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*Journal of Disability Policy Studies* published online 9 April 2012

DOI: 10.1177/1044207312439102

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# Examining the Experiences and Decisions of Parents/Guardians: Participant Directing the Supports and Services of Adults With Significant Intellectual and Developmental Disabilities

Journal of Disability Policy Studies  
XX(X) 1–14  
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DOI: 10.1177/1044207312439102  
http://dps.sagepub.com  


Judith M. S. Gross, PhD<sup>1</sup>, Luchara Wallace, PhD<sup>2</sup>, Martha Blue-Banning, PhD<sup>1</sup>, Jean Ann Summers, PhD<sup>1</sup>, and Ann Turnbull, EdD<sup>1</sup>

## Abstract

Participant direction is a service delivery model in which the consumer of public benefits, or his or her surrogate decision maker, exercises some level of choice and control over the consumer's supports and services. In this case study, the authors examined the decisions and experiences of parents/guardians who directed supports and services for an adult with significant intellectual and developmental disabilities (SIDD). Respondents included the parents/guardian of the adult as well as others in the circle of support identified by the parents/guardians. Data analysis revealed an overarching theme in which respondents perceived participant direction as a *means* to achieve an *end*, with the end being their desired outcomes for the adult with SIDD. Implications for policy include developing and providing supportive services to adults with SIDD and their parents/guardians due to the increased responsibilities associated with directing supports and services for the adult with a SIDD.

## Keywords

participant direction, consumer direction, Medicaid home and community-based services, self-direction

Supports and services for individuals with disabilities have evolved notably over the past 50 years. Historically, individuals with intellectual and developmental disabilities (IDD) were removed from the mainstream of society and placed in institutions (Pfeiffer, 1993; Wolfensberger, 1975) or were cared for by their families with little, if any, governmental financial support (Davis, Fox-Grage, & Gehshan, 2004). By the 1960s and 1970s, the disability rights and independent living movement sparked a need and desire for community services (University of California Berkeley, 2008). States responded to this by making the option of the Medicaid Home and Community-Based Services (HCBS) waiver available to their citizens with disabilities, allowing individuals otherwise eligible for institutional care to receive needed supports and services in home and community settings (Braddock, Hemp, & Rizzolo, 2008). Today, every state and the District of Columbia have at least one Medicaid waiver, and all but one of these are HCBS waivers. At least 45 states have waivers designed specifically to serve individuals with intellectual or developmental disabilities and/or their family caregivers (Centers for Medicare and Medicaid Services [CMS], 2010).

Generally, HCBS waiver services are provided through one of two models of service delivery: agency direction or participant direction (also known as consumer direction, self-determination, and self-direction among other terms; Turnbull & Turnbull, 2006). Although consumers have increasingly received services in their homes or communities for the past few decades, the services have traditionally been agency directed. In agency-directed programs, the individual with a disability typically has little choice (“the act of making a selection from a range of options”; Gross, 2010, p. 3) or control (act of “making substantive decisions” and “taking responsibility” for them; Gross, 2010, p. 4) over the services received or who provides them (Doty, Mahoney, & Simon-Rusinowitz, 2007). More recently, however, ever-increasing numbers of states have begun

<sup>1</sup>University of Kansas, Lawrence, USA

<sup>2</sup>Western Michigan University, Kalamazoo, USA

## Corresponding Author:

Judith M. S. Gross, Beach Center on Disability, University of Kansas, 1200 Sunnyside Ave., Haworth Hall 3123, Lawrence, KS 66045, USA  
Email: jgross@ku.edu

offering adults with IDD or their surrogate decision makers (i.e., parents, guardians, other family members, friends) the opportunity to participant-direct the HCBS waiver supports and services of the adult (Breihan, 2007; Walker, Hewitt, Bogenschultz, & Hall-Lande, 2009). In a program of participant direction, the adult with a disability and/or surrogate decision maker may act as the “participant” and take responsibility for such activities as recruiting, hiring, training, scheduling, and firing service providers; developing an individualized budget; and purchasing goods and services.

Many states have participated in waiver demonstration programs that have enabled individuals with IDD and their families (e.g., parents/guardians) to gain greater choice and control over the individuals’ supports and services. In the mid 1990s, the Robert Wood Johnson Foundation (RWJF) sponsored one of the largest waiver demonstration programs, authorizing funding to 19 states for the purpose of developing and implementing programs of participant direction for individuals with IDD (RWJF, 2004). In 1998, the Center for Outcome Analysis (COA) conducted an independent evaluation to assess the impact of the RWJF waiver demonstration programs on the participants’ quality of life. The COA evaluators found that participants in the programs reported improvements in “health, relationships, safety, activities, comfort, and other aspects of their lives” (RWJF, 2004, p.7). Respondents also reported greater involvement in decision making, with decisions ranging from personal preferences (e.g., where to go eat dinner) to budgeting and services purchasing.

Since then, other studies have also found an association between increased levels of choice and control over supports and services and positive changes in quality of life. Specifically, studies have found that providing individuals with IDD and/or their surrogate decision makers increased opportunities for participant direction in the individuals’ supports and services resulted in

- increased levels of community participation for the individual (Caldwell & Heller, 2003; Caldwell & Heller, 2007),
- increased satisfaction with services (Benjamin, Matthias, & Franke, 2000; Brown et al., 2007; Caldwell & Heller, 2003; Caldwell & Heller, 2007; Heller, Miller, & Hsieh, 1999; Neely-Barnes, Graff, Marcenko, & Weber, 2008),
- increased financial well-being due to increased caregiver employment and/or fewer expenditures (Caldwell, 2006; Caldwell, 2007; Caldwell & Heller, 2003; Foster, Brown, Phillips, & Carlson, 2005),
- increased emotional and/or physical well-being (Benjamin et al., 2000; Brown et al., 2007; Caldwell, 2006; Foster et al., 2005), and
- decreased unmet needs (Benjamin et al., 2000; Caldwell & Heller, 2007; Heller et al., 1999).

