviewed so I could not be sure how they

felt, although they seemed happy enough during my observation. Mark, one of the individuals observed at Suburban Employment and Day Services, likewise had never tried employment. Another participant at the same provider, Nancy, had worked in the past and had been moved to CBNW because her behaviors indicated that she did not like the structure of working; the staff reported that she seemed to like the CBNW program as evidenced by her improved behavior. Although I interviewed both Mark and Nancy, their direct support staff were also present and did most of the talking, so I did not have a clear response regarding their satisfaction. Nancy did answer yes to the question, "Is there something else you would rather be doing during the day?" although she was unable to articulate what it was she wanted to do. Kate, Thomas, and Oliver, the three participants in the "seniors group" at Community Day and Employment, had all worked in the past and had been moved into CBNW as they aged. Again, although they seemed happy enough during observations, none of these individuals was interviewed, so it was difficult to ascertain their level of satisfaction. William, who had an individual support agreement, had had the clearest opportunity to exercise choice in his life; he had always liked to cook and wanted to become a chef, so his individualized supports had been used to pursue that dream.

As in State 2, state and provider interviewees in State 1 indicated that individuals and their families were empowered through a variety of feedback mechanisms, including satisfaction surveys and "open-door" policies at both provider and state levels. There was, however, less evidence of widespread support for self-advocacy in State 1. Self-advocacy activities were taking place in State 1, according to state and provider interviewees, but none of the individuals I observed were participants in self-advocacy activities and none of the providers chosen as cases supported self-advocacy groups.

Independence

Independence in State 2

As described in the Analysis section, I examined two concepts related to independence: whether independent living skills were being gained through CBNW and whether CBNW was helping the individual work toward an employment goal. In State 2, goals related to independent living (such as learning, growing, and skill building) were expressed as goals by state, provider, and family interviewees, although other goals such as individualization and building relationships were more predominant. One state agency interviewee said that "what we look for [in CBNW] is, we look for opportunities to promote individuals' growth, what kind of learning opportunities they have, what skills are they learning." An individual's father mentioned that she had seemed more mature in the past few years, in part because in her CBNW supports "they have been working with her on some independent things that she can do by herself." In keeping with these statements, several of the individuals I

observed in State 2, according to interviews of the staff supporting them, were using CBNW supports to pursue goals related to learning or developing independent living skills. For example, a couple of individuals were learning skills related to grocery shopping, three had communication skills goals, and one was volunteering and hoping to find a part-time job.

Employment was also prioritized in State 2; although trying to encourage choice in day activities, managers and staff at the state and provider levels described employment as the preferred option for working-age adults. Because of the emphasis on employment, it was common for individuals to receive both employment and non-work supports. A state employee described how CBNW could fill out the day for people working only a few hours a week:

We have some folks with very, very significant disabilities working, and may only be able to work two or three hours a week, but they're doing something that they enjoy. And so they do spend other parts of their day in community supports doing other leisure, and recreation and social activities.

Consistent with these state-level statements, staff interviewed at all three State 2 providers described individuals to whom they provided a combination of work and non-work supports, and a couple of the individuals I observed in State 2 had such arrangements. Two others were considering or working toward employment, and three were not considering work because they were of retirement age. Only one person who was not old enough to be considered retired had no employment or employment goals.

Independence in State 1

In State 1, although state and provider interviewees described the primary emphasis of CBNW as getting out in the community and making connections, improving skills toward independent living was also described as a goal. Consistent with the interviews, skill-building activities being pursued by the people I observed included learning to recycle cans, learning to grocery shop, and learning to behave appropriately in public settings such as restaurants.

Employment seemed to be less consistently embraced as a goal at the state level in State 1 than that in State 2; some state agency interviewees saw employment as the preferred option for working-age adults, whereas others emphasized choice and community participation and de-emphasized the preference for employment. There was also considerably less emphasis on the primacy of employment at the provider level in State 1, with staff and/or management at each of the three providers stating that certain people simply would not ever be expected to work. Two providers observed in State 1 offered both employment and nonwork supports, and both had people who did some of each. It seemed more common, however, for individuals with severe disabilities not to have been exposed to employment at all, as was the case for four of the

eight individuals I observed; the other four had worked before, but only in group settings.

