

IDENTIFYING AND DEFINING THE COMPONENTS AND INDICATORS
OF PARTICIPANT DIRECTION

BY

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ABSTRACT

In this dissertation, I analyzed the design of various programs of participant direction in long-term care in the U.S. programs of participant direction offer the consumer (i.e., individuals with a disability and individuals who are elderly) or surrogate decision maker some level of choice and control over the consumer's long-term care supports and services. I conducted a qualitative documentary analysis using grounded theory methods in order to identify and define the range of components and indicators available in programs of participant direction. I sampled 53 documents from 2004 through 2008 representing multiple disabilities and program funding sources. Findings resulted in the development of a grounded theory of program design and a conceptual framework depicting an ideal type of program and its organization. All programs were found to have two major theoretical constructs, *what* and *how*, under which all identified components and indicators could be organized. I identified and defined a total of five components and 28 indicators. Each indicator was represented by one or more continua depicting the range of consumer or surrogate choice and control over the indicator. The findings of this study have implications for improving the rigor of research and development of long-term care policy.

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CHAPTER ONE: INTRODUCTION

Statement of the Problem

In this dissertation study, I analyze the design of various programs of participant direction that offer consumers (i.e., individuals with a disability and individuals who are elderly) or their surrogate decision makers the opportunity to have some level of choice and control over the consumer's long-term care supports and services. These programs vary significantly in their design; the level of choice and control afforded to the participant (i.e., consumer or his or her surrogate decision maker) varies significantly as well (Feinberg & Newman, 2005; Infeld, 2005; Moseley, 2005; Tritz, 2005). Even programs implemented under the same demonstration program (e.g., Cash and Counseling) offer different design elements and different levels of choice and control from state to state and program to program (Brown et al., 2007). In addition, as a survey conducted by Infeld (2005) revealed, there is a "continuing lack of clarity of what is meant by [participant] direction" (p. 14). Some states claiming to offer participant direction limit consumer or surrogate input to the care planning process alone, requiring agencies to provide all care and assume employer responsibilities, while others allow the consumer or surrogate complete decision-making authority regarding employer responsibilities and budgeting. It is this variability that makes cross-program research challenging. For researchers and policy makers, the question becomes clear: How can we identify the causal factors of participant outcomes when the dependent variables (i.e., program design elements) differ so greatly?

This dissertation, focusing on the design elements of programs of participant direction, analyzed multiple programs described as participant direction in an effort to discover an "ideal type" (Hekman, 1983, p. 31) of participant direction program. The ideal type is a synthesis of the common components and indicators of participant direction programs, representing the design

elements most commonly found, but not necessarily present, in all programs of participant direction. By identifying and defining the components and indicators of participant direction programs, I have responded to the need identified by the National Council on Disability (2004) six years ago, which was to create a

coherent taxonomy that could form the basis for the evaluation of diverse programs serving the broad spectrum of disability . . . making it possible for researchers to tailor studies to particular interventions [e.g., design elements] while promoting comparability across and clarity within individual studies. (p. 104)

This dissertation creates the “coherent taxonomy,” or common nomenclature, and thereby fills a significant gap in the current research and unifies the field under a common understanding of participant direction. The results of this study are needed to move research in this field forward so that we may begin to identify the specific causal variables (or program design elements) that lead to successful outcomes for individuals with disabilities who are receiving long-term care supports and services through programs of participant direction.

Study Purpose and Research Question

The purpose of this study was to analyze the design of programs of participant direction. Since programs of participant direction exist in every, or nearly every, state in the U.S. (Claypool & O'Malley, 2008; Doty & Flanagan, 2002), many of which have been documented in the literature, an analysis of recent literature was the most efficient and effective way to gather and analyze data regarding the design of these various programs. Specifically, the question guiding this document analysis was: What are the components and indicators of participant direction programs in U.S. long-term care?

Definitions of Terms

Below is a listing of the definitions of 12 key terms used throughout this dissertation. I have chosen not to alphabetize them, but instead have organized the terms into relevant groupings and in the order of their appearance in the problem statement and research question.

Participant Direction

Participant direction is a service delivery model in which program participants eligible for long-term care benefits are allowed the authority to direct some or all of their supports and services, including budget management. When directing supports and services, the participant may be responsible for activities such as managing service providers and selecting and paying for goods and services. The following terms are also used in the literature to refer to participant direction of supports and services: consumer direction, self direction, self-determination, individualized funding, and consumer control.

Choice

Choice is the act of making a selection from a range of options (e.g., service options, levels of participation, degree of control). In order for choice to exist, there must be a range of options from which to choose. The more limited the range, the more limited the choice. Choice also includes the option to give up control. Choice may be equated with the disability policy core concept of “Autonomy” (Turnbull, Beegle, & Stowe, 2001, p. 138), which refers to the act of consenting. To consent involves making a choice; thus, choice equates with consent and autonomy, and both are manifest in participant direction (with direction being the action of choice and consent).

Control

Control refers to the consumer or surrogate making substantive decisions regarding and taking responsibility for the consumer's supports and services. Control is represented by the disability policy core concept of "Empowerment/Participatory Decision-Making" (Turnbull, Beegle, & Stowe, 2001, p. 138), which refers to shared decision-making power and responsibility between the professional/service provider and the consumer or surrogate. As participant direction is referenced in the literature with regard to what the consumer or surrogate does in concert with or in independent of a professional/service provider, participant direction manifests empowerment/participatory decision-making.

Core Concepts

The core concepts refer to those elements of public policy in the United States that are indispensable, always-present, and foundational for other policies and practices; together, they represent a framework within which disability policy, particularly as it relates to families and individuals with disabilities, can be analyzed (Turnbull, Beegle, & Stowe, 2001).

Long-term Care

Long-term care refers to the supports and services needed to meet individual care and assistance needs over an extended or ongoing period of time for those who are unable to be fully independent.

Supports

Supports consist of unpaid assistance or material items (e.g., visual schedule, social story) that facilitate the completion of daily activities by individuals with a disability, such as accessing community resources, supporting employment, caring for personal hygiene, and assisting with daily living skills such as cooking, cleaning, housekeeping, budgeting, shopping.

Services

Services are paid assistance with activities of daily living provided to individuals with a disability. Services support the individual in a number of activities such as accessing community resources, obtaining or maintaining employment, caring for personal hygiene, and assisting with daily living skills such as cooking, cleaning, housekeeping, budgeting, shopping.

Consumer

The consumer is the individual with a disability (elderly or non-elderly) receiving benefits for the purpose of meeting the consumer's long-term care support and service needs.

Surrogate Decision maker

The surrogate decision maker (or surrogate) is someone who provides assistance to the consumer with decision-making and the various responsibilities of participant direction. The surrogate typically is a family member, friend, parent, or guardian of the consumer.

Participant

Participant refers to the individual (e.g., consumer or his or her surrogate decision maker) who is responsible for directing the consumer's long-term care supports and services.

Components

Components are the parts or aspects that comprise participant direction programs.

Indicators

Indicators are the activities or structures that indicate the range of expression or implementation of the components.

Literature Review

Below I present a review of the literature relevant to the topic of participant direction and the purpose of this dissertation, which is to analyze the design of programs of participant

direction. Since this dissertation reports on the results of a documentary analysis that included qualitatively analyzing 53 documents about participant direction of long-term care supports and services in the U.S., the typical approach of devoting a chapter to an extensive literature review was not appropriate. Therefore, in this section I present an abbreviated literature review including the (a) two models of service delivery (agency direction and participant direction), (b) variations in the design of programs of participant direction, (c) state of existing research on participant direction, and (d) gaps in the existing research.

Two Models of Service Delivery

In the U.S. there are nearly 11 million people needing long-term care supports and services, approximately half of who are non-elderly (Kaye, Harrington, & LaPlante, 2010). The majority of these individuals (92%) receive unpaid help, while only 13% receive paid help, which is primarily funded through either Medicaid or Medicare. Traditionally, publicly paid long-term care supports and services have been provided through an agency-directed model in which the consumer has little input regarding the decisions made and the services provided to meet his or her long-term care needs (Clark, Hagglund, & Sherman, 2008; O'Keefe, Wiener, & Greene, 2005). In an agency-directed model, typically the agency draws down the money from the benefit source (e.g., Medicaid); service providers are employed by the agency, and the consumer is a recipient of the agency's services. The agency generally assumes the responsibilities of recruiting, hiring, training, scheduling, managing, disciplining, and paying the service providers as well as determining the wages to be paid and tasks to be performed for the consumer (Jamison Rissi, 2007). In contrast to this is the model of participant direction.