Participant direction of supports and services is most often implemented within the Medicaid program (e.g., state plans and waiver programs). Because Medicaid allows states the latitude to determine what populations to serve, services to offer, and degree of choice and control to extend to benefits consumers in directing their own supports and services (Nadash & Crisp, 2005; National Council on Disability, 2004; Tritz, 2005), participant direction differs across states. In addition, sometimes there is variance in implementation within a state, as states are not required to offer participant direction on a statewide basis (CMS, 2005). Because there is no consensus on how this service model is implemented, multiple program designs of participant direction exist across and within states (Gross, 2010; Nadash & Crisp, 2005; Tritz, 2005).

Participant-direction programs vary not only by structure and organization but also by number of people served, years in place, funding sources used for services, services allowed to be consumer controlled, who can be hired, and how much support is provided to consumers in making these choices and ensuring that legal obligations are met (Doty & Flanagan, 2002; Gross, 2010). Some programs of participant direction only permit consumers to have *employer authority* (i.e., the authority to hire, fire, and train service providers; CMS, 2010). However, other programs allow consumers greater levels of participant direction with regard to supports and services by allowing them to also have *budget authority* (i.e., the authority to develop an individualized budget and determine how to allocate the money in a way that individualizes the supports and services; CMS, 2010). The CMS acknowledge that some individuals with a disability may need support to exercise these authorities. Therefore, CMS allows states to permit waiver recipients to have representatives, or surrogate decision makers, to direct their supports and services. Often these surrogate decision makers are the waiver recipients’ parents/guardians.

Although parents/guardians are allowed to act as the “participant” in a significant number of states (Doty & Flanagan, 2002), little is known about their experiences and decisions relative to participant direction. The findings of a recent qualitative study, which had the purpose of documenting the experiences of parents participant directing their child’s Medicaid funded and services, suggested that some parents/guardians may have chosen participant direction because it was a philosophical match with what they envisioned for their child’s services (Nebeker, 2007). Others chose participant direction because of their son’s or daughter’s specialized needs (e.g., therapies and equipment) or simply a need for more support hours than could be funded through agency direction (Nebeker, 2007). The parents/guardians participating in a mixed methods study by Vinton (2010) indicated that the flexibility of participant direction facilitated meeting the unique needs of the family member with a disability. Still other parents/guardians

expressed that they chose participant direction in response to previous negative experiences with agency-directed services (San Antonio et al., 2010; Vinton, 2010). Such studies are few, despite the many programs of participant direction that allow parents/guardians to direct the supports and services of an individual with a disability. Additional research on this topic would shed light on the motivation for parent/guardian involvement and inform Medicaid waiver program directors regarding the supports needed by parents/guardians to manage their new responsibilities.

## Study Purpose

The purpose of this case study was to examine the catalysts for parents'/guardians' decision to assume the significant responsibilities of participant directing the supports and services of an adult with a significant intellectual and developmental disability (SIDD). As such we focused our research on the following question: In what ways do the experiences of parents/guardians influence their decisions to participant direct services for an adult with SIDD?

For the purposes of this research, participant direction is defined as a service delivery model in which the consumer of public benefits (in this study, Medicaid HCBS waiver services) has some level of choice and control (e.g., employer authority, budget authority) over the supports and services received. SIDD is defined as an intellectual or developmental disability that is characterized by the individual's need for pervasive supports "to participate in activities linked with normative human functioning" (Thompson et al., 2009, p. 135).

## Method

In the following section, we present the (a) strategy of inquiry, (b) case description, (c) data collection, (d) data analysis, (e) measures of trustworthiness, and (f) limitations of the study.

### Strategy of Inquiry

When identifying reasons for selecting a case study design, both Merriam (1998) and Yin (2003) explain that case study designs are best paired with topics that are complex in nature and are bounded by the context, or real-life environment, in which they occurred. We chose to collect qualitative data only for this case study because (a) participant direction is a complex process not easily evaluated using survey or experimental designs and (b) participant direction is a process that is clearly bound by the context (e.g., state, community, agency, family) in which it is implemented, and qualitative data collection best facilitates an examination of contextual factors. Most states offer some degree of participant direction in Medicaid waiver

supports and services (Breihan, 2007; Walker et al., 2009). Because each state is given discretion in defining participant direction and determining its program of implementation (Nadash & Crisp, 2005; The University of Minnesota Research and Training Center on Community Living, 2000), the context of participant direction is influential with regard to how and where it is implemented due to the lack of uniform policy, across and within states, regarding access and implementation.

### Case Description

The case, or unit of analysis, for this study is defined as follows: parents/guardians acting in the role of "participant" as a surrogate decision maker, exercising both employer and budget authority, to direct the supports and services of an adult with SIDD. This unit of analysis was investigated in the context of the adult's circle of support, which included the parent/guardian of the adult with SIDD, the participant-direction program director, and the adult's case manager and service providers. In the following, we describe the site selected and the sampling procedures used in this study.

*Site.* Due to the variation in participant-direction programs, we chose to identify respondents from only one program site. By including respondents from only one organization, we held constant the possible variations in experiences due to the widely different programs of participant direction in other local and state contexts. We selected a participant-direction program operated by a nonprofit organization located in the Midwest that provided community supports and services to people with IDD. This site had previously been a recipient of a RWJF demonstration grant for the purpose of assisting adults with IDD and their families to gain control and freedom of choice over needed supports and services. This organization continued to implement its program of participant direction after the grant ended in 2001. The director of the participant-direction program was our point of contact for identifying potential respondents for our study. The program director was responsible for the initial implementation of the RWJF grant as well as all participant-direction program services because the grant ended. In her role, the program director had personal contact with the program participants and was responsible for assisting all participants with the development of their individualized budgets.

*Sample.* We used purposeful sampling to identify respondents who could provide a rich collection of data. Purposeful sampling is a strategy where respondents "are selected deliberately in order to provide information that can't be gotten as well from other choices" (Maxwell, 2005, p. 88). We identified several criteria for study respondent selection.

