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Identifying and defining the activities
of participant direction programs: A
document analysis

by Judith M. S. Gross
Martha Blue-Banning
H. Rutherford Turnbull III
Grace L. Francis

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Author Note

Judith M. S. Gross jgross@ku.edu, Martha Blue-Banning mbb@ku.edu, H. Rutherford Turnbull rud@ku.edu, and Grace L. Francis glucyf@ku.edu, Department of Special Education, University of Kansas, Lawrence, KS 66045-7534.

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Correspondence concerning this article should be addressed to Judith M. S. Gross, Center for Educational Testing and Evaluation, Joseph R. Pearson Hall, 1122 West Campus Rd., rm 742, Lawrence, KS 66045; jgross@ku.edu.

ABSTRACT

We analyzed the design of various U.S. programs of participant direction offering participants (individual with a disability or his/her surrogate decision-maker) some level of choice and control over the individual's long-term care supports and services. We used grounded theory methods to conduct a document analysis of 53 documents published from 2004 through 2008 representing multiple disabilities and program funding sources. In our analysis, we identified three major components (planning, budgeting, and employing) over which participants had the opportunity to exercise choice and control and the activities associated with each. Activities were represented by one or more continua illustrating the range of participant choice and control over the indicator. The component of planning consisted of the activity of care plan development. The budgeting component included the activities of (a) development, (b) individualization, and (c) authority. The employing component included the activities of (a) identifying/selecting providers, (b) hiring/employing providers, (c) scheduling providers, (d) training providers, (e) managing/directing/supervising providers, (f) disciplining/dismissing providers, (g) keeping records, (h) managing payroll, (i) locating emergency back-up, and (j) monitoring service quality. The findings of this study have implications for improving policy, practice, and research in the field of long-term care.

Keywords: consumer direction, participant direction, self-direction, disability, long-term care

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Identifying and Defining the Activities of Participant Direction Programs: A Document Analysis

Models of Long-Term Care Service Delivery

Nearly 11 million Americans, half of which are non-elderly, need long-term supports and services (Kaye, Harrington, & LaPlante, 2010), including personal assistance services, home and community based services, and institutional services (Ng, Harrington, & Kitchener, 2010). The paid supports and services these individuals receive are funded primarily through Medicaid and are traditionally provided through agency direction models that provide little opportunity for participant decisions making regarding the services provided (Clark, Hagglund, & Sherman, 2008; O’Keeffe, Wiener, & Greene, 2005). Individuals are recipients of the agency’s services and the agency generally recruits, hires, trains, schedules, manages, disciplines, and pays the service providers, determining provider wages and job tasks (Jamison Rissi, 2007).

Conversely, participant direction models hold that individuals or their surrogate decision-makers (hereafter referred to as “participants”) should “have the primary authority to make choices that work best for them, regardless of the nature or extent of their disability or the source of payment for services” (National Institute of Consumer-Directed Care Services, 1996, p. 3). As such, service providers work for participants, and participants may have input or authority over multiple aspects of service delivery, including how money is spent, how and where services are implemented, and who provides them. However, there are many variations in these programs that blur the line that divides agency direction and participant direction programs.

There is a “lack of clarity of what is meant by [participant] direction” (Infeld, 2005, p. 14), and no two programs are identical. Programs of participant direction vary in a myriad of ways: (a) number of participants enrolled (e.g., fewer than 100 participants to more than 5,000 participants; Doty and Flanagan, 2002), (b) disabilities of participants (e.g., intellectual and/or developmental, traumatic brain injury, physical, frail elderly), (c) funding sources (e.g., state

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Medicaid plans or waivers, Medicare, Department of Veterans Affairs Housebound and Aid and Attendance Program, National Family Caregivers Support Program, state funds; Infeld, 2005; Jamison Rissi, 2007; Nadash & Crisp, 2005; O’Keeffe et al., 2005; Tritz, 2005), and (d) extent of participant input and decision-making (O’Keeffe et al., 2005; Tritz, 2005). Some programs limit participant input to care planning, while others permit more extensive decision-making authority over additional aspects such as services provision, provider management, and budgeting. These variances make it difficult to conduct rigorous research on participant outcomes across programs (Nadash & Crisp, 2005; National Council on Disability, 2004).

What We Know

Most studies of participant direction have researched individual or family caregiver outcomes, focusing on quality of life. The most common outcomes included participant satisfaction with services (Benjamin & Matthias, 2000; Caldwell & Heller, 2003; Caldwell & Heller, 2007; Clark et al, 2008; Foster, Brown, Phillips, & Carlson, 2005; Heller, Miller, & Hsieh, 1999), existence of unmet needs (Beatty, Richmond, Tepper, & DeJong, 1998; Caldwell & Heller, 2007; Clark et al., 2008; Doty, Benjamin, Matthias, & Franke, 1999; Foster, Brown, Phillips, Schore, & Carlson, 2003), and physical well-being, including health and safety (Beatty et al., 1998; Clark et al, 2008; Foster et al., 2003; Foster et al., 2005). Other participant quality of life outcomes researched included emotional well-being (Foster et al., 2005), financial well-being (Caldwell, 2006; Caldwell & Heller, 2003; Foster et al., 2003; Foster et al., 2005), community integration (Caldwell & Heller, 2003; Caldwell & Heller, 2007), satisfaction with life (Foster et al., 2005), and empowerment (Benjamin & Matthias, 2000; Doty et al., 1999). In all the studies associated with the outcomes identified above, participants directing their supports and services experienced greater positive outcomes than their agency direction program peers.