Discussion

The findings of this study indicate that CBNW is neither a success nor a failure as a concept. Although neither of the two state cases studied was entirely successful in advancing the goals of individualization, integration, choice/empowerment, and independence, there were elements of success in both states. Interviews, observations, and document review all indicated that CBNW in State 2 was individualized, both in the use of person-centered planning and in the actual provision of services and supports, whereas in State 1 individualization was considered a good idea conceptually (as evident in interviews of state and provider personnel) but not achieved in practice in the cases I observed. Integration took place in both states at the most basic level of having presence in the community but was limited in the sense of interactions, acquaintanceships, and friendships with community members, more so in State 1 than that in State 2. Choice and empowerment were embraced as ideas by state and provider interviewees in both states, but observations revealed that these were more practically available in State 2, with choice in particular being related to the individualization of supports. The contribution of CBNW to independence appeared to be limited in both states, although there were opportunities for skill building and some examples of people both working and participating in CBNW.

The issues and challenges identified in these case studies were consistent with those in previous studies of CBNW and with Walker's (2007) suggested key components for successful CBNW (pursuit of individual interests, importance of place and being in social spaces, and having opportunities for social relationships and community connections). For example, as described in the findings, despite the stated goal of offering individuals choices, pursuing individual interests was challenging in both states. In State 1, the provision of group supports made it difficult to support individual choices. State 2 had more success in this area because of its individualized supports, but even there challenges such as communication barriers and lack of exposure to the community posed challenges to staff. Sowers et al. (1999), in their study of ATE in Oregon, likewise found that

most programs focused on a limited range of recreational, leisure and social activities, as well as personal and health care ... popular community activities included going to parks, fast food restaurants, walks, and window or in-store shopping. Staff worked to fill each individual's day with "fun" and to keep each person occupied while they were away from home (p. 2).

This finding is consistent with the types of activities I observed. I noted in my observations that some (but not

all) CBNW outings, across both states, seemed to involve simply "having fun" (as stated by one provider staff interviewee in State A) and being out and about in the community. In particular, I observed a number of the same activities described by Sowers et al. (1999), including going for walks, window shopping, and going to fast food restaurants.

Regarding the importance of place and being in social spaces, my findings on integration were consistent with previous studies regarding the role of facilities. For example, Hall and Walker (1997) reported that Common Ground had started renting a small apartment to provide a private space for personal care, a similar situation to the use of day spaces for certain activities by the community-based providers I observed in State 2. Walker (1998) also found that determining how to use the facility base (without falling back on it to such an extent that community connections were impeded) was a challenge at Options for Individuals. KFI (Walker, 2000) had committed to closing down its facilities out of a belief that maintaining a facility meant "maintaining a dual system of services." Although each agency's approach was different, the difficulty of determining how, if at all, to use facilities was a clear theme both in the previous literature and in my case studies.

Finally, I found that building social relationships and community connections was a real challenge for CBNW in both states. Likewise, Sowers et al. (1999) found that there was little focus on relationship building in ATE, and Hall and Walker (1997) reported that figuring out how to make social connections and build relationships was a challenge for Common Ground. In contrast, Walker (1998) reported that key promising practices at Options for Individuals included recognizing the importance of spending time in the right places to make connections and actively facilitating the formation of quality relationships with community members; at KFI, Walker (2000) also found that a focus on a variety of relationships among individuals with disabilities, families, staff, and community members was important. Whether a challenge or a positive outcome, relationships were clearly a key issue.

Limitations and Suggestions for Future Research

This study has several limitations. First, the data were collected in 2004–2005 and as such are several years old. There have not, however, been any substantial policy changes since then that would make these data irrelevant. Furthermore, there are few other sources of detailed information about CBNW, which has continued to be a growing service category, reaching 31% of individuals served nationally in FY2007 (Butterworth, Smith, Hall, Migliore, & Winsor, 2008).

A second limitation is that because of the small number of people with disabilities interviewed, the limited verbal communication capacity of the those who were

interviewed, and the presence of staff and/or a family member at each interview of a person with a disability, the direct voice of people with disabilities is largely absent in the findings presented here. As such, the findings reported about participants with disabilities, particularly around issues such as choice, must be regarded with a critical eye. Augmenting the interview data with observations did address this issue somewhat by providing reinforcement (or in some cases contradiction) of what staff said in interviews. Despite this limitation, the opportunity to meet with them, to hear their reactions in whatever way they offered them, and to observe them was an important component of data collection. Becker, Roberts, Morrison, and Silver (2004) note that the decision whether to interview people with severe disabilities inevitably involves a trade-off between bias generated by having others speak for individuals who cannot speak for themselves and bias due to leaving out a considerable segment of the population. For the purposes of this study, it seemed particularly important not to leave out the experiences of people with severe disabilities because they can be expected to be overrepresented in nonwork (rather than employment) supports.