First, we requested the program director to identify adults with SIDD in the participant-direction program who required pervasive support of a parent/guardian with the

**Table 1.** Sample Demographics

Program participant with SIDD	Characteristics (age, gender, race, primary disability, communication mode)	Circle of support members	Length of time in participant direction program
Doug	29 years old Male Caucasian Intellectual disability Verbal	Guardian Three service providers One unpaid support Case manager—A Program director	3 months
Amelia	21 years old Female Caucasian Intellectual and developmental disability (with trisomy 18) Verbal	Mother Father Three service providers Case manager—A Program director	9 months
Brad	20 years old Male African American Autism Nonverbal—no alternative mode of communication	Mother Father Two service providers Case manager—B Program director	1½ years
Nick	27 years old Male Caucasian Autism Nonverbal—no alternative mode of communication	Foster mother Guardian One service provider Case manager—A Program director	6 years

Note: SIDD = significant intellectual and developmental disabilities.

array of tasks inherent in budget and employer authority. Our rationale for this criterion was that we sought to target parents/guardians acting as the “participant,” or surrogate decision maker, and directing an adult’s supports and services.

Second, we asked the program director to identify parents/guardians who she perceived had demonstrated success using participant direction to meet the adult’s support needs. We used the criterion of success because we were particularly interested in learning the perceptions of participants about “what works” in surrogate decision making.

Third, we requested individuals with a range of experiential longevity with participant direction (i.e., individuals who just started using participant direction as well as those who had been using it for years). Our study did not allow for prolonged engagement or an extended look at the respondents’ experiences and decisions over time, so we selected respondents with a range of experiential longevity with the program in an effort to capture the experiences of both novice and experienced parents/guardians.

Using these criteria, the program director identified a number of program participants for the study and provided us with brief descriptions (i.e., age, disability, race/ethnicity, gender, and level of support and service need) of each adult. On the basis of these descriptions, we selected a total of four program participants who best met the sample criteria

identified above. The program director obtained written consent to participate in the study from the guardian of each adult with SIDD. For two of the four adults, their guardians were their parents. The other two adults with SIDD shared a guardian, who was a former staff member at the secondary school they had attended. For the purpose of gathering a broad and rich description, we had the parents/guardian identify additional respondents from each adult’s circle of support (e.g., case manager, support providers, family members) whom they thought would be able to discuss their experiences and decisions related to participant direction. Consents from these additional study respondents were collected at the time of the interviews.

Table 1 provides characteristics of each of the four adults with SIDD and identifies the circle of support members and the length of time each adult had been receiving supports and services through the program of participant direction at the time of the interview. A total of 22 respondents participated in our study. All parents/guardians were invited to have the adults with SIDD participate in the interviews. Two of the four adults with SIDD (Doug and Amelia) participated briefly in the group interviews. The other two adults with SIDD did not participate. One individual (Nick) was present at the group interview but did not actively participate, and the other individual (Brad) was absent based on parental decision regarding their knowledge of his

preferences. The two individuals who did not participate had severe autism and were functionally nonverbal; neither individual used any form of assistive technology to facilitate communication in their daily lives. Although both Doug and Amelia participated in the group interviews, the content of their responses were not aligned with the research question of this study.

### *Data Collection*

Three group interviews, three individual interviews, and supporting documentation (i.e., person-centered plans and individualized budgets) were the sources of qualitative data for this case study. Group interviews were approximately 2 hr in length, whereas individual interviews were approximately 1 hr in length. Respondents received a compensation of US\$30 each for their time and contribution to the study.

All group interviews were scheduled and coordinated by the parents/guardians and took place in a location of their choosing. Because the circles of support for two of the four adults (Nick and Doug) overlapped in members, we conducted one group interview that focused on both men and their circles of support. We conducted all group interviews and two individual interviews in person and one individual interview via the telephone. We conducted individual interviews with any member of the circle of support who was unable to meet with the group and desired to be a part of this study. The individual interview that was conducted via the telephone was a follow-up interview with the case manager for three of the four adults with SIDD.

Our research team of seven collaboratively developed the interview protocol, which included a collection of grand tour questions and probes. The protocols for the group and individual interviews were the same. When necessary, we modified the order and wording of the questions during the interviews as a result of (a) interviewee response, (b) interviewee role (e.g., support provider, parent/guardian, individual with a disability, case manager, program director), and (c) interviewee capacity (e.g., phrasing was simplified for individuals with SIDD). The interview protocol provided direction in a semistructured interview format and ensured that all key points and topics were adequately addressed in each group and individual interview that we conducted.

We audio recorded and transcribed both the group and individual interviews. We reviewed and edited each transcript for errors and identified possible follow-up questions for clarification.

Supporting documentation provided a third source of data that was used to confirm respondent information. These documents included copies of person-centered plans and individualized budgets obtained via the case manager and program director upon receipt of written permission from the parent/guardian.

### *Data Analysis*

Throughout the data analysis phase, the research team used weekly meetings to discuss study structure, recent data, progress, next steps, analysis, and theme development. We also held a 1-day retreat during which we engaged in bias acknowledgment to check our assumptions and predispositions regarding the data prior to beginning the initial coding. We used theme and memo documents generated during team meetings to identify emerging themes as well as areas of uncertainty, questions about the data, and ideas for further exploration.

Codebook development was a recursive process, beginning with the use of the memos and emergent themes as a basis for development of an initial codebook to apply to the transcripts. As Rubin and Rubin (2005) suggested, we labeled, defined, and identified clear examples of each code. We repeatedly refined the codebook, collapsing some codes and expanding or adding others, until we were able to retain the codebook structure across transcripts and coders. Dependability is a term in qualitative research analogous to reliability (Miles & Huberman, 1994); we achieved dependability by arriving at consensus about the definitions and examples of the codes and by having multiple coders code the same sets of data.