Existing research also describes, to a lesser degree, differences in participant direction

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and agency direction programs regarding costs (Dale, Brown, & Phillips, 2004; Dale, Brown, Phillips, Schore, & Carlson, 2003b); reliability or quality of service providers (Doty et al., 1999; Foster et al., 2003); access to needed services (Meng et al., 2006); receipt, amount, or timing of services (Dale et al., 2003b); working conditions for service providers (Dale, Brown, Phillips, & Carlson, 2003a; Doty et al., 1999), provider satisfaction (Doty et al., 1999) and characteristics (Benjamin & Matthias, 2004). Though, few studies have addressed variability in program design.

Some studies have compared several participant direction programs and identified their similarities and differences (Doty, Kasper, & Litvak, 1996; Doty & Flanagan, 2002; Infeld, 2005; Powers, Sowers, & Singer, 2006). Kendrick and colleagues (2006) reviewed programs developed by Real Choice Systems grantees and identified six levels of participant choice and control: (a) passive recipient, (b) informed recipient, (c) consulted participant, (d) minority decision-maker, (e) majority decision-maker, and (f) “almost all” decision-maker (pg. 63).

Although, no research has conducted a cross-sectional analysis across multiple disabilities and funding sources to address variability in program design and improve generalizability and rigor of participant direction research (Nadash & Crisp, 2005; National Council on Disability, 2004).

What We Don't Know

The National Council on Disability (2004) noted that “the field [of participant direction] suffers from inconsistent definitions of predictors and outcomes across studies, vague explanations of variables..., and study designs that do not support credible generalization” (p. 104). Existing research has not yet addressed the issue of design variability. As such, there is no research supporting what type of program design or which design elements lead to the most promising and positive outcomes for participants. Because of the lack of consistency in program design and implementation, researchers lack a way to compare programs or conduct research that will determine which design elements facilitate meeting participants’ needs and achievement of

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their personal goals and positive life outcomes (e.g., employment, independent living, community participation). By determining the menu of design elements that are possible or are commonly a part of participant direction programs, researchers can begin to conduct research that spans across programs and evaluates program designs in light of participant outcomes.

What We Want to Know

The purpose of a larger study that we conducted was to address the issue of variability in participant direction programs by analyzing the design elements of participant direction programs across disability types and funding sources. In this manuscript, we address a portion of the findings from the larger study that answered the question: What are the activities over which participants could have some level of choice and control in participant direction programs in U.S. long-term care?

Methods

We used a grounded theory approach involving constant comparative analysis (Charmaz, 2006) of the literature on programs of participant direction to better understand the design of programs in the U.S. Below we describe the (a) strategy of inquiry, (b) source selection, (c) sample compilation, (d) coding and categorizing, (e) trustworthiness measures, and (f) limitations of the study.

Strategy of Inquiry

We conducted a document analysis (also known as “textual analysis,” Charmaz, 2006, p.35; “ethnographic content analysis,” Altheide, 1987, p.65; and “mining data from documents,” Merriam, 1998, p.112), to systematically examine documents on participant direction of long-term care supports and services. Examining documents allowed us to access a wide variety of materials such as program evaluation documents, reports, state agency-developed materials (e.g., handbooks, PowerPoint presentations, brochures), and peer-reviewed articles offering a broad

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array of participant direction program descriptions. Analyzing documents allowed us to collect program description data from a variety of comparison groups across multiple states (Glaser & Strauss, 1967). To collect data using interview methods on such a wide representation of programs in the U.S. would have taken an unwieldy amount of time (Merriam, 1998). Finally, documents are a “product of the context in which they were produced and therefore grounded in the real world” (Merriam, 1998, p. 126), making them a desirable source of data.

Source Selection

We conducted preliminary literature searches to determine the most appropriate sources for peer-reviewed and gray literature using three terms commonly associated with participant direction: self-determination, self-direction, and consumer direction. We chose these terms due to their common usage in literature, policy, and grant-funded demonstration programs. We conducted preliminary searches of 12 social science library databases to determine the peer-reviewed data sources offering the greatest quantity and diversity among documents (i.e., type of document, disability categories and programs represented). We then selected the databases yielding the greatest quantity and diversity of results. We determined the sources for gray literature (i.e., written material not published commercially or generally accessible, such as agency reports, position statements, policy briefs) on the topic of participant direction based on site descriptions, prior research (Gross, Wallace, Blue-Banning, Summers, & Turnbull, 2012), and quantity and diversity of results retrieved in the preliminary source searches.