In participant direction, the service providers work for the consumer (to some degree), and the consumer or his or her surrogate decision maker has input or decision-making authority

over multiple aspects of service delivery, which may include decisions such as what goods and services are purchased, how and where they are implemented, and by whom. These programs are premised on the belief that consumers or their surrogates “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 as quoted in Jamison Rissi, 2007, p. 3). However, the distinction between these two models of service delivery is not black and white; rather it is characterized by shades of gray.

Variation in Programs of Participant Direction

In 2001, Doty and Flanagan (2002) estimated that there were 486,000 consumers or their surrogate decision makers participant-directing consumers’ supports and services in 139 different home and community-based programs in 49 states. These programs ranged in size from fewer than 100 participants to more than 5,000 participants. Since 2001, federal legislation (e.g., New Freedom Initiative of 2001 and Deficit Reduction Act of 2005; Claypool & O’Malley, 2008; Jamison Rissi, 2007) and an expansion of grant-funded demonstration projects (e.g., Systems Change Grants and Cash and Counseling; Tritz, 2005) have increased the availability and variability of participant direction programs across the country. These programs transcend disability categories (e.g., intellectual and/or developmental, traumatic brain injury, physical, elderly) and funding sources (e.g., state Medicaid plans, Medicaid 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’Keefe et al., 2005; Tritz, 2005).

Each of these funding sources has its own rules and regulations regarding the expenditure of the funds (O’Keefe et al., 2005). Some funding comes from state administered programs (e.g.,

Medicaid Waivers), which vary in design from state to state and program to program (Ng, Harrington, & Kitchener, 2010). As a result, no two programs are identical in their design; each offers differing levels of choice and control as well as support to the consumers or surrogates participating in these programs. While some funding sources (e.g., Department of Veterans Affairs Housebound and Aid and Attendance) allow the consumer or surrogate extensive or unregulated choice and control regarding how to spend the monies allotted to the consumer for long-term care supports and services (Grana & Yamashiro, 1987; Tritz, 2005), others (e.g., Medicaid) have very specific rules and regulations regarding who is eligible and is permitted to be responsible for the allotted monies and on what the monies may be spent (Nadash & Crisp, 2005).

Programs of participant direction also vary regarding the assistance available to or required to be used by the participant. Some programs offer multiple forms of assistance (e.g., worker registry, training, counseling) to participants, whereas others offer few or no supports or assistance. For example, some programs require participants to use a financial management service to account for funding and ensure that legal responsibilities, such as worker's compensation insurance and payroll withholdings, are met (CMS, 2005; Nadash & Crisp, 2005), while others provide a cash benefit allowing participants the budget authority to purchase any needed services or goods from any service provider or vendor (Grana & Yamashiro, 1987; Tritz, 2005). Most programs allow participants to assume common employer responsibilities (e.g., identifying, training, scheduling, managing service providers), although many require that the responsibility of employer of record remain under agency direction (Barnes, Logsdon, Sutherland, & Gonzales, 2006; "Kansas," 2004; Nadash & Crisp, 2005). This variability in

design has left little opportunity for rigorous research regarding participant outcomes (Nadash & Crisp, 2005; National Council on Disability, 2004).

State of Existing Research

There currently exist a large number of studies on participant direction conducted using both qualitative and quantitative methods. A significant portion of this research has focused on topics specific to consumer or family caregiver outcomes, including:

- Satisfaction with services (Beatty, Richmond, Tepper, & DeJong, 1998; Benjamin & Matthias, 2000; Caldwell & Heller, 2003; Caldwell & Heller, 2007; Doty, Benjamin, Matthias, & Franke, 1999; Foster, Brown, Phillips, Schore, & Carlson, 2003; Foster, Brown, Phillips, & Carlson, 2005; Heller, Miller, & Hsieh, 1999),
- Existence of unmet needs (Beatty et al., 1998; Benjamin & Matthias, 2000; Caldwell & Heller, 2007; Clark et al., 2008; Doty et al., 1999; Foster et al., 2003;),
- Physical well-being, including health and safety (Beatty et al., 1998; Benjamin & Matthias, 2000; Clark et al, 2008; Doty et al., 1999; Foster et al., 2003; Foster et al., 2005),
- 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; Heller, Miller, & Factor, 1999),
- General quality of life (Benjamin & Matthias, 2000; Foster et al., 2003),
- Satisfaction with life (Foster et al., 2005), and
- Empowerment (Benjamin & Matthias, 2000; Doty et al., 1999).

The majority of studies have found that consumers or their family caregivers participating in programs of participant direction had more positive outcomes or no difference in outcomes as compared to their agency direction counterparts.

These frequently evaluated outcomes can be organized using two broad quality of life frameworks: individual quality of life (Schalock, 2000) and family quality of life (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006). The individual quality of life framework (Schalock, 2000) addresses individual or consumer outcomes associated with participant direction under the categories of (a) material (or financial) well-being, (b) emotional well-being, (c) physical well-being, (d) self-determination, and (e) social inclusion. The family quality of life framework (Hoffman et al., 2006) addresses family outcomes of participant direction under the categories of (a) emotional well-being, (b) physical/material well-being, and (c) disability-related support.

Existing research has also ventured to a lesser degree into the realm of program functioning by addressing:

- 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
- Provider characteristics (Benjamin & Matthias, 2004).

The majority of this research compares consumers, surrogates, or service providers in participant directed programs to those in comparable agency directed programs, providing some insight into program differences and program functioning.

Of all the studies conducted on participant direction, research on the Cash and Counseling demonstration program has been the most rigorous. Cash and Counseling research has addressed multiple disabilities and multiple states. However, as previously mentioned, even the programs created and studied under Cash and Counseling were designed and implemented differently from state to state (Brown et al., 2007). Typically the studies included consumers interested in participant direction who were randomly assigned to either the participant direction or agency direction program for home and community based services. The agency direction populations used in the study of the Cash and Counseling demonstration programs were consumers who were either on wait lists for home or community based long-term care services or were receiving services under an agency directed model, but were not receiving all authorized services due to a lack of available direct care service providers in the system (Dale et al., 2004; Dale et al., 2003b). Using comparative populations such as these can skew the results when considering the actual costs of services, satisfaction with services, quantity of services received, preferences for a specific service model, and existence of unmet needs.

Although little research has addressed the issue of variability in program design, some advocates and researchers have tried to describe the primary components of participant direction programs and the continua of choice and control that may be associated with them. On the Community Works website (http://www.communityworks.info/articles/sd_structures.htm), which is an advocacy site devoted to the planning for and development of community living opportunities, Wetherow (2003) has posted an article offering a description of participant

direction. Wetherow (2003) identifies the elements that define participant direction and the elements that may be supportive of participant direction but do not define it as a service model. Some of the supportive elements Wetherow (2003, p. 2) identified included: (a) allowing the consumer, his or her family, or other support network member to manage the resources; (b) providing “second-level” support services such as assistance with planning, inviting and creating a support network, counseling and advice, training and education, and assistance with daily operations and management; (c) purchasing goods and services with a budget managed by the consumer or his or her surrogate; and (d) creating or requiring accountability such as through the use of financial management services. While Wetherow does offer an organizational structure regarding the design of programs of participant direction, it is not backed by research, and he suggests that programs of participant direction should be developed with system support without the need to identify the “‘perfect’ form” (2003, p. 6).

Available research has not yet attempted to identify the “perfect form” of participant direction; however, some research has attempted to look across multiple programs of participant direction and identify the similarities and differences in approaches to implementing participant direction programs for long-term care services (Doty, Kasper, & Litvak, 1996; Doty & Flanagan, 2002; Infeld, 2005). In a review of programs developed by Real Choice Systems grantees, Kendrick, Petty, Bezenson, and Jones (2006), attempting to define participant direction, summarized and categorized six levels of choice and control a consumer or surrogate may have, the common elements over which a consumer may have authority, and examples of support or assistance that may be in place to assist the consumer or surrogate in directing the consumer’s supports and services. However, to date no research has looked across multiple disabilities and funding sources to address the commonly acknowledged issue of variability in program design,

which significantly influences the level of rigor and generalizability of participant direction research studies (Nadash & Crisp, 2005; National Council on Disability, 2004).