Next, the research team engaged in paired coding with primary and secondary coders. First, the primary coder coded a transcript, and then the secondary coder reviewed the coded transcript, adding additional codes if needed. The primary and secondary coders met to discuss and reach consensus on any areas of discrepancy. All coding was entered into QSR International's N6, qualitative research software (QSR N6; 2002).

While coding transcripts in QSR N6, we used the memo function to record questions and observations about the data and any ideas for further exploration. In QSR N6, the memo function allowed us to make notes in an open window that was linked to the transcript being coded. We also continued to add thoughts about the data to the theme document. These two methods of recording facilitated our discussions regarding emerging themes. Throughout the process of theme development, we obtained the assistance of a colleague, not involved in the study, as a peer reviewer to comment on the identified themes as we worked through our analysis of the data. The job of the peer reviewer was to ask the "hard questions about methods, meanings, and interpretations" (Creswell, 2007, p. 208).

### *Measures of Trustworthiness*

We used four measures of trustworthiness in this study. First, we repeatedly acknowledged our personal biases in our retreat, meetings, and documents (Merriam, 1998). Second, we used a peer reviewer, asking a colleague not

engaged in the study to comment on the identified themes as we worked through our analysis of the data (Creswell, 2007). Third, we triangulated the data in three ways: (a) using different types of data, (b) interviewing respondents in various roles, and (c) engaging multiple researchers at every stage of the study (Creswell, 2007; Maxwell, 2005; Merriam, 1998). Finally, all transcripts were transcribed verbatim, providing thick and detailed descriptions and quotations. Through these four strategies for validation (Creswell, 2007), we worked to ensure the credibility of the findings.

### Limitations of the Study

The results of this study must be interpreted carefully in light of several factors. First, purposeful sampling and the single-setting design limit the scope of the data. Collecting data in only one setting limited the variability of the contextual factors that influence the implementation of participant direction. Because the study's research question examined how the experiences of parents/guardians influenced their decisions to participant direct supports and services for an adult with SIDD, we only interviewed participants who were actively using participant direction of Medicaid waiver funds to direct the supports and services of an adult with SIDD. Including individuals who used agency direction or who had not successfully implemented participant direction would have answered a broader research question regarding why some parents/guardians choose to participant direct and others do not.

Second, it is unclear whether individual interviews with each member in the circles of support, rather than a group interview, would have yielded significantly different information. Although the relationships of the members of each group were friendly and personable, there was still a hierarchy of relationships present (e.g., program director, case manager, service providers, family members, individual with SIDD) that may have influenced the responses of the individual group members.

Finally, we lacked prolonged engagement with the study respondents. Time spent with respondents consisted primarily of the interview interactions (each approximately 2 hr in length) and any preceding or follow-up communications conducted via telephone.

### Findings

The purpose of this case study was to examine the catalysts for parents'/guardians' decisions to participant-direct supports and services for an adult with a SIDD. Specifically, our research focused on the following question: In what ways do the experiences of parents/guardians influence their decisions to participant-direct services for an adult with SIDD? Data analysis indicated an overarching theme in which respondents perceived participant direction to be

**Table 2.** Summary of Findings

Means—participant direction	Ends—desired outcomes
Individualized supports and services	Increased independent behavior and communication
Service provider management	Improved general well-being
Individualized budget	Improved health and safety
Increased parent/guardian responsibility	Increased community participation and social inclusion

a *means* to achieve an *end*. Parents/guardians decided to participant-direct the adults' supports and services due to a desire for the adults to achieve certain outcomes (ends); participant direction was the means by which to achieve those ends for the individual. Respondents' comments related to participant direction collapsed into two broad categories: (a) the means—participant direction and (b) the ends—desired outcomes for the individual with SIDD (see Table 2 for a summary of these findings).

### Means—Participant Direction

Respondents were unified in their perception of participant direction as a means to achieve an end, rather than participant direction being an end in itself. Respondents felt that participant direction provided parents/guardians with the opportunity to have “more control and more access and more, more choices” with regard to the supports and services provided to the adult with SIDD. Respondents' comments related to the means (participant direction) fell into two subcategories: (a) what participant direction allows and (b) what participant direction requires.

**What Participant Direction Allows.** Respondents identified three opportunities made possible through participant direction of Medicaid waiver funds: (a) individualized supports and services, (b) service provider management, and (c) individualized budget.

**Individualized supports and services.** Individualized supports and services related to the opportunity for parents/guardians to choose the services the individual with SIDD needs (including nontraditional services) and to ensure that the opportunities afforded to the individual through those services reflected the individual's desires and preferences. Respondents universally expressed the belief that participant direction enabled them to tailor the individuals' supports and services to their specific needs. In the respondents' experiences, agency-directed supports and services generally offered one type of program focused on serving larger groups, whereas participant direction enabled them “to individualize and to figure out just exactly what it is [the person] wants.”

Being able to individualize supports and services was reflected in the employment choices of the individuals.

When switching to participant-directed services, Doug expressed a desire to continue working at the local sheltered workshop a couple of days a week because that was where his girlfriend worked. Therefore, his guardian respected his decision and purchased two days of employment services from the agency and set aside the other three weekdays for volunteering and other community outings to increase Doug's exposure to community employment opportunities. Nick had supported employment part-time for approximately 5 hr a week at the local Pizza Hut where he folded boxes and applied stickers, supported by the same provider he had for over 12 years.

Another way participant direction allowed the individualization of supports and services was by making it possible for the parents/guardians to create needed life experiences with the supports available to accommodate the individual's unique needs. Amelia's father talked about the fact that she did not have the opportunities in childhood "for being away from [her] parents" that typically developing children have. "She didn't have any of the things that a regular kid has in terms of separation experiences . . . If she's ultimately going to move out, she needs experiences like that," her father explained. He continued, saying that participant direction allowed them to creatively design those types of opportunities for her as an adult, giving her the opportunity "to have experiences with other people both in terms of recreational and temporary living situations" so that she may become aware that there are options other than living with her parents for the rest of her life. Prior to participant direction, Amelia had no concept of or desire for a life that did not include living with her parents.