For this study, we identified four sources of documentary data (two library databases, a search engine, and a clearinghouse) for conducting an in-depth document search: (a) Proquest Research Library, (b) Academic Search Premier, (c) Google Scholar, and (d) The Clearinghouse for the Community Living Exchange Collaborative. Each data source had different search options available to target the search results. Both Proquest Research Library and Academic

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Search Premiere had the option to use an asterisk as a wildcard character, facilitating searching multiple derivations of a term in one search. See Table 1 for the search terms used.

<<insert table 1>>

Sample Compilation

Initial sample. A total of 54,170 search results were returned from the four data sources. Google Scholar returned 44,260 of those results from the searches of three terms: self-determination, self direction, and self directed. Searches of these terms in the two library databases revealed that less than .5% of self-determination results and 1% or less of results returned for self direction and self directed were relevant to the service delivery model of participant direction. Considering the rate of return on these terms from the library database sources, we decided not to review the 44,260 items found for these three terms in Google Scholar. We reviewed the remaining 9,910 documents, applying the inclusionary criteria below.

We identified the initial document sample using three inclusionary criteria: (a) currency (a publishing timeframe of 2004 to 2008; documents were analyzed in 2009-2010), (b) location (i.e., documents addressed participant direction programs in the U.S.), and (c) relevance (i.e., documents had content specific to the service model of participant direction). We applied the inclusionary criterion of relevance by ensuring that all documents had at least one of the terms from the expanded search term list in the title, keywords, topics, or subjects of the document. To verify that the content was relevant to the service model of participant direction, we conducted a cursory review of the abstract, summary, or table of contents. Although we applied the inclusionary criteria sequentially, due to the large quantity of documents reviewed for the initial sample, we overlooked some references in the application of each criterion, requiring it to be an iterative process. In doing so, we selected approximately 550 documents for the initial sample.

Final sample. We reviewed the initial sample for more details, adding the name of the

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participant direction program addressed in the document (e.g., California's In-Home Supportive Services Program), disability populations represented (e.g., intellectual and developmental disabilities), and type of document (e.g., handbook, research article) to the table of references and used it to sort documents and apply exclusionary criteria. As with the inclusionary criteria, application of the exclusionary criteria was an iterative process.

We applied three exclusionary criteria to determine the final sample: (a) emphasis (i.e., documents that did not emphasize participant direction of long-term care supports and services), (b) method (i.e., documents whose primary purpose was to review the research literature on participant direction), and (c) disproportion (i.e., multiple documents written by the same authors or about the same programs). With regard to authorship, we selected the most recent when multiple documents with the same person as the first or second author appeared. Regarding redundancy of programs, we selected one document per program (e.g., if there were three articles on the Cash and Counseling program in Arkansas, we selected one). We selected documents based on relevancy of content to the study purpose and question. However, we did not apply the third exclusionary criterion to documents that provided a broad overview of several programs.

The final sample for our document analysis consisted of 53 documents that (a) referenced programs in all 50 states (including District of Columbia and American Samoa), (b) represented multiple disabilities (i.e., intellectual and/or developmental disability, mental illness, other health impaired, physical disability, sensory disabilities, traumatic brain injury, and frail elderly), and (c) included a variety of documentary materials (i.e., dissertation, forum, handbook/manual, presentation, peer-reviewed and non peer-reviewed informative articles, qualitative and quantitative peer-reviewed research articles, report, and Medicaid waiver application).

Coding and Categorizing

Initial coding. Qualitative data analysis is an inductive process (Miles & Huberman,

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1994). The purpose of the initial coding stage is to develop a list of provisional codes to apply to a larger portion of the data. To develop the initial codebook, we coded 12 of the 53 documents using line-by-line coding, looking for design elements of participant direction programs. We used constant comparative methods (Glaser & Strauss, 1967), looking for differences and similarities among the coded data. We gathered the data in a table containing the (a) components (i.e., broad categories), (b) raw data (i.e., coded or quoted material that described each component), and (c) reference source for the data. At this stage, the coding team met every two weeks with senior researchers for peer debriefing sessions. The senior researchers also provided check-coding (Miles & Huberman, 1994) for five of the 12 documents in the initial coding stage and acted as a sounding board for codebook development.

Categorization. As we coded each new document, we compared the coded data to the existing data in the table. If the coded data from the new document were *not* already represented in the table, we added the data with the reference to an appropriate existing or new category. If the coded data from the new document *were* already represented in the table, we added a reference to the new document to be associated with the relevant data. We repeated this process with each new document that we coded. We often used *in vivo* coding, a process in which the codes are shorthand terms specific to an organization or setting (Charmaz, 2006); in this study, the *in vivo* codes were descriptive of how participant direction programs were organized and implemented. We revised, added, and collapsed categories throughout the coding and categorization process until a revised and stable codebook emerged (Miles & Huberman, 1994).