Third, the study addressed CBNW primarily from a policy standpoint, as related to the Emerging Disability Policy Framework and its goals. Because of a combination of this policy focus and the lack of direct interview data from a number of participants with disabilities, the study did not comprehensively address other important questions such as whether individuals are happy in CBNW or whether it contributes to their quality of life. Also, the emphasis on independence as a component of the framework did not address the limitations of the concept of independence, that is, that total independence is neither desirable nor achievable for most people. The idea of interdependence may represent a better and more realistic goal.

Fourth, the selection method for the cases studied was imperfect. Because of a lack of available data on outcomes, I chose the state cases on the basis of the data that were available, including information about how established CBNW was and how it was defined. Inherent in this decision was an assumption that the most established and well-defined CBNW programs would be the best ones. Furthermore, I relied on state agency contacts to select the best CBNW programs at the provider level and on provider contacts to select the best individual cases, assuming that they would be a reliable source of information on which programs had the best outcomes. It is possible that I missed better examples at each level by making these assumptions. The reliance on selected case studies also means that the cases studied, and the conclusions made from these cases, were not representative of the full population of CBNW programs or of individuals in each state.

Fifth, all coding was conducted by one researcher. I did not use the checks for interrater reliability recommended by Miles and Huberman (1994). The only method of

checking for bias was informal reviews of emerging themes and codes with knowledgeable colleagues. This approach may have allowed for bias in my coding and qualitative analysis.

Future research on CBNW could follow any of three strategies. First, the limitations of the current study could be addressed by applying different methods to the same topic. Where these case studies delved into selected cases in some depth, a survey of a random sample of CRPs across the country would better illustrate CBNW practices and outcomes across the population of service providers. Such a survey could be used to determine whether some of the issues and themes discovered in the case studies are indeed issues for a substantial proportion of people and programs. It would be particularly interesting to pair a survey of CRPs with data on state-level policies, either collected through a separate survey of state I/DD agencies or gathered from other research studies. Combining state and CRP survey data would allow for determining if the same patterns of similarities and differences seen in these two states are happening elsewhere. For example, the difference between these two states in individualization of supports seemed to be substantially related to differences in state policies and standards, and it would be of interest to see if similar policy differences have led to similar differences in outcomes in other states.

A different approach would be to address the limitations in terms of the amount of input on and focus on the individual CBNW participants. This limitation could be addressed by conducting a second qualitative study of CBNW experiences, this time based more on a quality of life framework and relying more heavily on interviews and observations of individuals and family members and less on state and provider staff interviews.

Second, in this study, certain topics arose as being particularly interesting or essential, and each of these is worthy of further exploration. For example, the topic of integration, particularly as it relates to relationships and community connections, has clearly emerged as an important one both in this study and in previous research on related topics (Abery, 2004; Amado, 1993; Putnam & Feldstein, 2003; Walker, 2007; Wetherow & Wetherow, 2004). Further exploration of how people with I/DD form relationships in their communities and how support systems can better support those relationships is clearly warranted. An approach such as social network analysis (Hanneman & Riddle, 2005) may be particularly applicable to this topic. Another topic worth exploring, potentially through the surveys of CRPs and states described earlier, is how CBNW interacts with other parts of the system of supports, including employment and residential supports, to create full lives for people with IDD. In particular, there is a need for more understanding of the extent to which CBNW supplements or replaces other day activities such as employment and how state and local policies affect the role of CBNW. Information on how

CBNW intersects with other day supports, in particular, would help in understanding the implications of the growth in CBNW seen in data from surveys of state DD agencies (Butterworth et al., 2008).

Third, the observations made in these case studies, along with those from other studies of CBNW (Hall & Walker, 1997; Hulgín & Searle, 1996; Sowers et al., 1999; Walker, 1998, 2000, 2007), could be expanded upon to develop and test a set of recommended policies and practices related to CBNW. In this strategy, a panel of experts in the DD and supported employment fields might be convened to review current research findings and expand on those using their expertise to develop a set of standards for good CBNW implementation. CRPs could then be recruited to participate in training and technical assistance on the basis of these standards and the outcomes for participants compared with a control group. Such a study would allow for more practical application of the concepts and recommendations in this manuscript.

Policy Recommendations

The variation in success in meeting the goals examined here (individualization, integration, choice/empowerment, and independence) indicates that CBNW can achieve those goals but currently only does achieve them under specific circumstances. As a result, there is a need for more clearly articulated expectations for CBNW. If CBNW is to achieve goals such as individualization, integration, choice, and independence, those goals must be clearly set forth and adhered to both by the state agency and by each provider. The need for clear goals is apparent in the differences between the generally stronger individual outcomes in State 2, where state policy and funding models require individual services in integrated settings, and State 1, where community integration supports are still embedded in a more group-based programmatic model of services. The expectations for CBNW should be made clear in both state policy and provider practice. Recommended expectations follow.