**Service provider management.** Respondents identified service provider management as another opportunity made possible through participant direction. Service provider management encompassed duties such as identifying, hiring, supervising, and replacing support providers. All respondents felt that allowing parents/guardians to choose and manage the service providers was one of the primary benefits of using participant direction.

For some parents/guardians, however, one of the challenges in service provider management was finding someone with whom they felt comfortable and in whom they had confidence to care for the adult with SIDD. Brad's service provider described his parent's hesitancy to hire her initially to support Brad by saying that "they were scared" to hand over care to someone else because they had been doing it themselves for so many years. Amelia's mother expressed that one of her concerns with regard to service provider management was "being able to find people that . . . I like, that Amelia likes, that we're comfortable with and that they're comfortable with her."

Parents/guardians resolved this challenge by hiring service providers for whom this was "more than just a job."

These parents/guardians focused on the importance of the relationship between the provider and the individual with SIDD. When one support provider explained how she was recruited to support Amelia, she said that participant direction allowed Amelia's parents to look for "people that [were] going to have a relationship with her." The importance of building a relationship with the individuals with SIDD was clearly evident, as all individuals knew their service providers as friends, family, acquaintances, or as agency-directed service providers prior to hiring them to provide services through participant direction. In many cases, the service providers had a lengthy (e.g., 12 years) relationship (professional or personal) with the adult with SIDD prior to providing services through participant direction.

**Individualized budget.** Finally, all respondents identified the ability to craft an individualized budget as an important opportunity afforded through participant direction, which allowed parents/guardians to decide how to allocate the funding to pay for needed supports and services. All respondents agreed that participant direction "allowed [them] the flexibility to be able to design the program to meet the need[s]" of the individual. As Amelia's father said, "We . . . have more flexibility [with participant direction] to do this . . . I don't think that what we designed, we could have designed with an agency."

Respondents expressed that, with an individualized budget, the level and type of supports could be adjusted at any time the individual's needs or preferences changed. Nick's and Doug's guardian said that participant direction enabled them to plan for times when additional support was needed because they could "apply the money where [they] need it." Amelia's parents gave an example of this as they explained how they planned for a vacation. Amelia's parents typically provided some supports to their daughter on a daily basis. So when Amelia's parents wanted to take a vacation, they were able to individualize the budget and allocate funds for additional paid provider supports during that time to cover their absence.

Parents/guardians also associated an individualized budget with the ability to negotiate service providers' wage rates. This allowed "families [to] pay their staff more" than an agency paid, which they felt resulted in obtaining and retaining better quality service providers. Nick and Doug's guardian explained,

With [participant direction], I'm able to pay our staff enough that makes it a real job. [At the sheltered workshop], by the time staff people get paid, you're looking at such a low [pay rate] . . . you could go to McDonald's and make better money. . . . With a higher wage, you get better quality. . . . You're not going to get somebody at [the sheltered workshop] to stay there for long . . . at \$7.50 an hour.

Respondents noted “very, very little turnover” of service providers in participant direction. In contrast, turnover was identified by respondents as a major problem in agency-directed programs, where the case manager noted it seemed like “the staff changes every other month.” Respondents expressed that individuals with SIDD rely on those who know them well to assist in selecting activities of their preference, structuring their day, and building in familiar routines. Emphasizing the importance of stable, consistent service providers, one guardian summed it up when she said, “People need to know [the individual well] to better work with him.”

**What Participant Direction Requires.** In addition to these opportunities, respondents noted that participant direction requires increased responsibility for the parents/guardians. The program director described the increased responsibility parents/guardians experienced when directing supports and services saying, “At first it seems a little overwhelming because . . . you become the director of a lot of things that you weren’t before.” Respondents identified that the increase in responsibility associated with participant direction was evident in planning services, managing service providers, and completing the paperwork required for the individual’s supports and services. Planning services entailed scheduling the paid and natural supports needed for each day/week for personal care assistance, as well as any other supports and services (e.g., transportation, doctor’s appointments, community activities). Managing service providers included being responsible for identifying, hiring, supervising, and replacing service providers. Completing paperwork included keeping and submitting “the documentation that people are providing services,” such as the retention of receipts and reviewing and signing timesheets.

Although all parents/guardians initially found participant direction to be challenging, most felt it got easier as they became more experienced with it. As Amelia’s father observed, “It’s a complicated thing to do and there is no training about how you organize it because each one is apparently different. . . . It’s just taken months to get to where this sort of feels sort of semi-automatic.” Nick and Doug’s guardian, reflecting on her increased responsibilities stated, “[Participant direction] was a little bit more of a challenge to get going and then to do [it] . . . learn [it] all . . . Now that I got the system going, it’s going pretty smooth.” Amelia’s mom had been worried about being “glued to the phone and calendar trying to set these things up and make sure people are available,” but she explained, things have “evolved so that people [support providers] kind of know” the schedule and work together to cover the times support is needed, so it requires less of her time now.

Brad’s parents, however, felt the additional responsibilities were more burdensome:

You have to jump through these hoops . . . if you want your son to have the supports and services in place to make his life what you want it to be and what he wants it to be. Here’s the list of crap you have to do; [it] is just disheartening.

### *Ends—Desired Outcomes*

As previously stated, respondents seemed to feel that participant direction was a means to achieve an end—with the end being the desired outcomes for the adult with SIDD. Often, parents/guardians identified that these desired outcomes provided the catalyst for choosing participant direction of Medicaid waiver funds for the individual with SIDD. One parent exemplified this when she initially investigated the possibility of participant direction for her son, “We all came to the table and told [the participant-direction program director] our dream for Brad and what we wanted for his life,” which included living in his own home. She continued, “We vowed to ourselves that we would never . . . put him in an institution . . . or a group home.” His father agreed saying that participant direction is “really beneficial to a family that wants their child to . . . not [be] in the [provider] system [or] a group setting.”