Focused coding. We began focused coding by recoding the 12 initial documents using the revised codebook. In this process, we confirmed the revised codebook and added new data to the table (Charmaz, 2006). Next, we tested the revised codebook against the remaining 41 documents. As recommended by Altheide (1987), we developed a document analysis tool to

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facilitate coding of the remaining 41 documents. We clearly defined each category and the activities associated with it, describing their properties or characteristics (Charmaz, 2006). We tested the tool on three of the initial 12 documents before applying the tool to the remaining sample. The tool evolved through an iterative process of coding new documents and comparing new data against existing coded data and assessing their fit with the existing coding structure.

Using the tool, two of the researchers engaged in paired coding of 10 documents. Each worked independently to code the same document, then met to review codes and supporting raw data. During meetings, we identified codes that needed clarification or amendment and refined the tool as needed. We worked to achieve “an unequivocal, common vision of what the codes mean[t] and which blocks of data best fit which code” (Miles & Huberman, 1994, p. 64). On the 7th and 8th documents, we achieved 85% reliability for consistency of coding using the tool, computing reliability using the method shown below (Miles and Huberman (1994):

$$\text{Reliability} = \text{Number of agreements} / \text{Total number of agreements and disagreements}$$

Following the 8th document, we began independently coding the remaining 33 documents, with the principal investigator check-coding several documents independently coded by team members. These measures verified reliability and reduced the opportunity for coder drift (Miles & Huberman, 1994). We continued to meet every two weeks to review data collection, discuss emerging categories, and modify the document analysis tool, if appropriate. In all, pairs of researchers coded 19% of the documents; single coders independently coded 81%, of which 19% were check-coded by another author and 28% were recoded during multiple stages.

We reached theoretical saturation (Glaser & Strauss, 1967) within the 53-document sample, eliminating the need for further sampling. We determined we had met saturation when the coding of the last eight documents in the sample failed to produce any new data requiring modification to the document analysis tool used to facilitate coding.

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Trustworthiness Measures

We employed several trustworthiness measures in this study. First, two senior researchers served as peer-debriefers, reviewing document coding, category development, and the organizational structure of the identified components (Miles & Huberman, 1994). Second, we conducted paired coding and check-coding to reduce coder drift and check continued reliability. Third, we triangulated the data by (a) involving multiple investigators, (b) relying on multiple data sources, and (c) using multiple types of documents developed for multiple purposes (Creswell, 2007; Maxwell, 2005; Merriam, 1998). Finally, throughout the study the principal investigator kept a dated journal to: (a) document decisions regarding the study design, data collection and analysis (Charmaz, 2006); (b) record notes about meetings with team members; and (c) document observations of the data and changes to the codebook or analysis tool.

Limitations

There are limitations associated with using documents as a data source. First, because documents reflect the author's perceptions of participant direction, the level of detail, accuracy of recollection and transcription of the author limit the data. Second, the documents were not produced for the purpose of this study; therefore, content may have been misinterpreted in our coding process. Third, regarding the type of documents selected, we did not include books, book chapters, or websites as sources of data, despite the possibility that these sources may have offered a more in-depth look at the organization and implementation of participant direction programs. Finally, limitations existed regarding content and date of publication. This study focused solely on participant direction programs in the U.S. Analyzing documents referencing programs outside of the U.S. would have broadened both the study question as well as the data collected. In addition, articles published since the gathering of the sample for this study, due to their recent publication, would offer an even more current understanding of participant direction.

Findings

The purpose of this study was to analyze the design elements of various participant direction programs. Specifically, we sought to identify and define the activities over which participants could have some level of choice and control in participant direction programs in U.S. long-term care. Using qualitative document analysis, we analyzed a 53-document sample for indicators of these activities. We categorized the identified activities under the following three components of participant direction programs: (a) planning, (b) budgeting, and (c) employing (see Table 2 for activities under each component and their definitions). Below we describe each component's activities and the participant's level of choice or control over each.

<<insert table 2>>

Planning

The planning component referred to the activity of identifying support needs and setting goals. Although planning emerged as a common component of participant direction, documents did not define or describe the process of planning, except to mention that a person-centered process was used. Often planning was mentioned only in passing with the assumption that the readers understood person-centered planning and how it was conducted. We identified one activity relevant to planning, care plan development, which had two continua associated with it. The first reflected the participant's role in planning. Some programs emphasized the participant directing planning (Claypool & O'Malley, 2008, p. 2), stating that "the individual's own identification of existing needs and resources should be paramount in a participant directed model" (McGaffigan, 2008, p. 9). Others clearly identified the professional (e.g., case manager) as guiding the planning process (Loughlin et al., 2004), particularly in Medicaid funded programs. The second continuum reflected the opportunity for participants to invite anyone they wished to participate in and contribute to the planning process (Cloutier, Malloy, Hagner, &

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Cotton, 2006), such as “key family and friends” (Revell & Inge, 2007, p. 125).