Gaps in the Existing Research

Indeed, 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). Because every program is different, researchers lack a way to compare programs or to conduct research that will help determine how best to design participant direction programs to ensure that participants are successful and achieving personal life goals and experiencing positive outcomes (e.g., employment, independent living, community participation). By determining the menu of components and indicators that are possible, typically used, or a part of programs of participant direction, researchers can begin to try to determine how much choice and control are associated with various participant outcomes and to conduct research that spans across programs. Existing research focusing on participant outcomes has not yet addressed which type of program design, or which specific design elements, lead to the most promising and positive outcomes for program participants. There are no studies that have sought to address the issue of design variability, much less identify and define the individual design elements, as this dissertation study does. By determining the menu of components and indicators that are characteristic of programs of participant direction, the results of this research will propel the field forward, allowing research that spans across programs.

Organization of the Study

The remainder of the dissertation is organized as follows:

- Chapter 2 details the methodology employed, specifically the strategy of inquiry, source and sample identification and selection, and data collection and analysis;
- Chapter 3 presents the findings, including an explanation of the grounded theory and conceptual framework developed;
- Chapter 4 provides a summary of the study and implications of the findings for future research and policy development.

CHAPTER TWO: METHODOLOGY

In this section, I discuss the methods and procedures of this study. Qualitative methods were best suited to the research question because I sought to identify and define the components and indicators of participant direction programs. I used a grounded theory approach that involved a constant comparative analysis of the data. Grounded theory enables the researcher to “theorize how meanings, actions, and social structures are construed” (Charmaz, 2006, p. 151). Below I describe the (a) strategy of inquiry, (b) source selection, (c) sample compilation, (d) coding and categorizing, (e) theory development, and (f) trustworthiness measures employed in the study.

Strategy of Inquiry

According to Glaser and Strauss (1967), there are “two major kinds of qualitative data – field and documentary” (p. 161). I chose to conduct an analysis of documentary data, rather than to conduct and analyze field interviews or observations, which are more commonly used in qualitative research (Glaser & Strauss, 1967). Document analysis has been described as “textual analysis” (Charmaz, 2006, p. 35), “ethnographic content analysis” (Altheide, 1987, p. 65), and “mining data from documents” (Merriam, 1998, p. 112). In research, documents are generally used as a prelude to a researcher’s own study (as in the literature review presented in chapter one) for the purpose of “informing rather than as data for analysis” (Glaser & Strauss, 1967, p. 162). Documents, however, can also serve as a source of data, whether the documents were generated for the purpose of the study or some other purpose entirely.

The analysis in this study consisted of a systematic examination of current documents on participant direction of long-term care supports and services. I chose documents for several reasons, in addition to being free and easily accessible (Merriam, 1998). First, with the increased federal legislation (e.g., New Freedom Initiative and Deficit Reduction Act) supporting

participant direction of supports and services, newly developed programs likely were subjected to an evaluation process. Those evaluations likely contained descriptions of the structure of the programs and were documented in either peer reviewed or non-peer reviewed articles. Second, as states have developed new programs of participant direction, state agencies have also developed materials to support participants and service providers in those programs (e.g., handbooks, PowerPoint presentations, worksheets, brochures). I believed such documents would contain greater detail on the types of choice and control participants may exercise. Third, documents would probably contain such a wide array of information about a variety of programs across multiple states, offering a variety of comparison groups (Glaser & Strauss, 1967), that it would take an unwieldy amount of time to collect the information otherwise (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 for a grounded theory study of participant direction.

Source Selection

I determined the sample sources through a preliminary search using three terms commonly associated with participant direction. The terms used were self-determination, self direction, and consumer direction. I chose these three terms for the preliminary searches due to their common usage in literature, policy, and grant-funded demonstration programs. I did not use the term *participant direction* in these preliminary searches because my previous research in this field revealed that it has been rarely used in the literature and only recently (starting in approximately 2005) used by the Centers for Medicare and Medicaid Services (CMS, 2005).

I reviewed the preliminary search results for quantity (i.e., how many results were returned) and diversity (i.e., type of document, disability categories and programs represented) of

results returned from each potential data source. I sought to determine the most fruitful sources of professional and gray literature (i.e., written material that is not published commercially or generally accessible, such as agency reports, position statements, policy briefs) on the topic of participant direction. In this process, I identified four sources of documentary data: two library databases, a search engine, and a website.

I selected the two library databases based on results yielded from preliminary searches of 12 social sciences library databases. I excluded databases in this preliminary search due to insufficient search results. I initially selected the search engine and website based on site descriptions and previous experience using them as sources for prior research (Gross, Blue-Banning, Summers, & Turnbull, 2010); additionally, I verified their viability as data sources during the preliminary searches of their content. I conducted preliminary searches of these data sources to test the potential richness of each source for use in a more thorough document search.

I selected the following data sources because they yielded the greatest quantity and diversity (i.e., various genres of documents reporting on a variety of programs) of results in the preliminary searches: (a) Proquest Research Library, (b) Academic Search Premier, (c) Google Scholar, and (d) The Clearinghouse for the Community Living Exchange Collaborative. Proquest Research Library and Academic Search Premiere are library databases with comprehensive collections of professional literature in the social sciences, with emphases on peer-reviewed journals. Google Scholar is a search engine that facilitates searching across disciplines and various web sources for scholarly literature. Google Scholar facilitates searching websites, such as government agency sites, for gray literature not typically available through library database periodicals. The Clearinghouse for the Community Living Exchange Collaborative (<http://www.hcbs.org/>), also a source for gray literature, is a website designed to facilitate

sharing information and resources (e.g., manuals, handbooks, state reports, policy briefs) across state and local entities implementing Home and Community-Based Services programs. Next, using these four data sources, I compiled the document sample using an expanded search term list as described below.

Sample Compilation

The vetting process to compile the sample of documents occurred in two stages: initial sample and final sample. First, I determined the initial sample through a systematic search of the four data sources using three inclusionary criteria to collect a broad sample of potentially useful documents. Next, I applied four exclusionary criteria as a data reduction method to eliminate redundant and irrelevant results, restricting the final sample to 53 references for documents descriptive of participant direction of long-term care supports and services.

Initial Sample

I identified the initial sample using three inclusionary criteria in the search process. The first criterion was a restricted timeframe; I included only documents published from 2004 to 2008. I used this criterion to ensure that the identified documents represented current policy, practice, and data from various programs of participant direction. Considering the time that may pass between the gathering of data and writing and publication of an article or report, I anticipated that by limiting the sample to the five years prior to initiating this study, the policy and data that the documents' content reflected would be current within the last 10 years.

Second, all documents in the sample must have had content relevant to the service model of participant direction. I achieved this by initially assuring that all documents had at least one of the terms from the expanded search term list (described below for each source searched) in the (a) title, (b) keywords/topics/subjects, (c) abstract/summary, or (d) table of contents of the

document. Once I had satisfied that preliminary criterion, I reviewed the title and abstract/summary of the documents for content relevant to participant direction.

Third, all documents must have covered participant direction programs in the U.S. I used this criterion to limit the sample and sharpen the research focus. Next, I discuss the determination of search terms with respect to the methods for each source searched.

Library databases. I searched the two library databases first, Proquest Research Library and Academic Search Premiere, because the databases had more advanced search options than the other two sources, which facilitated strictly limiting the results based on inclusionary criteria. Search options included: (a) using truncation (root words) and wildcard characters (an * to indicate multiple suffixes to the root word) to get at every term derivation in one search; (b) searching the title, abstract, and keywords/subjects simultaneously; (c) and limiting the range of dates to January 1, 2004 through December 31, 2008. While searching the first database, Proquest Research Library, with the expanded search term list, I reviewed the search results and realized that I had omitted a key search term (consumer direct*), which I then added to the list. I searched the following truncated key terms in both library databases: self-determin*, consumer control*, self direct*, participant direct*, individual* fund*, individual* budget*, person direct*, and consumer direct*. Once I had gathered preliminary collections of results from each database, I compiled the references into a table and sorted them, facilitating the elimination of duplicate references. Then I used the resulting list as a base sample against which to compare the results from the remaining two sources.