An expectation that group activities are a matter of choice, not convenience

All but one of the provider agencies studied for this project provided some group-based activities, services, and/or events. On the one hand, grouping people not only leads to less individualization of supports but also limits choices, opportunities for interaction outside the group, and opportunities to learn and grow. On the other hand, there are genuine friendships and relationships among people with disabilities that should not be discounted or discouraged. It is important, therefore, not to discontinue group activities altogether but to pay careful attention to each instance of grouping to ensure that it is the preference of the people with disabilities and not grouping for the convenience of agency support staff or for logistical reasons.

An expectation of integration and community membership

According to state and local interviewees in both State 2 and State 1, a major goal of CBNW was integration, yet for many people integration was taking place at only the most basic level of physical presence in the community. Previous case studies of CBNW (Hall & Walker, 1997; Walker, 1998, 2000, 2007) have likewise identified helping people make social connections and build relationships as both an important role and a challenge of CBNW. For CBNW to really accomplish integration, it needs to be expected not just to physically locate supports in the community but also to move people toward community membership and provide opportunities for formation of relationships with other community members.

Clearly more than simply “getting people out” is required to achieve social integration. To increase integration requires closer examination of the types of opportunities for interaction provided. Many of the interactions observed for this study were brief, superficial interactions with people such as store clerks; even when people did participate in more involved activities such as volunteer work, there frequently was limited interaction with community members without disabilities. To promote relationships, there is a need to focus on activities with certain characteristics, such as longer periods of contact, redundancy of contact, and shared interest or purpose (Abery, 2004; Amado, 1993; Putnam & Feldstein, 2003; Walker, 2007; Wetherow & Wetherow, 2004).

An expectation of individual choice and life planning

One way for CBNW to be better individualized and better promote choice is to have a strong emphasis on person-centered planning, with CBNW serving as simply one aspect of a person's plan to achieve his or her goals and desires in life. Both of the states studied for this project had person-centered planning in place, but it could have been applied more consistently and effectively. There was a tendency to focus on filling the day with individual activities and/or learning individual skills rather than looking at how CBNW fit into the individual's life plan and meshed with other supports and services. As CBNW becomes a substantial part of the service mix, it is important to consider what each individual's goals and interests are and how CBNW fits into the larger picture of his or her life.

An expectation of employment

One part of the role of CBNW in promoting independence is how CBNW relates to employment. Employment enables people with disabilities to take on typical adult roles, be more active participants in the community, and become more self-sufficient financially. Moreover, if people with disabilities are to be treated as equal by society, then to some extent they should have equal obligations as well—which includes an obligation to contribute to society through working. Consequently, it is important that

CBNW be considered a supplement to employment, with employment as the first priority.

An expectation for strong models of CBNW

In both research and practice, much more attention in recent years has been paid to community-based employment than to nonwork supports. The field of supported employment consequently has an established set of best practices for supporting people one on one in integrated, community-based settings. Certain elements of those practices, such as fading of supports and use of natural supports, could be applied to CBNW. By examining how practices such as these can be applied to CBNW, a clearer model of how to do CBNW could be developed to inform individual providers' implementation of CBNW.

Finally, it is important to remember that CBNW alone cannot achieve such lofty goals as individualization, integration, choice, and independence. Nonwork day supports are only one part of a much larger support system that includes formal residential supports, family members, friends, self-advocacy and other peer groups, places of employment, churches, and other community spaces and groups. To truly accomplish goals such as individualization, integration, choice, and independence, all of these sources of support and membership must be involved.