Budgeting

The second component, budgeting, referred to the activities related to the allocation and distribution of monies to pay for the supports and services identified in the participant’s individualized budget. Monies referred to a cash allowance (Infeld, 2005; Kim, Fox, & White, 2006; Phillips & Schneider, 2007), vouchers (Infeld, 2005; Meng, et al., 2006) or number of service hours (Barnes, Logsdon, Sutherland, & Gonzales, 2006; O’Keeffe et al., 2005) allocated to meet the needs of the individual. Under budgeting, we identified three activities: (a) development, (b) individualization, and (c) authority.

Development. Development referred to how the amount of money or quantity of supports and services a person received was determined. Development presented with two continua: one addressing method of development and the other addressing level of a participant’s engagement in the process. Individual budgets were typically developed in three ways. The first, and most individualized method, involved a “developmental process” of first identifying the individual’s “support needs, services and costs through a person-centered planning process” (Moseley, 2005, p. 167) and then basing the quantity of monies allotted on what was needed to implement that plan of care. A more restrictive, still somewhat individualized, approach used a “statewide uniform assessment process to determine the functions of daily living [that individuals were] unable to perform on their own” (Barnes et al., 2006, p. 5). The results of the assessment determined the quantity of monies allotted annually to fund an individual’s care. Third, offering the least individualization, a budget was allocated using capped spending where all participants received the same quantity, such as “a monthly personal assistance voucher benefit of up to \$250” (Meng, et al., 2006, p. 185), regardless of abilities, needs, or goals.

Although the participant had no choice or control over the method of budget development

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a state used to determine his or her allocation, different methods offered participants differing levels of input or involvement in the process. In some programs, the participant was not involved in the activity of budget development (beyond compliance with a required assessment), and a designated professional (e.g., case manager, program director) was responsible for developing the budget amount based on state or program guidelines (Barnes et al., 2006). Other programs allowed the participant's input but required the use of a designated professional, or "trained facilitator" (Koyanagi, Alfano, & Carty, 2008, p. 4), to help develop the budget (Research and Training Center on Community Living, 2004). A designated professional directed these approaches to budget development with minimal input from the participants.

Individualization. The activity of individualization presented with multiple continua related to participant choice and control over the creation of an individualized budget. The individualized budget typically identified the goods or services (e.g., personal assistance care, respite, supported employment) to be purchased, how much was needed (e.g., hours or units of service, quantity of a good), who would provide the goods or services (i.e., name of service provider or business), and over what time period the services would be provided. The level of choice and control given to participants in the creation and maintenance of the individualized budget ranged from having little input to "significant flexibility" (Tritz, 2005, p. 33). Some programs gave participants "an opportunity to allocate resources across a range of permissible uses" (Griffin, 2005, p. 39), selecting goods and services needed to implement the care plan and "enhance their independence" (Kassner, 2006, p. 1). In other programs, "trained consultants work[ed] with participants to determine the type and amount of personal care services they need[ed]" (Spillman, Black, & Ormond, 2007, p. 40). While in others, a professional "assess[ed] how many hours of service you need[ed] per month" (Kennedy, 2004, p. 229).

A small number of documents addressed the continuum associated with altering the

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budget to meet the individual's changing needs. Centers for Medicare and Medicaid Services (CMS) required programs operating under a Medicaid 1915(c) HCBS waiver to designate a timeframe for a review, "at least annual[ly] ... or more frequently when necessary" (CMS, 2008, Appendix D-1:2), to update the individualized budget. Budget revisions could be recommended by the professional responsible for supporting the individual or by the participants "as they learn new and innovative ways to meet [the] needs" of the individual (McGaffigan, 2008, p 10).

Authority. The activity of authority involved multiple continua regarding (a) who determined the distribution of monies, (b) how payments were made, (c) who determined the rate of pay for service providers, (d) from what kind of vendor goods could be purchased, and (e) what could be done with unspent monies.

Participants could be "responsible for all facets of funding" (National Mental Health Association, 2005, p. 2), including provider or vendor payment. Participants could "receive an actual cash budget payment into an individual bank account they control[led]" (Spillman et al., 2007, p. 10) or use "vouchers to purchase service hours" (Whitlatch & Feinberg, 2006, p. 129) directly from providers. Some programs required that the participants "sign-off on services before providers [were] paid by a third-party fiscal agent" (O'Brien, Ford, & Malloy, 2005, p. 72), relieving the participants of the financial responsibilities, yet still allowing some level of control over the funding. Finally, it was also possible that participants could be completely excluded from the payment process and not granted any authority over the monies (CMS, 2008).