Respondents identified four desired outcomes (ends) of participant direction for the adults with SIDD: (a) increased independent behavior and communication, (b) improved general well-being, (c) improved health and safety, and (d) increased community participation and social inclusion.

*Increased independent behavior and communication.* Respondents identified an increase in individuals’ independent behavior and communication as a desired outcome of participant direction. Brad’s mother observed that her son “just shows more of a sense of independence.” Likewise, one support provider reported that Doug was “more independent now, he’s more outgoing, more talkative now.” While another provider reported that “Doug’s communication is better . . . he communicates with people a lot more than when I first met him. He didn’t talk hardly at all and now it’s . . . awesome.” Providers observed that as Doug was provided with more opportunities for choice making, he began to express his preferences more frequently. One support person explained how he supported choice-making opportunities, “I try not to push anything on him. I always ask him what he is in the mood for . . . I mean I try to make him independent and let him make his own decisions.”

In addition, increased independence in activities of daily living was identified for several participants. A service provider for Amelia, who finally had opportunities to spend nights away from her parents, observed, “I think [she] made a developmental jump that week she stayed here . . . [while] her parents were gone.” A second service provider agreed saying, “[She] put her clothes on in the morning and got herself dressed . . . I saw a lot of really independent behavior

. . . that I don't know they [Amelia's parents] get to see as much."

*Improved general well-being.* Respondents also identified improved general well-being as a desired outcome of participant direction for all four adults with SIDD. This was observed as an increase in overall happiness and as a reduction in challenging behaviors.

Happiness was a frequently mentioned indicator of well-being. Doug's case manager had observed that while Doug was receiving traditional agency-directed supports, "He ran away [from the group home] . . . because he was just that unhappy." After beginning participant direction, one of Doug's service providers observed, "Since I've been around him, everywhere I take him, the people that had known him before we started [participant direction] they just see 100 percent improvement of Doug . . . he's happier . . . and I've noticed it too." As the foster parent of Nick observed, "now he can proudly hold up his head and be himself because he is learning, and he's strong, and he has support."

Reduced behavioral challenges were also associated with improved general well-being. Brad's father noted that before Brad moved into his own home "he would just have an outburst. [Now] I think . . . because he has his own space, and he can do his own thing, he just seems . . . happier." Both parents and service providers felt that participant direction resulted in Brad's increased "maturity level" and improved behavior, "He still does stuff [inappropriate behaviors] . . . it's just that it's decreased. He's just doing good."

*Improved health and safety.* Improved health and safety were also identified as outcomes associated with participant direction for the adult with SIDD. Respondents thought that the longevity of service providers made a big difference with regard to knowing the individuals' preferences, needs, and mode of communication and, hence, ensuring their health and safety.

Improved health was an outcome for several individuals with SIDD. The respondents observed notable improvement in Doug's oral health. With the consistent one-on-one support possible through participant direction, his service providers and his guardian were able to monitor his teeth brushing daily. Respondents in Doug's circle of support indicated that while living in the group home, little care was taken to ensure that he maintained good oral health. Doug's weekend service provider felt that overall "[Doug's] hygiene [was] better."

Improved dietary health was also identified as a desired outcome for the adults with SIDD in this study. Service providers assisted them with menu planning, grocery shopping, and cooking nutritious meals. A case manager believed that service providers in participant-directed services tended to be "more focused on [the individuals'] diets and what they're eating," which in turn translated to improved health.

Doug experienced improved safety after moving from agency-directed to participant-directed supports and services. His guardian described his prior behaviors of running away from the group home and roaming the city alone as "very scary" because he lacked the knowledge to safely navigate the city streets. After switching to participant direction, he no longer lived in the group home; he lived in a home of his choice. He no longer roamed the streets during the day; a service provider took him into the community to do the activities he preferred while ensuring his safety.

*Increased community participation and social inclusion.* Finally, respondents expressed that increased community participation and social inclusion for all four individuals with SIDD were outcomes achieved since beginning participant direction. The case manager for three of the four individuals noted that an advantage of participant direction was that it provided the "opportunity to hire somebody to take [the adult with a disability] out and do the activities that he wants to do." Respondents perceived that having one-on-one support facilitated the increased community participation and social inclusion of the individual with a disability.

Amelia's dad shared that she now has the "closest thing to a peer group that [she] has ever had" because two of her service providers are near her age and include her in some social activities with their friends. As a result, Amelia was "having a college experience. She's having a little bit post-high school experience. It's kind of cool." Amelia's father explained that the service provider became the "conduit into a whole other [group of] people" and gave Amelia "access to a group by having support for her condition within that group." He observed that she now had "her own social life as opposed to it being one that revolved around us [her parents] or the things we were doing."

All the individuals with SIDD engaged in a variety of community activities with their service providers. Doug now had new opportunities to make choices regarding where to go and what to do, such as playing miniature golf and billiards, going shopping, renting movies, and eating out. His service providers also worked on increasing his social inclusion through the use of community businesses such as the local athletic club. His guardian explained that club membership was less about working out and more about it being the "kind of a place for the guys to hang out, and it's kind of a man thing, really."

For Nick, engagement in activities in the community had increased his social circle through "Cheers locations" (a place where "everybody knows your name"). His service provider described it this way, "They know us at all the grocery stores and just around the neighborhood, I mean, they just get to know him, and it's really kind of cool because [people will say,] 'Well hi, Nick. How are you?'"

## Discussion and Implications

Participant direction is a service delivery option that has the potential to substantially change the service landscape for families and individuals with disabilities. The foundation of participant direction lies in empowering individuals with disabilities and their surrogates through the direction of supports and services to create meaningful, valued, and desirable lives for individuals with a disability based on their needs and preferences as fully participating members of their community (Benjamin, 2001; Nerney, 2007). As discussed in the introduction, current research has confirmed that affording individuals with disabilities and/or their parents/guardians the opportunity to make choices and take control of various aspects of the individuals' supports and services results in desirable quality of life outcomes.