References

- Abery, B. (2004). Social inclusion through recreation: What's the connection? *TASH Connections*, 30, 29–31.
- Amado, A. N. (1993). Steps for supporting community connections. In A. N. Amado (Ed.), *Friendships and community connections between people with and without developmental disabilities*. Baltimore: Paul H. Brookes.
- Becker, H., Roberts, G., Morrison, J., & Silver, J. (2004). Recruiting people with disabilities as research participants: Challenges and strategies to address them. *Mental Retardation*, 42, 471–475.
- Bernard, H. R. (2000). *Social research methods: Qualitative and quantitative approaches*. Thousand Oaks, CA: Sage Publications.
- Butterworth, J., Smith, F. A., Hall, A. C., Migliore, A., & Winsor, J. E. (2008). *StateData: The National Report on Employment Services and Outcomes*. Boston: Institute for Community Inclusion.
- Draheim, C. C., Williams, D. P., & McCubbin, J. A. (2002). Prevalence of physical inactivity and recommended physical activity in community-based adults with mental retardation. *Mental Retardation*, 40, 436–444.
- Gaventa, B. (1994). Religious participation for all. *Exceptional Parent*, 24, 22–25.
- Grigal, M., Neubert, D. A., & Moon, M. S. (2002). Postsecondary options for students with disabilities. *Teaching Exceptional Children*, 35, 68–73.
- Hahn, H. (1993). The political implications of disability definitions and data. *Journal of Disability Policy Studies*, 4, 42–55.
- Hall, M., & Walker, P. (1997). "This is still a work in progress": *Common Ground*. Littleton, New Hampshire. Syracuse, NY: Center for Human Policy, Syracuse University.
- Halpern, A. S. (1993). Quality of life as a conceptual framework for evaluating transition outcomes. *Exceptional Children*, 59, 486–498.
- Hamill, L. B. (2003). Going to college: The experiences of a young woman with Down syndrome. *Mental Retardation*, 41, 340–353.
- Hanneman, R. A., & Riddle, M. (2005). *Introduction to social network methods*. Retrieved from <http://faculty.ucr.edu/~hanneman/>.
- Hulgin, K., & Searle, J. A. (1996). *Job path: Shifting the focus beyond just work*. Syracuse, NY: Center on Human Policy, Syracuse University.
- Institute for Community Inclusion. (2007). National Survey of State Systems and Employment Outcomes for People with Disabilities. Unpublished data.
- McNair, J. (2005). Community integration through faith networks. *Community Services Reporter*, 12, 5–6.
- McNair, J., & Swartz, S. L. (1997). Local church support to individuals with developmental disabilities. *Education and Training in Mental Retardation*, 32, 304–312.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded source book* (2nd ed.). Thousand Oaks: Sage Publications.
- Minton, C. A., & Dodder, R. A. (2003). Participation in religious services by people with developmental disabilities. *Mental Retardation*, 41, 430–439.
- Oliver, M. (2000). *The politics of disablement: A sociological approach*. New York: St. Martins Press.
- Putnam, R. D., & Feldstein, L. M. (2003). *Better together: Restoring the American community*. New York: Simon & Schuster.
- Silverstein, R. (2000). Emerging disability policy framework: A guidepost for analyzing public policy. *Iowa Law Review*, 85, 1691–1796.
- Sowers, J. A., Dean, J., & Holsapple, M. (1999). *The Alternatives to Employment (ATE) study: Toward full inclusion*. Eugene, OR: University of Oregon.
- Stanish, H. I., & Draheim, C. C. (2005). Walking habits of adults with mental retardation. *Mental Retardation*, 43, 421–427.
- Sulewski, J. S., Butterworth, J., & Gilmore, D. S. (2006). *Community-based non-work services: Findings from the National Survey of Day and Employment Programs for People with Developmental Disabilities*. Boston: Institute for Community Inclusion.
- Sulewski, J. S., Butterworth, J., & Gilmore, D. S. (2008). Community-based nonwork supports: Findings from the National Survey of Day and Employment Programs for People with Developmental Disabilities. *Intellectual and Developmental Disabilities*, 46, 456–467.
- Sullivan, J., Boeltzig, H., Metzel, D. S., Butterworth, J., & Gilmore, D. S. (2004). *The national survey of community rehabilitation providers, FY2002–2003: Report 2: Non-work services*. Boston: Institute for Community Inclusion.
- van Evera, S. (1996). *Memo 2: What are case studies? How should they be performed?* Cambridge, MA: Massachusetts Institute of Technology.
- Walker, P. (1998). *Creating meaningful daytimes: Community building at Options for Individuals*. Louisville, Kentucky. Syracuse, NY: Center on Human Policy, Syracuse University.
- Walker, P. (2000). *Acting on a vision: Agency conversion at KFI, Millinocket, Maine*. Syracuse, NY: Center on Human Policy, Syracuse University.
- Walker, P. M. (2007). Promoting meaningful leisure and social connections: More than just work. In P. M. Walker & P. Rogan (Eds.), *Make the day matter!: Promoting typical lifestyles for adults with significant disabilities*. Baltimore: Paul H. Brookes Publishing Company.
- Wetherow, D., & Wetherow, F. (2004). Adult recreation as a bridge to friendship. *TASH Connections*, 30, 16–19.
- Yin, R. K. (2003). *Case study research: Design and methods* (3rd ed.). Thousand Oaks, CA: Sage Publications.

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