The participant could also have increased choice and control over "how much each worker [would] be paid" (Claypool & O'Malley, 2008, p. 7). Some programs allowed participants "to negotiate provider payment rates" ("Wyoming," 2004, p. 1); while other programs permitted participants to determine pay rates within certain limits (e.g., minimum/maximum) designated by the state (CMS, 2008). Yet, in other programs, the state, a

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designated agency, or “intermediary service organization ... set the wages” (Gage, Khatutsky, & Wiener, 2005, p. 10), and participants were not permitted to adjust that rate (Caldwell, 2007). For the purchase of goods, some programs allowed only “authorized vendors” (Loughlin et al., 2004, p. 230) contracted with the state to provide goods, while others allowed the participant “to purchase goods and services not available in the traditional system” (Nadash & Crisp, 2005, p. 11), such as online businesses and store fronts (e.g., Walmart, Lowe’s; Alakeson, 2008). In some programs, a financial management agency was “considered the provider and [was] able to directly pay [nontraditional providers] for purchases without having them sign provider agreements” (O’Keeffe et al., 2005, p. 5), increasing participant choice while still leaving control of the payment for goods in the hands of the financial management agency.

Finally, budgeting authority also extended to the use of unspent monies. If participants were efficient managers and were able to meet the individual’s needs at a lesser cost than anticipated in the individualized budget, the participants may have been able to use some or all unspent monies for a variety of purposes. Some programs permitted participants to (a) purchase one-time expenses, typically goods, to increase independence or decrease dependence on paid supports (Department of Health and Human Services in State of North Carolina, 2005; O’Keeffe et al., 2005); (b) purchase “additional personal assistance hours” (Clark et al., 2008, p. 689); or (c) deposit it in a savings account (e.g., a LIFE account) that does not negatively affect eligibility for benefits (Bates, 2007; O’Keeffe et al., 2005). However, in some programs of participant direction, being an efficient manager of monies resulted in a return of some or all unspent monies to the state (Spillman et al., 2007) or program agency, to be put into a risk pool or “development fund” (Research and Training Center on Community Living, 2004, p. 13).

Employing

The third component was employing, which referred to the activities typically identified

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as the responsibility of the employer of the service providers. The component of employing was the most commonly described component in the documents. Under the component of employing, we identified ten activities over which participants could have some choice and control: (a) identify/select providers, (b) hire/employ providers, (c) schedule providers, (d) train providers, (e) manage/direct/supervise providers, (f) discipline/dismiss providers, (g) keep records, (h) manage payroll, (i) locate emergency back-up, and (j) monitor service quality. Participant choice and control over these activities was represented by a three-tier continuum:

- Participant could choose to be completely responsible for the activity.
- Participant could have some input but was required to share responsibility for the activity with a designated professional.
- Designated professional was fully responsible for the activity.

Participants “can and should have options to choose the personnel or provider entities that deliver their services, manage the delivery of services, and monitor the quality of services” (National Council on Disability, 2004, p.19). Most programs allowed participants to act as the “managing employer who recruits and trains the service worker, sets the terms and conditions of employment, manages and, if necessary, discharges the worker” (“Kansas,” 2004, p. 1). It was common for certain employing activities (identify/select, train, manage, dismiss) to be grouped together when discussing the primary responsibilities of participants (e.g., Claypool & O’Malley, 2008; Infeld, 2005; Kitchener, Ng, & Harrington, 2007; Minnesota Department of Human Services, 2004; Scherzer, Wong, & Newcomer, 2007; Surpin, 2007). The activity of scheduling providers, often included as the responsibility of the participants, emphasized the importance of being able to “schedule [providers] during early mornings, nights, and weekends, when other paid help [was] hard to find” (Kassner, 2006, p. 1) and “at home and in other locations” (Topeka Independent Living Center, 2005, p. 1) as appropriate.

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In some documents, the authors failed to provide a clear distinction between identifying/selecting a provider and hiring/employing a provider. This became evident in documents where the author referred to the participant hiring the provider in one paragraph and then later described an agency as being the employer of record (e.g., Barnes et al., 2006; “Kansas,” 2004). In some programs, the participant was the employer of record and was responsible for “supervising [his or her] PCA [personal care assistant], withholding and paying payroll taxes and taking charge of [his or her] home care needs” (Bradshaw, Nehus, & Hart, 2006, p. 16). In other programs, an agency was the employer of record while the participant was the managing employer, avoiding the risk and responsibility of being the legal employer yet still retaining a great level of choice and control over service providers (“Kansas,” 2004; The ARC of Tennessee, 2004). When an agency assumed the responsibility of employer of record, it was responsible for “paying workers, providing workers compensation insurance, and withholding, filing, and paying federal, state, and local income and employment taxes” (“Kansas,” 2004, p. 1). The participant was frequently “responsible for keeping a record of hours worked,... verifying and signing the provider’s timesheet” (Barnes et al., 2006, p. 11), and “documenting expenditures” (Barnes et al., 2006, p. 67) to be submitted to the agency for payment or reimbursement.