The purpose of this case study was to examine the catalysts for parents'/guardians' decision to assume the significant responsibilities of participant directing services of an adult with SIDD. To that end, our research question was as follows: In what ways do the experiences of parents/guardians influence their decisions to participant-direct services for an adult with SIDD? Using a case study design, we collected and analyzed qualitative data (i.e., interviews and supporting documentation) and identified a common theme indicating that participant direction was perceived as a means to an end. In this study, the desire for the adult with SIDD to achieve certain quality-of-life outcomes was the catalyst for the parents'/guardians' choice of participant direction.

### Means

Parents/guardians in this case study who chose to participant-direct the supports and services of an adult with SIDD did so because they perceived participant direction to be a means to an end. If the existing service system could have met the individuals' support needs and resulted in desirable quality of life outcomes, then the parents/guardians would have used it instead of taking on the increased responsibilities associated with participant direction. However, they chose participant direction because they had a series of unsatisfactory and frustrating experiences in dealing with the service system; thus, they did not believe that the services and environments available through the existing service system made it possible to accomplish their desired ends for the adults with SIDD.

*Individualized supports and services.* Participant direction allowed the parents/guardians in this study to individualize the supports and services of the adults with SIDD. Other studies have reported that the ability to individualize supports and services based on the individual's support needs resulted in greater satisfaction with services (Benjamin et al., 2000; Brown et al., 2007; Caldwell & Heller, 2003,

2007; Neely-Barnes et al., 2008) and fewer unmet needs (Benjamin et al., 2000; Caldwell & Heller, 2007; Heller et al., 1999). In addition, such individualization may also reduce costs. In a study by Head and Conroy (2005), individuals with the highest support costs, when previously served in an agency-directed model, tended to have the greatest decrease in costs once engaged in participant direction of their supports and services. The authors identified two possible related reasons for this. Participants were not required to accept unwanted or unneeded services under participant direction, and, as a result, they were able to individualize their supports and services by choosing those that more specifically addressed their individual needs and preferences.

*Individualized budget.* Individualized budgeting gives consumers or their surrogate the decision-making power to determine how to allocate the money in a way that individualizes the supports and services, meeting the individual's needs and supporting personal goals (The Kaiser Commission on Medicaid and the Uninsured, 2007). Despite concerns of fraud and abuse regarding individuals with a disability and/or their surrogates having control over public dollars (Stone, 2006), recent research has found that "families seem to be good stewards of government money" (Caldwell, 2007, p. 558), seeking out the most economical use of the dollars.

These case study respondents felt the positive influence of individualized budgeting was evident in obtaining and retaining service providers. In this study, individualized budgeting permitted the parents/guardians to set the pay rate for service providers. This enabled the parents/guardians to pay the service providers a rate of pay that exceeded the local norm in agency-directed services. This is a notable observation considering that low pay rates are consistently correlated with high turnover of service providers (Larson, Hewitt, & Lakin, 2004; Larson & Lakin, 1999; Mitchell & Braddock, 1994). Respondents reported that being able to offer a higher wage contributed to the long-term commitment of the support providers in the participant-direction program and, thus, to the quality of services and achievement of desired outcomes for the individual with SIDD.

*Service provider management.* Not only could parents/guardians set the rate of pay for providers, but they also had the opportunity to choose and manage the service providers. The parents/guardians indicated it was important for the service providers to form a relationship with the adults with SIDD—this needed to be more than just a job. Other studies have found that service providers in participant-direction programs tend to have a close relationship with the individual for whom they provide support (Dulio, Perry, Claypool, & O'Malley, 2008; San Antonio et al., 2010). Having a close, friendly, or familial relationship with the service provider was important to the parents/guardians because they perceived it resulted in higher quality care. Other studies

have demonstrated that having a close relationship inclined the service providers to be more sensitive to persons' needs (San Antonio et al., 2010) and to work additional unpaid service hours, unlike service providers in agency-directed programs (Matthias & Benjamin, 2008).

*Increased responsibility.* The results of this case study suggested that the opportunities provided through participant direction, resulted in parents/guardians experiencing increased responsibility and initial implementation challenges as a result of their decision to direct the supports and services of the adult with SIDD. In an evaluation of 10 participant-direction project initiatives from Canada, the United States, and Australia, Lord and Hutchinson (2003) found supportive services to be important to the successful implementation of participant direction. In the Cash and Counseling program, researchers found that program participants took advantage of the counseling and fiscal intermediary services that were made available to them and were very satisfied with those services (Brown et al., 2007). Although similar services (i.e., a certified public accountant, case management) were made available to the respondents in this study to facilitate implementation and accountability, the parents/guardians expressed that implementation was still challenging, particularly in the beginning.

## Ends

Despite the responsibilities associated with participant direction, parents/guardians uniformly reported that participant direction made possible the achievement of desired outcomes for the adults with SIDD. One of the primary complaints about agency-directed services is the lack of individualization of goals and activities and the emphasis that is, instead, placed on compliance with paperwork and procedures (Benjamin, 2001; Nerney, 2007; Shea, 1992). In contrast with traditional agency direction, participant direction emphasizes individualization of budgets, supports, and services to achieve quality outcomes (Lord & Hutchinson, 2003). In a Michigan study of the outcomes associated with moving to a participant-directed model, Head and Conroy (2005) found that the ability to individualize supports and services resulted in desirable outcomes (i.e., increased community integration, increased satisfaction, and improved quality of life) similar to those ends achieved by the adults with SIDD in this study.

Parents/guardians had a vision for the quality of services and the quality of life they desired for their family member with SIDD. Most family member respondents desired for their family member with a disability to be able to "live as normal a life as possible." According to most parents/guardians, a high quality of life included, but was not limited to, living in the housing arrangement most preferred by the

individual with SIDD, having community employment opportunities, and participating actively in their community. Thus, the reason that they chose participant direction was to actualize their visions for quality of life. Aligned with this reasoning, parents/guardians also wanted their family member to have experiences comparable to peers without disabilities, and they felt that participant direction accomplished this outcome as well.