Search engine. Next, I searched for documents using the search engine Google Scholar. Using Google Scholar's advanced search options, I was able to limit the subject areas searched to Social Sciences, Arts, and Humanities as well as limit the years searched. Although Google

Scholar did not allow for search term truncation, I was able to search for an exact phrase. Therefore, I searched the following expanded terms in Google Scholar: self-determination, consumer control, consumer controlled, self direct, self direction, self directed, participant direct, participant directed, participant direction, consumer direct, consumer directed, consumer direction, person-directed, individualized funding, individual budget, individual budgeting, and individualized budgets. Although Google Scholar allowed for the option of searching terms in the title only, this option was not functioning during this research. Each time I attempted to use that search option, the results appeared to reflect searching for the term anywhere in the document; therefore, the results returned were broader than those returned from the library databases. Once I had gathered a preliminary collection of results from Google Scholar for each search term, I reviewed the resulting references for the elimination of duplicate documents and documents whose content was not relevant to participant direction of long-term care supports and services. Then I added the remaining documents to the existing reference table.

Website. Finally, while searching The Clearinghouse for the Community Living Exchange Collaborative, I encountered additional challenges, as I did with Google Scholar. The advanced search options available for The Clearinghouse could be used in isolation but not in combination. For example, I could search a specific phrase, subject, or set of dates, but I could not use these in combination. Therefore, I conducted my search of The Clearinghouse in two ways. First, I searched the years 2004 through 2008. Then I conducted the search again, this time searching the exact terms used previously in searching Google Scholar. Once I had searched The Clearinghouse using both search methods, I compared the results from each search and eliminated duplicate references and documents with dates outside of the 2004 through 2008 inclusionary criteria. I compiled the remaining search results and reviewed them for content

relevant to participant direction of long-term care supports and services. Then I added the references of the remaining documents meeting the inclusionary criteria to the table as I had done with the previous three data sources.

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. Previous searches of these three 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. The returned results for self-determination primarily referenced the definition of “acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference” (Wehmeyer, Kelchner, & Richards, 1996, ¶2). The returned results for self direction and self directed appeared to primarily refer to the fields of psychology and learning. For these reasons I did not review the 44,260 items found when searching these three terms in Google Scholar. Instead, I reviewed the remaining 9,910 documents, screening them by title and, if needed and available, a cursory review of the abstract or introduction. Although I applied the inclusionary criteria in as linear of a process as possible, due to the sheer quantity of documents in the initial sample I overlooked some document references in the application of each criterion, requiring it to be an iterative process. Approximately 550 documents comprised the initial sample that I selected based on the inclusionary criteria.

Final Sample

Once I had identified the initial sample using the inclusionary criteria, I reviewed the documents for more details and added information (if available) regarding the name of the

specific program of participant direction researched (e.g., California's In-Home Supportive Services Program, Arkansas' Cash and Counseling Program), the disability populations represented (e.g., intellectual and developmental disabilities, elderly, physical disabilities), and the type of document (e.g., handbook, research article, report, forum) to the existing table of references. I used this additional information to enable computerized sorting of the results, which facilitated removal of any remaining duplicate references and the application of exclusionary criteria. As with the inclusionary criteria, application of the following exclusionary criteria was an iterative process.

I applied four exclusionary criteria to the initial sample in order to determine the final sample of documents for analysis. First, since the focus of this study was on the investigation of participant direction in long-term care (i.e., the supports and services needed to meet individual care and assistance needs over an extended or ongoing period of time for those who are unable to be fully independent), I excluded any documents that did not emphasize long-term care supports and services as the focus of the document. Second, since the strategy of inquiry for this study was to conduct a documentary analysis of current literature on participant direction, I excluded documents whose primary purpose was to review the research literature on participant direction; I did, however, review bibliographic references to ensure that the search process was finding key documents in the field. Next, because I was looking for the range of implementation of participant direction and did not want a disproportionate representation of one program (e.g., Cash and Counseling has over 100 articles on its demonstration programs), I used the third and fourth exclusionary criteria to reduce redundancy of authorship and program in the literature sample. With regard to authorship (third criterion), I selected the most recent document when multiple documents with the same author as the first or second author appeared within the search

results since researchers often write multiple articles on the same line of research or research project. I used the fourth exclusionary criterion to reduce redundancy of the same program of participant direction in the literature sample; therefore, I selected one document per identified program of participant direction (e.g., if there were three articles on the Cash and Counseling program of participant direction as applied in Arkansas, I selected one of the three). I selected documents based on relevancy of content to the study purpose and research question by reviewing the document's abstract. If more information was needed, I scanned the body of the document. I applied this criterion to documents that focused exclusively on a specific program or a small number of programs, typically for the purposes of research. I did not apply the fourth criterion to documents that provided a broad overview of several programs of participant direction.

The final sample for my document analysis consisted of 53 references (2,639 total pages; see Table 1) out of over 54,000 total search results. The documents in the final sample referenced programs in all 50 states, including the District of Columbia and American Samoa.

Table 1

References of Final Sample of Documents for Analysis

Document Reference	Disability Category	Program of Participant Direction (e.g., name and state)	# of Pages	Type of Document
Alakeson, V. (2008). Self-directed care for adults with serious mental illness: The barriers to progress. <i>Psychiatric Services</i> , 59(7), 792-794.	Mental Illness	Overview FL, MD, AK, OR, TN, MI	3	Forum
Barnes, C., Logsdon, V., Sutherland, S., & Gonzales, E. (2006). <i>The in-home supportive services (IHSS) program consumer handbook</i> . Sacramento: California State University. Retrieved from http://www.hcbs.org/moreInfo.php/doc/1958	Elderly, Non-specific, Sensory	California In-Home Supportive Services (IHSS) Program	107	Handbook
Bates, K. (2007). <i>The true costs and benefits of self-directed care: Living with independence, freedom, and equality (LIFE) account feasibility study & implementation plan</i> . Southern New Hampshire University. Retrieved from http://www.hcbs.org/moreInfo.php/doc/2241	Elderly, Non-specific, Physical	New Hampshire and Wisconsin, Living with Independence Freedom and Equality (LIFE) Savings Account Program	12	Report
Blue-Banning, M. (2007). A Journey Toward Participant Direction. <i>The Exceptional Parent</i> , 37(10), 61-63.	ID	Overview – general description	3	Informative, Peer-reviewed
Bradshaw, Y., Nehus, V., & Hart A. (2006). <i>Consumer-directed model training manual</i> . Arkansas Disability and Health Program, Partners for Inclusive Communities. Retrieved from http://www.hcbs.org/moreInfo.php/doc/1645	Non-specific	Arkansas Independent Choices Program	234	Handbook
Breihan, A. W. (2007). Who chooses service providers? The spread of consumer choice, 1992-2004. <i>Intellectual & Developmental Disabilities</i> , 45(6), 365-372.	ID	Overview of programs across nation (1992-2004) (50 states)	8	Qualitative Research, Peer-reviewed

Caldwell, J. (2007). Experiences of families with relatives with intellectual and developmental disabilities in a consumer-directed support program. <i>Disability & Society, 22</i> (6), 549-562. doi:10.1080/09687590701560139	ID	Illinois Home Based Support Services Program (HBSSP)	14	Qualitative Research, Peer-reviewed
Centers for Medicare & Medicaid Services (CMS). (2008). <i>1915(c) Waiver application version 3.5 - The web-based application</i> . Retrieved from https://www.hcbswaivers.net/CMS/help/version_3_5	Non-specific	HCBS (not state-specific)	125	Waiver Application
5 1915c Waiver Application and Accompanying Materials.zip				
Clark, M.J., Hagglund, K.J. & Sherman, A.K. (2008). A longitudinal comparison of consumer-directed and agency-directed personal assistance service programs among persons with physical disabilities. <i>Disability & Rehabilitation, 30</i> (9), 689-695. doi:10.1080/09638280701463878	Physical	Missouri Personal Assistance Services	7	Qualitative Research, Peer-reviewed
Claypool, H., & O'Malley, M. (2008). <i>Consumer direction of personal assistance services in Medicaid: A review of four state programs</i> . Kaiser Commission on Medicaid and the Uninsured. Retrieved from http://www.hcbs.org/moreInfo.php/doc/2197	Elderly, Non-specific	California, Colorado, New York, and Virginia Personal Assistance Services	28	Report
Cloutier, H., Malloy, J., Hagner, D., & Cotton, P. (2006). Choice and control over resources: New Hampshire's Individual Career Account demonstration projects. <i>Journal of Rehabilitation, 72</i> (2), 4-11.	Elderly, Mental Illness	New Hampshire Dollars and Cents Individual Career Account Project	8	Qualitative Research, Peer-reviewed
Colorado Department of Health Care Policy and Financing. (2007). <i>Consumer direction presentation(s): Colorado</i> . Retrieved from http://www.hcbs.org/moreInfo.php/doc/1861	Non-specific	Colorado HCBS waiver programs	123	Presentation