In some programs, if the service provider identified by the participant was legally employed by an agency, the agency could “arrange for adequate backup support” (Rosenberg, William, & Sievert, 2005, p. 15) when regularly scheduled service providers were unable to work. In other programs, the participant was completely “responsible for finding back-up help” (The ARC of Tennessee, 2004, p. 3). Still other programs made available or required the participant to receive support from a professional who “help[ed] [with] planning back-up support for when a scheduled employee cannot work” (“New Jersey,” 2005, p. 2).

The last activity under the employing component, monitoring service quality, was least

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addressed of all identified activities under the employing component. Many programs allowed participants to “complete the majority of monitoring that takes place” (McGaffigan, 2008, p. 12). Other programs designated a professional (e.g., case manager, service facilitator, agency, Griffin, 2005; Infeld, 2005) as having the primary responsibility, allowing for some participant “input into or direction of program evaluation efforts” (National Council on Disability, 2004, p. 41).

Discussion

We analyzed the designs of programs of participant direction across disabilities and funding sources to identify and define the activities over which participants have some choice and control in directing their services and supports. We conducted a 53-document qualitative analysis of both peer-reviewed and gray literature, using a grounded theory approach. We found three components of participant direction programs (planning, budgeting, and employing) into which we categorized 14 activities over which participants could exercise some level of choice and control. We defined each of these components and activities and described the continua of choice and control associated with each.

Of the three components identified, participants were least likely to be engaged in *budgeting* activities. Budgeting activities were frequently delegated to a state agency representative or a fiscal intermediary. This could be because agencies and organizations are more easily held accountable for spending than individuals are. Additionally, most funding sources typically required and had in place a process that involved a standardized measure of the individual’s abilities and/or support needs. While standardized processes ensure equality of opportunity/access for participants, they lack the individualization (i.e., consideration of other contextual factors) that is important for persons with disabilities, particularly those who have chosen participant direction due to dissatisfaction with agency direction (Gross et al., 2012).

Participants were most likely to be engaged in *planning* and *employing* activities, which

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tended to reflect more opportunities for participant direction than *budgeting*. While planning activities were limited, care plan development nearly always emphasized the participation of the individual with a disability and his or her primary caregivers. Employing activities presented with the greatest number of opportunities for participant direction. Although participants typically had more choice and control with regard to employing activities, the activities we identified often were divided in responsibility between participants and an agency. Participants commonly were responsible for identifying/selecting providers, scheduling providers, training providers, managing providers, and recordkeeping, while the activities of an employer of record (i.e., hiring providers, dismissing providers, payroll management, locating backup, monitoring service quality) were typically the responsibility of an agency working with the participant. Some programs permitted participants to have full authority over all employing activities, which require a substantial increase in new responsibilities (Gross et al., 2012).

The findings of this study indicated that the design of participant direction programs vary significantly since each is designed for a specific disability population and follows the rules and regulations of its funding source. Additionally, there exists no standard vocabulary for the activities identified in our findings. Documents revealed “inconsistent definitions of predictors and outcomes across studies, vague explanations of variables,” as described by the National Council on Disability (2004, p. 104). Finally, the level of choice and control over these activities afforded to participants is inconsistent from program to program and varying significantly.

These findings are important because they fill a void in the research on participant direction by “defining critical terms” and creating a “coherent taxonomy” that can be used to “form the basis for the evaluation of diverse programs serving the broad spectrum of disability” (National Council on Disability, 2004, p. 105). Clearly identified components and activities have implications for the way we conduct our research, allowing us to create more rigorous studies to

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compare outcomes across programs. Using the identified components and activities, lawmakers, state and national organizations and agencies promoting programs of participant direction can begin to use a common vocabulary and consider participants level of choice and control over each of the activities of each of the three components (planning, budgeting, and employing).

Implications

Research

As the National Disability Council (2004) noted, “few strategies [used in participant direction programs] ... have been subjected to sufficiently rigorous research to be characterized as ‘best practices’ or ‘standards of care’” (p. 99). There are significant challenges to overcome in conducting rigorous, comparative research on programs with such varied designs. The results of this study are the first step to directly address research regarding “best practices,” allowing for advances in research and a standard of comparison for policy discussions and development. We foresee a need for three stages of future research: (a) an examination of the structures (e.g., policy, supports) in place to facilitate the implementation of participant direction, (b) the development of a tool to assess a participant’s level of choice and control over the activities identified in this study, and (c) the use of that tool in outcomes-based, cross-program research to assess which activities and what level of participant choice and control are commonly associated with positive quality of life outcomes for participants.

Examination of structures. While this study clearly identified over what activities participants may have some level of choice and control, it did not address how those activities are determined and what types of structures are in place to facilitate their implementation. The literature we examined revealed that supports provided to participants in directing their services varied. A systematic examination of existing structures (e.g., policy, supports) to facilitate implementation of participant direction would provide a clear explanation of how participant

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direction is implemented across programs and what variations exist or are most common.