## Implications for Research

This case study represents a snapshot in time. Although we gathered data from respondents with a wide range of experience with participant direction, conducting a longitudinal study across time, beginning with the initiation of participant direction through the first year of implementation may provide greater detail regarding the initial challenges experienced by participants and how best to support them in their new roles and responsibilities. In addition, considering the catalyst for choosing to participant direct the supports and services for adults with SIDD was directly related to the achievement of desired outcomes for the adult, an important question for future research would entail examining the barriers to accomplishing desired outcomes using agency-directed services. The respondents in this study had full employer and budget authority, which is not available in all programs of participant direction (Gross, 2010; Nadash & Crisp, 2005; National Council on Disability, 2004; Tritz, 2005). A study comparing outcomes for adults with SIDD across sites with different levels of authority to participant direct may provide even greater detail regarding what components of participant direction (i.e., hiring and managing service providers, allocating monies for services) actually facilitate accomplishment of improved quality of life outcomes. Finally, a limitation of this study was that we only examined the experiences and decisions of parents/guardians who chose participant direction over agency direction. A comparison study examining the reasons why some parents/guardians choose to participant direct and others do not would expand this research. Understanding why some parents/guardians do not choose to participant direct may answer even greater questions about adequacy of agency-directed services to meet needs, availability of support resources for participants, and their vision for the quality of life of the adult with SIDD.

## Implications for Policy and Practice

We suggest cautious implications for policy and practice given the qualitative nature of our study. To better support parents/guardians choosing to participant direct and to support the achievement of desirable quality of life outcomes for individuals with SIDD, policymakers should consider building the capacity of surrogate decision makers with

regard to the responsibilities associated with participant direction. Capacity building could occur through the development and provision of supportive services (e.g., counseling, financial management services, support brokerage, training) for individuals with SIDD and their surrogates who choose to participant direct.

Another way to build capacity is to share information about participant direction with individuals with disabilities and parents/guardians who are considering taking on the responsibilities associated with participant direction. Although the CMS (<http://www.cms.hhs.gov>), many state agencies, and university centers have developed materials (see the appendix for a sample of materials) to support individuals choosing to direct their own supports and services, how well these resources are promoted and shared with consumers may vary significantly depending on the culture of state and local policies with respect to the promotion of participant direction of supports and services (Turnbull, Blue-Banning, & Klein, 2007).

Capacity building through supportive services and information dissemination may increase the capacity as well as the self-efficacy of individuals with a disability or their surrogate decision makers as they embrace the opportunities of individualized supports and services, service provider management, and an individualized budget. Information sharing can also be facilitated through the development of peer-to-peer mentorship programs. Parents/guardians who have experience as surrogate decision makers for their children with SIDD can provide significant information and resource assistance to those just beginning the participant direction of supports and services for their sons and daughters.

## Conclusion

We sought to examine the ways the experiences of parents/guardians influenced their decisions to participant direct the supports and services of an adult with SIDD. Surrogate decision making can be an especially sensitive topic in the field of IDD. Research has indicated that parents/guardians step into the role of participant, directing the supports and services of an adult with SIDD, primarily for the purposes of protection (Vinton, 2010). For some, as in this case study, this may be due to previous negative experiences with agency-directed services (San Antonio et al., 2010; Vinton, 2010), such as unreliable service providers, inattentive caregiving, and the lack of consistent staffing. For others, it may be the result of the difficulty in acquiring and retaining high-quality workers in rural regions (Putnam, Pickard, Rodriguez, & Shear, 2010).

Overall, findings of this case study indicated that parents/guardians chose participant direction as a means to achieve desired outcomes (end) for the adult with SIDD. Respondents identified desired quality outcomes as an

impetus for choosing participant direction. As quality outcomes should be the benchmark for which policies and programs strive, this study supports current policy development, funding, and implementation trends toward providing individuals with disabilities greater opportunities for participant direction of supports and services. Breihan's (2007) identification of the trend toward participant direction of supports and services indicates that, in the near future, all states will offer some level of choice and control over at least some services offered to individuals with IDD. Finally, these findings provide even greater impetus for future research to focus on a wide variety of outcomes (e.g., housing, employment, socioeconomic status, empowerment, quality of life, quality of services) for adults with disabilities, including those with SIDD, for "without satisfactory outcomes, expenditures on services are a poor investment for society" (Stancliffe & Lakin, 2005, p. 2).

## Appendix

### Sample of Participant Direction Support Materials

*Consumer-directed services in Virginia's mental retardation home and community based services waiver.* (2004, April). Retrieved from Virginia Commonwealth University website: <http://www.vcu.edu/partnership/cdservices/cdservicesworkbooks.htm>

Kansas personal assistance supports and services (k-pass) self-direction toolkit: A comprehensive guide to assist individuals in self-direction. (2006, April). Retrieved from Shawnee Country Community Developmental Disability Organization (CDDO) website: <http://www.sncddo.org/k-pass.htm>

*Louisiana self-direction orientation.* (n.d.). Retrieved from HCBS Clearinghouse for the Community Living Exchange Collaborative website: [www.hcbs.org/moreInfo.php/doc/1982](http://www.hcbs.org/moreInfo.php/doc/1982)

Rowe, J., Smith, G., Bradley, V., Martin, D., & Crisp, S. (2006, March). *Individual providers: A guide to employing individual providers under participant direction.* Retrieved from Centers for Medicare and Medicaid Services website: [http://www.cms.hhs.gov/HCBS/02\\_QualityToolkit.asp#TopOfPage](http://www.cms.hhs.gov/HCBS/02_QualityToolkit.asp#TopOfPage)

### Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This

research was supported by the National Institute for Disability Rehabilitation and Research, U.S. Department of Education (H133B031133) in 2003–2009.

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