Department of Health and Human Services in State of North Carolina (DHHS of NC). (2005). <i>Consumer-directed supports toolbox</i> . Retrieved from http://www.hcbs.org/moreInfo.php/doc/1834	Elderly, ID, Mental Illness, Other Health, Physical, Sensory	North Carolina - overview of consumer-directed supports	189	Handbook, Presentation
Doty, P. (2004). <i>Consumer directed home care: Effects on family caregivers</i> . San Francisco, CA: National Center on Caregiving, Family Caregiver Alliance. Retrieved from http://www.hcbs.org/moreInfo.php/doc/1070	Elderly, Other Health, Physical	Description / overview of available consumer direction – public and private	17	Report
Flanagan, S. A. (2006). <i>Consumers' perceptions of consumer-directed personal assistance and intermediary services: Eight states' experiences</i> (Doctoral dissertation). Unpublished doctoral dissertation, Brandeis University. (OCLC No. 179621674).	Elderly, ID, Other Health, Physical, TBI	GA, ID, ME, MA, MO, NH, NY, PA Medicaid and state-funded Personal Assistance Services	308	Dissertation
Fleming-Castaldy, R. P. (2008). <i>Consumer-directed personal care assistance and quality of life for persons with physical disabilities</i> (Doctoral dissertation). Unpublished doctoral dissertation, New York University. (OCLC No. 227163389).	Physical	Pennsylvania Personal Care Assistance	164	Dissertation
Gage, B.M., Khatutsky, G., & Wiener, J.M. (2005). <i>Consumer-directed options</i> . RTI International, Massachusetts . Retrieved from http://www.hcbs.org/moreInfo.php/doc/1122	Elderly	Vermont consumer-directed programs	24	Report
Griffin, E. (2005). <i>Access, choice and control: A comparative analysis of Maine's personal assistance services programs</i> . Institute for Health Policy, University of Southern Maine. Retrieved from http://www.hcbs.org/moreInfo.php/doc/1301	Elderly, Non-specific	Maine's Personal Assistance Services	60	Report

Infeld, D. L. (2005). <i>States experiences implementing consumer-directed home & community services: Results of the 2004 survey of state administrators, opinion survey & telephone interviews</i> . Washington, DC: National Association of State Units on Aging and The National Council on Aging. Retrieved from http://www.hcbs.org/moreInfo.php/doc/1071	Elderly	HCBS – nationwide survey	110	Report
Jamison Rissi, J. (2007). <i>You Call the Tune: The Promise and Challenge of Consumer-Directed Care</i> . Arizona Health Futures, St. Louis Health Initiatives. Retrieved from http://www.hcbs.org/moreInfo.php/doc/1907	Elderly, Mental Illness, Physical	Arizona Long-Term Care System and Senior Adult Independent Living	32	Informative, Non Peer-reviewed
Kansas - Providing choice among providers of financial management services. (2004). <i>Prepared by Medstat for Centers for Medicare & Medicaid Services, Promising Practices in HCBS</i> . Retrieved from http://www.hcbs.org/moreInfo.php/doc/1190	Elderly, ID, Physical, TBI	Kansas HCBS participant direction waivers overview	3	Report
Kassner, E. (2006). <i>Consumer-Directed Home and Community-Based Services</i> . Washington, DC: AARP Public Policy Institute. Retrieved from http://www.hcbs.org/moreInfo.php/doc/1610	Elderly, Non-specific	HCBS overview - AK, CT, NH, NY, OK, WV	2	Informative, Non Peer-reviewed
Kendrick, M. J., Petty, R. E., Bezanson, L., & Jones, D. L. (2006). <i>Promoting self-direction and consumer control in home and community based service systems</i> . Houston, TX: ILRU Community Living Partnership. Retrieved from http://www.hcbs.org/moreInfo.php/doc/1581	Elderly, Non-specific	HCBS (not state specific)	22	Report
Kennedy, M. J. (2004). Living outside the system: The ups and downs of getting on with our lives. <i>Mental Retardation</i> , 42(3), 229-231.	Physical	New York Self-Directed Personal Services (SDPS)	3	Forum

Kim, M. K., Fox, M. H. & White, G. W. (2006). Comparing outcomes of persons choosing consumer-directed or agency-directed personal assistance services. <i>Journal of Rehabilitation, 72</i> (2), 32-43.	Physical	Kansas Medicaid HCBS Disability Waiver	12	Quantitative Research, Peer-reviewed
Kitchener, M., Ng, T., & Harrington, C. (2007). State Medicaid home care policies: Inside the black box. <i>Home Health Care Services Quarterly, 26</i> (3), 23-38. doi:10.1300/J027v26n03_02	Elderly, ID, Physical	HCBS and other Medicaid programs	16	Quantitative Research, Peer-reviewed
Koyanagi, C., Alfano, E., & Carty, L. (2008). <i>In the driver's seat: A guide to self-directed mental health care</i> . Washington, DC: Bazelon Center for Mental Health Law. Retrieved from http://www.hcbs.org/moreInfo.php/doc/2285	Mental Illness	Non-specific	40	Handbook
Loughlin, D. M., Simon-Rusinowitz, L., Mahoney, K. J., Desmond, S. M., Squillace, M. R., & Powers, L. E. (2004). Preferences for a cash option versus traditional services for Florida children and adolescents with developmental disabilities. <i>Journal of Disability Policy Studies, 14</i> (4), 229-240.	ID, Physical	Florida Cash and Counseling Demonstration and Evaluation	12	Quantitative Research, Peer-reviewed
Massachusetts Department of Mental Retardation, MASS C-PASS Policy Subcommittee. (2007). <i>Recommendations for achieving system-wide, sustainable self-determination and self-direction in the commonwealth of Massachusetts</i> . Retrieved from http://www.hcbs.org/moreInfo.php/doc/1994	Elderly, ID, Mental Illness, Physical	Massachusetts Community-integrated Personal Assistance Services and Supports (C-PASS)	42	Report
Masters, J. (2006). The benefits of consumer-directed services for caregivers of persons with Alzheimer's Disease. <i>Families in Society, 87</i> (4), 583-589.	Mental Illness	Demonstration project – caregivers volunteer for project (not state specific)	7	Quantitative Research, Peer-reviewed
McGaffigan, E. (2008). <i>Discussion paper: Redefining quality: Participant-directed services</i> . New Brunswick, NJ: Rutgers Center for State Health Policy. Retrieved from http://www.hcbs.org/moreInfo.php/doc/2199	Elderly, ID, Mental Illness, Physical	Overview - various participant direction models and strategies	28	Report

Meng, H., Friedman, B., Dick, A. W., Wamsley, B. R., Eggett, G. M., & Mukamel, D. (2006). Effect of voucher benefit on the demand for paid personal assistance. <i>The Gerontologist</i> , 46(2), 183-192.	Elderly, Non-specific	New York, West Virginia, and Ohio Medicare Primary and Consumer-directed Care	10	Quantitative Research, Peer-reviewed
Minnesota Department of Human Services, Disability Services Division. (2004). <i>Personal care assistance (PCA) program: Consumer guidebook</i> . St. Paul, MN: Author. Retrieved from http://www.hcbs.org/moreInfo.php/doc/1232	Elderly, Non-specific, Other Health	Minnesota – Personal Care Assistance	81	Handbook
Moseley, C.R. (2005). Individual budgeting in state-financed developmental disabilities services in the United States. <i>Journal of Intellectual & Developmental Disability</i> , 30(3), 165-170.	ID	U.S. state government developmental disabilities agencies (all states except AK, GA, FL, CO, IL, MI, NM and NY)	6	Quantitative Research, Peer-reviewed
Nadash, P., & Crisp, S. (2005). <i>Best practices in consumer direction</i> . Retrieved from the Centers for Medicare & Medicaid Services at http://www.cms.gov/DemoProjectsEvalRpts/downloads/Section648_Report.pdf	ID	Overview – nationwide best practices to inform Medicare demonstration	114	Report
National Council on Disability. (2004). <i>Consumer-directed health care: How well does it work?</i> Washington, DC: Author. Retrieved from http://www.nationaldisabilityrightsnetwork.org/issues/comment/consumerdirected.pdf	Non-specific	Overview – nationwide broad policy	203	Report
National Mental Health Association. (2005). <i>Consumer control and choice: An overview of self-determination initiatives for persons with psychiatric disabilities</i> . Alexandria, VA: Author. Retrieved from http://www.hcbs.org/moreInfo.php/doc/1203	Mental Illness	Overview - FL, MI, GA, Cash and Counseling	21	Report
New Jersey - Cash allowances and support services for people with disabilities. (2005). <i>Prepared by Medstat for Centers for Medicare & Medicaid Services, Promising Practices in HCBS</i> . Retrieved from http://www.hcbs.org/moreInfo.php/doc/758	ID	New Jersey Cash and Counseling	3	Report