Tool development. Research to date has assessed outcomes for individuals or family caregivers in specific programs of participant direction. However, due to the significant variability in the design of these programs, it is impossible to attribute outcomes to specific causal variables, such as the level of control a participant has over a particular activity. The development of an innovative tool that assesses a participant's level of choice and control over various activities would facilitate much needed cross-program research, which could be translated into effective and efficient program design and development.

Cross-program research. An assessment tool would clearly define variables, allowing cross-program research to identify the impact of varying levels of participant choice and control on participant outcomes. The proposed tool could be piloted along with measures of anticipated outcomes of participant direction (e.g., community participation, employment, independent/supported living, met needs, service satisfaction, access to services) to determine feasibility for use in cross-program research. Such research could identify which activities, or combinations of activities, are necessary for participants to control in order to achieve desirable outcomes.

Policy

There is no research addressing the effectiveness of various participant direction program designs on participant outcomes; therefore, cross-program research is an essential step to providing data to support the inclusion or exclusion of various activities in participant direction policy and program design. Research on the impact of participant directing specific activities would influence policy and program development. With the evidence-based data resulting from cross-program research using the assessment tool and outcomes measures described above, states could confidently design, develop, and expand programs. States would have research to support the impact of different design options (e.g., allowing participants budget authority) on participant

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outcomes and could make educated and informed decisions regarding funding programs, policy development, and program designs. The components and activities defined in this study provide state policy makers with a common vocabulary to facilitate program design and support participants to better understand their options in participant direction.

With the rising prevalence of autism (Kogan et al., 2009; Newschaffer, Falb, & Gurney, 2005) as well as the impending aging of the baby boom generation (Allen, 2005), an intense need for long-term care home and community based supports and services is anticipated in the coming years. Budget shortfalls and the shortage of direct care providers will significantly impact the availability of long-term care for both elderly and non-elderly populations with disabilities in the future. As the need for long-term care increases, long-term care policy will have to respond with more efficient and effective means to meet the growing need. Increasing the number of participant direction programs could alleviate some of the pressure by providing more cost effective supports and services and increasing the overall pool of providers.

Conclusion

Participant direction is both a young and broad field of research, in its adolescence and in need of organization. This study provides some much needed organizational structure, clearly defining critical terms that can be used in the pursuit of more rigorous research and comparable program design and development. In the pursuit of rigorous research, an essential next step is the development of a tool to assess a participant's level of choice and control so that we may begin to identify the specific design elements that lead to positive and desirable outcomes for individuals and family caregivers. The findings of this study are the first step in the development of truly evidence-based practice with regard to design of participant direction programs and the development of policy surrounding long-term care supports.

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Table 1

Search Terms Used in Document Sample Collection

Proquest Research Library Academic Search Premiere	Google Scholar Clearinghouse for the Community Living Exchange Collaborative
self-determin*	self-determination
consumer control*	consumer control
self direct*	consumer controlled
participant direct*	self direct
individual* fund*	self direction
individual* budget*	self directed
person direct*	participant direct
consumer direct*	participant directed
	participant direction
	consumer direct
	consumer directed
	consumer direction
	person-directed
	individualized funding
	individual budget
	individual budgeting
	individualized budgets

Note. Asterisk denotes a wild card character allowing the search of all variations of the search term (e.g., “self-determin*” will allow the database to search “self-determine,” “self-determined,” “self-determination,” etc.).

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Table 2

Components and Activities of Participant Direction Programs

Components	Activities	Definitions
Planning	Care plan development	Development of a care plan, typically using a person-centered planning approach to address the consumer's preferences, capacities, needed supports, and desired outcomes/life goals
Budgeting	Development	Determination of the amount of money or quantity of supports and services a person will receive (allocated via cash, vouchers, or service hours)
	Individualization	Creation of an individualized budget that outlines how the monies will be allocated for the specific goods and services needed to implement the care plan, and the extent to which it may be altered, as a person's needs change
	Authority	Control over the distribution of monies provided to meet the consumer's needs and goals identified in the care plan
Employing	Identify/select provider	Act of choosing the service provider(s) to provide the designated services to the consumer
	Hire/employ provider	Act of legally hiring/employing the service provider, being the employer of record
	Schedule provider	Act of determining when and where services will be provided
	Train provider	Act of training service providers in how to provide consumer-specific supports and services
	Manage/direct/supervise provider	Act of directly managing or supervising the day-to-day activities of the service provider, including determining specific tasks to be performed and providing feedback on performance
	Discipline/dismiss provider	Act of disciplining (reprimanding or correcting) and dismissing (firing) the service provider
	Keep records	Maintenance of records regarding the purchase of goods or services, such as saving receipts, signing and archiving timesheets
	Manage payroll	Act of financial management of all payroll functions, such as payment for services, worker's compensation, tax and social security deductions
	Emergency back-up	Development and implementation of a back-up plan for when a regularly scheduled service provider is unable to work
	Monitor service quality	Act of determining what constitutes quality and monitoring of services provided to the consumer

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