O'Brien, D., Ford, L., & Malloy, J. M. (2005). Person centered funding: Using vouchers and personal budgets to support recovery and employment for people with psychiatric disabilities. <i>Journal of Vocational Rehabilitation</i> , 23(2), 71-79.	Mental Illness	Oklahoma Keys to Employment and New Hampshire Dollars and Sense Individual Career Account Project	9	Quantitative Research, Peer-reviewed
O'Keefe, J., Wiener, J., & Greene, A. (2005). <i>Consumer direction initiatives of the FY 2001 and 2002 grantees: Progress and challenges</i> . Department of Health and Human Services, Centers for Medicare and Medicaid Services. Retrieved from http://www.hcbs.org/moreInfo.php/doc/1601	Non-specific	11 Real Choice Grantees' programs NH, KS, WI, SC, WV, WA, CO, OK, NC, IN, ME	83	Report
Phillips, B., & Schneider, B. (2007). Commonalities and variations in the Cash and Counseling programs across the three demonstration states. <i>Health Services Research</i> , 42(1p2), 397-413. doi:10.1111/j.1475- 6773.2006.00677.x	Non-specific	Arkansas, Florida, and New Jersey Cash and Counseling programs	17	Quantitative Research, Peer-reviewed
Research and Training Center on Community Living. (2004, Spring). <i>Impact: feature issue on consumer-controlled budgets</i> , 17(1). Minneapolis: Institute on Community Integration (UCEDDD). Retrieved from http://www.hcbs.org/moreInfo.php/doc/970	ID, Physical, TBI	Overview of available programs (CDCS, Real Choices grant, Partners in Community Support, HCBS) MI, MN, NJ, OR, MD, CO, NC, MO, UT, VA, AZ, OK, PA, TN	32	Informative, Non Peer- reviewed
Revell, W. G., & Inge, K. J. (2007). Customized employment Q and A: Funding consumer-directed employment outcomes. <i>Journal of Vocational Rehabilitation</i> , 26(2), 123-127.	Non-specific	Various programs - non-specific	5	Informative, Peer-reviewed
Rosenberg, L., William, E. M., & Sievert, A. L. (2005). <i>Consumer directed support: Lessons learned from Wisconsin's family care program</i> . Madison, WI: Department of Health and Family Services / Pathways to Independence. Retrieved from http://www.cow.waisman.wisc.edu/Documents/SD S_WI%20stuff/SDS%20Learned/pdf	Elderly, ID, Physical	Wisconsin Family Care Program	34	Report

Scherzer, T., Wong, A., & Newcomer, R. (2007). Financial management services in consumer-directed programs. <i>Home Health Care Services</i> , 26(1), 29-42. doi:10.1300/J027v26n01_03	Non-specific	Overview of financial management services in Medicaid personal assistance services	14	Informative, Peer-reviewed
Spillman, B.C., Black, K. J., & Ormond, B. A. (2007). <i>Beyond cash and counseling: The second generation of individual budget-based community long-term care programs for the elderly</i> . The Kaiser Commission on Medicaid & the Uninsured, The Urban Institute. Retrieved from http://www.hcbs.org/moreInfo.php/doc/1884	Elderly	Overview - Cash and Counseling AK, OR, CO, SC, WI, DC, NJ, FL, NC, MA, MN	73	Report
Squillace, M.K., & Firman, J. (2005). <i>The myths and realities of consumer-directed services for older persons</i> . National Council on the Aging. Retrieved from http://www.hcbs.org/moreInfo.php/doc/1629	Elderly	Overview of California In-Home Supportive Services and Cash and Counseling AK, NJ, FL	24	Report
Surpin, R. (2007). Independence care system: A disability care coordination organization in New York City. <i>Journal of Ambulatory Care Management</i> , 30(1), 52-63.	Physical	New York City – Independence Care System	12	Report
The ARC of Tennessee. (2004). <i>Tennessee Personal Assistance Supports and Services (PASS) user's guide: A comprehensive guide to assist individuals in self-direction</i> . Nashville: Author. Retrieved from http://www.hcbs.org/moreInfo.php/doc/1025	Non-specific	Tennessee Personal Assistance Supports and Services Programs (PASS)	81	Handbook
Topeka Independent Living Resource Center, Inc. (2005). <i>Quality indicators for consumer-direction</i> . Topeka, KS: Author. Retrieved from http://www.hcbs.org/moreInfo.php/doc/1199	Elderly, Non-specific	Kansas - Non-specific program	1	Informative, Non Peer-reviewed
Tritz, K. (2005). <i>Long-term care: Consumer-directed services under Medicaid</i> . (Order code RL32219.) Washington, DC: Congressional Research Service, The Library of Congress.	Elderly, Non-specific, Other Health	Overview (IHSS, CMS, C&C, Medicaid) CA, ME, MI, OK, OR, NY, WA	37	Report

Whitlatch, C. J., & Feinberg, L. F. (2006). Family ID, Other Health	California Caregiver Resource Centers “direct pay” program	13	Quantitative Research, Peer-reviewed
and friends as respite providers. <i>Journal of Aging and Social Policy</i> , 18(3/4), 127-139. doi:10.1300/J031v18n03_09			
Wyoming - Individual budgets for Medicaid waiver services. (2004). <i>Prepared by Medstat for Centers for Medicare & Medicaid Services, Promising Practices in HCBS</i> . Retrieved from http://www.hcbs.org/moreInfo.php/doc/763	Wyoming HCBS	3	Report

Note. ID = Intellectual Disability; TBI = Traumatic Brain Injury.

Although some documents clearly identified one or more disability populations, others simply referred to *individuals with disabilities* as a broad category (see Table 2 and Appendix A). The final sample included a variety of documentary materials (e.g., handbooks, reports, peer-reviewed research; see Table 3). Merriam (1998) emphasized the responsibility of the investigator in determining a document’s “origins and reasons for being written, its author, and the context in which it was written” (p.121). Efforts to clearly type, categorize, and understand the context of the documents resulted in a glossary with each document type definition identifying: what the document contained, who created it, why it was created, and where it would typically be found (see Appendix B).

Table 2

Disability Categories Represented in the Sample

Disability Category	Number of Documents
Elderly	23
Intellectual and/or Developmental	17
Mental Illness	10
Non-Specific	19
Other Health	6
Physical	17
Sensory	2
Traumatic Brain Injury	3

Note. Authors may have identified one or more disability categories as the focus of the document.

Table 3

Document Types Represented in the Sample

Document Type	Number of Documents
Dissertation	2
Forum	2
Handbook	6
Informative, Non Peer-Reviewed	4
Informative, Peer-Reviewed	3
Presentation	2
Qualitative Research, Peer-Reviewed	4
Quantitative Research, Peer-Reviewed	9
Report	21
Waiver Application	1

Note. One document reference included two document types, a presentation and a handbook, resulting in 54 documents represented in this table.

Coding and Categorizing

Below I describe the coding and categorization process in three stages: (a) initial coding, (b) categorization, and (c) final coding.

Initial Coding

Having selected the documents for the final sample, I began line-by-line coding one document at a time looking for components and indicators of participant-directed service delivery models. I used constant comparative methods (Glaser & Strauss, 1967), looking for differences and similarities among the coded data. Because of the nature of coding documents of such varied origin and production, I used PDF reading and annotating software to facilitate

coding and Microsoft Word to organize the codebook and gather raw data in a table. The first column held identified components (i.e., broad categories) and the second column held raw data (i.e., coded or quoted material) that described the indicators of each component. The third column identified the reference source for the data in the second column. I coded 12 documents in this fashion during the initial coding stage (see Appendix C for document references).

At this stage, I was meeting every two weeks with senior researchers for peer debriefing sessions. The senior researchers also provided check-coding (Miles & Huberman, 1994) for 5 (42%) of the 12 documents coded in the initial coding stage. In addition, they acted as a sounding board for codebook and conceptual framework development.

Categorization

After coding each document, I analyzed the coded data and gathered it in the table depicting categorization of data by apparent components. I used the table to track the coding and categorization process. This table evolved into the codebook while coding the first 12 documents. As I coded each new document, the coded data were compared to the existing data in the table. If the coded data from the new document were *not* already represented in the table, I added the data to an appropriate existing or new component category, with the reference identified in the third column. If the coded data from the new document *were* already represented in the table, I added a reference to the new document to be associated with the relevant data. I repeated this process with each new document that I coded. I often used *in vivo* coding since the purpose of this study was to analyze the design of various programs of participant direction. *In vivo* codes are the shorthand terms specific to an organization or setting (Charmaz, 2006); in this study, the *in vivo* codes were characteristic of the ways in which programs of participant direction were organized and implemented. As with any qualitative coding process, categories

were revised, added, and collapsed throughout the coding and categorization process until an initial conceptual framework emerged.

Focused Coding

The focused coding stage requires the investigator to make “decisions about which initial codes make the most analytic sense to categorize [the] data incisively and completely” (Charmaz, 2006, p. 57). I began the focused coding stage by reviewing the 12 documents coded in the initial coding stage, using a newly reorganized codebook based on the conceptual framework. I reviewed and recoded the original 12 documents according to the new codebook. In this process, I both confirmed the new organizational structure and added new data to the revised codebook table (Charmaz, 2006).

The purpose of focused coding is to use “the most significant and/or frequent earlier codes to sift through large amounts of data” (Charmaz, 2006, p. 57); therefore, the next step in the focused coding stage was to test the new codebook structure and conceptual framework against the remaining 41 documents. As with the development of the initial codebook, the revised codebook and framework evolved during the focused coding stage 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. I completed the focused coding stage with the assistance of a peer colleague who had no prior involvement in the research and development of the codebook and conceptual framework.

For this stage, I developed a document analysis tool (see Appendix D) to facilitate focused coding of the remaining 41 documents and the discovery of new components and indicators (Altheide, 1987). In developing this tool, I clearly defined each component and

indicator, describing its properties or characteristics (Charmaz, 2006). I tested this tool on 3 of the initial 12 documents before applying the tool to the remaining 41 documents.

When we first began coding using the document analysis tool, the peer colleague and I engaged in paired coding of 10 documents over a period of eight weeks. During paired coding we would each independently code the same document, then meet and review all codes and supporting raw data (i.e., quoted content). During our meeting, we would identify codes that needed clarification or amendment and refine 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 response using the tool. I computed reliability as shown below:

$$\text{Reliability} = \frac{\text{Number of agreements}}{\text{Total number of agreements} + \text{disagreements}}$$

Following the 8th document, we began independently coding the remaining 33 documents. At different periods during independent coding, we engaged in paired coding of two additional documents, and I check-coded three documents independently coded by my peer colleague. I took these measures to check continued reliability and reduce the opportunity for coder drift as we completed coding the remainder of the sample. We continued to meet every two weeks to review data collection, discuss emerging indicators and modify the conceptual framework and document analysis tool as appropriate. In all, pairs of researchers simultaneously coded 19% of the 53 documents; independent researchers [principal investigator (myself) or senior researchers] check-coded 15% of documents; single coders (either principal investigator or peer colleague) independently coded 66% of documents.

Saturation was reached within completion of the coding of the 53-document sample, eliminating the need for further sampling. According to Glaser and Strauss (1967), saturation is achieved when “no additional data are being found whereby the [researcher] can develop properties of the category” (p.61). I determined that saturation of data in this study had been met when the coding of the last eight documents in the 53-document sample failed to stimulate any modification to the document analysis tool or the conceptual framework as a result of the emergence of new data.

Theory Development

Theory development was an iterative process that evolved with each modification to the document analysis tool and the conceptual framework. Theory development requires the researcher to move “reflexively between data collection, analysis, and reconceptualization” (Altheide, 1987, p. 73). In this process, I developed two theoretical constructs that provided the organizational structure for the identified components and indicators. These constructs provide the basis for all elements of participant direction programs. Within these constructs, I refined, revised, and reorganized the components and indicators of participant direction programs time and again until a solid conceptual framework emerged.

This conceptual framework formed an *ideal type*; “ideal types are syntheses of characteristics or significant features constructed on the basis of logical and meaningful compatibility” (Hekman, 1983, p. 33). The characteristics or features selected for syntheses are “more or less present and occasionally absent *concrete individual* phenomena” (Weber, 1949 as quoted in Hekman, 1983, p. 31); they are common to many but not present in all programs of participant direction. Hekman explains that the purpose of an ideal type is “to provide a comparison with concrete reality in order to reveal the significance of that reality” (p. 34); the

conceptual framework provides both an established point of reference, a standard for comparison of programs of participant direction, and a starting point for discussion on the theory of design of participant directed programs of long-term care supports and services.

Trustworthiness Measures

I employed several trustworthiness measures in the implementation of this study. First, throughout the study, I met with two senior researchers for debriefing sessions for the purposes of ensuring trustworthiness of the data. We met to discuss study structure, progress, next steps, coding and analysis. The two senior researchers served as check coders, reviewing document coding, category development, and the organizational structure of the identified components (Miles & Huberman, 1994). We held meetings 1-2 times monthly throughout the study.

Second, as previously mentioned, I conducted paired coding and check-coding with a doctoral research assistant during the focused coding stage. We engaged in paired coding of 10 documents over eight weeks and achieved 85% reliability before beginning independent coding. In addition, to reduce coder drift and check continued reliability, I provided check-coding for a portion of the assistant's independently coded documents.

Third, I triangulated the data in the following three ways, which I will describe in more detail below: (a) involving multiple investigators, (b) relying on multiple sources of data, and (c) using multiple types of documents developed for multiple purposes (Creswell, 2007; Maxwell, 2005; Merriam, 1998). First, a total of four investigators worked on this study: principal investigator, two senior researchers, and a doctoral research assistant. Second, data were collected from multiple sources. I searched four sources: two library databases with emphases on peer-reviewed journals, a search engine focused on scholarly works (peer-reviewed and gray literature) accessible through multiple sources on the web, and a website that is devoted to the

nationwide sharing of content (primarily gray literature) relevant to Home and Community Based Services programs. Regarding the third form of triangulation, the documents I gathered for the sample represented multiple types of documents (e.g., reports, handbooks, PowerPoint presentations, peer-reviewed qualitative and quantitative studies) developed for multiple audiences and purposes (see Appendix B for descriptions of each type of document).

Finally, throughout the study I kept an ongoing journal for the purposes of memo-writing in a Microsoft Word document, dating each entry. I used this journal for three reasons: (a) to document decisions regarding the study design, data collection and analysis, and general progress (Charmaz, 2006); (b) to record notes about debriefing meetings with research team members (i.e., senior researchers, doctoral research assistant); and (c) to document my thoughts regarding observations of patterns in and comparisons of the data and changes to the conceptual framework. This journal provided an ongoing record of the implementation of the study and accompanying thoughts, questions, and decisions regarding the data.

Limitations

When using documents as a data source, there are certain limitations to consider. First, documents are a record of an observer's (e.g., agency, researcher, individual) perceptions of participant direction. Therefore, the level of detail, accuracy of recollection and transcription of the observer limit my results. Documents often lacked the level of detail that could be acquired in an interview with pointed questions regarding program organization and level of consumer choice and control. However, the documents, due to their variability in form and content, provided sufficient detail to generate theory. Second, the documents were not produced for the purpose of this study; in fact, the documents were produced for multiple purposes and multiple audiences; therefore, the content may have been misinterpreted in the coding process.

Regarding the identification of the sample of documents, limitations existed regarding the type of document. I did not include books, book chapters, or websites as a source of data. Since books are generally developed based on prior work of the author, I believed that the content available in a book would be gathered in the collection of prior relevant documents. However, it is likely that a book may have offered a more in-depth look at the organization and implementation of programs of participant direction. I also did not include websites, although it could be posited that they are virtual documents. I did not include websites because it would have been unclear where one virtual document would begin or end (i.e., how many pages of a website constitute one “document”). There currently are several websites devoted to the implementation of participant directed supports and services that may have been able to offer more functional or detailed descriptions regarding the design of participant direction programs.

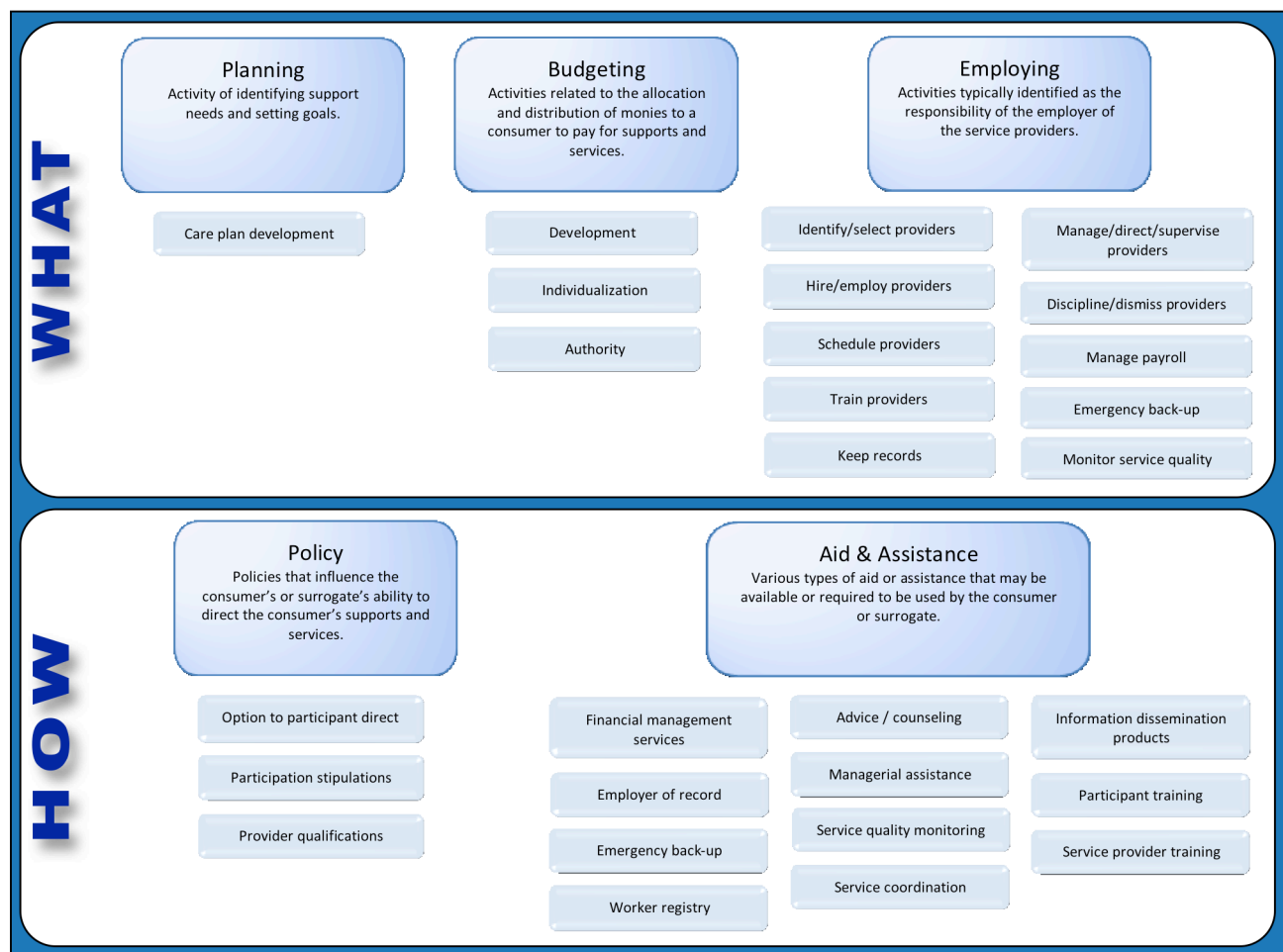
Finally, limitations exist regarding content and date of publication. This study focused solely on programs of participant direction in long-term care supports and services in the United States. Therefore, I did not collect or analyze documents referencing programs outside of the U.S., of which there appear to be many, most notably Great Britain’s movement to individualized budgets. International data would have broadened both the study question as well as the content of the data collected. In addition, articles published since the gathering of the sample are not represented in this study and, due to their recent publication, would have offered an even more current understanding of participant direction.

CHAPTER THREE: RESEARCH FINDINGS

The purpose of this study was to analyze the design of various programs of participant direction. Specifically, I sought to identify and define the components and indicators of participant direction programs in U.S. long-term care. Through qualitative analysis of the sample documents, I developed (a) a grounded theory of the design of participant direction programs and (b) a conceptual framework (see Figure 1) identifying and defining the components and indicators of participant direction programs.

Figure 1

Conceptual Framework of the Design of Participant Direction Programs



Grounded Theory

All programs offering consumers long-term care supports and services have some degree of choice and control afforded to the participants in the program, whether that choice and control are explicitly stated in the policy guiding that program or are freely given without undue pressure from regulatory agencies. In programs of participant direction, the level of choice and control afforded to consumers or surrogates is built into the design of the program. Because programs vary so significantly in their design, the level of choice and control given to participants exists on a continuum across a variety of activities and structures, from full agency-directed choice and control on behalf of the consumer to full participant-directed choice and control by the consumer or his or her surrogate decision maker. The grounded theory addresses participant direction program design through discussion of (a) ideal type, (b) organization, and (c) expression of participant direction programs in U.S. long-term care.

Ideal Type

The conceptual framework (see Figure 1) represents an *ideal type* (Hekman, 1983) of a participant direction program. The conceptual framework consists of a collection of activities and structures that facilitate the exercise of choice and control by the consumer or surrogate over the supports and services received by the consumer. I developed this ideal type by synthesizing the various characteristics and features (or *components* and *indicators* as defined in this study) of participant direction programs as described in the documents in the sample. The conceptual framework represents the comprehensive range of components and indicators present in the literature sample analyzed. The components and indicators identified in the conceptual framework are common to many programs of participant direction, but need not be present in or correspond to all of the characteristics of any one particular program. Neither is the ideal type

meant to be a model or example of how a program of participant direction *should* be designed. Rather the ideal type is a “yardstick” (Hekman, 1983, p. 33), a standard for comparison against which existing programs of participant direction may be compared. At present no such yardstick exists within the field of participant direction, as each program is individually designed, offering its own mix of components and indicators.

Organization

The conceptual framework delineates the organization of the identified components and indicators in a unified figure, showing the relationships among them. I have theorized that all programs of participant direction have two major theoretical constructs – *what* and *how* – into which all components and indicators present may be housed. These two theoretical constructs organize the various components and indicators in a logically compatible way. While not all components and indicators may be present in every program, every program has components and indicators that may be categorized either under the *what* or *how* construct. The literature I analyzed did not identify *what* or *how* as distinct categories of design or planning. I developed these constructs as a means for organizing the components and indicators and distinguishing their primary functions. Such a bright line of distinction does not presently exist in policy or practice and there is bound to be some overlap in existing programs; however, my purpose in drawing it and displaying my findings within these two constructs is to answer the research question and to respond to the call from National Council on Disability (2004) to create a clearly defined taxonomy and menu of indicators.

In this organizational structure, *what* houses the components and their respective indicators that represent the various activities common to programs of participant direction. Indicators demonstrating the expression of activities a consumer or surrogate may participate in

fall under the components of *planning, budgeting, and employing*. How houses the components and their respective indicators that represent the structures that may be in place to guide or facilitate the implementation of a program of participant direction. Indicators demonstrating the expression of the structures that may be present in programs of participant direction fall under the components of *policy and aid and assistance*. The level of choice and control afforded to consumers or their surrogates is addressed in more detail below regarding the expression of programs of participant direction.

Expression

Every program of long-term care supports and services offers some level of choice and control to its participants. The variation in these levels are best described as existing on “a continuum” (Jamison Rissi, 2007, p. 14; National Council on Disability, 2004, p.41) from full agency-directed choice and control on behalf of the consumer to full participant-directed choice and control by the consumer or surrogate decision maker. Jamison Rissi (2007) describes the continuum from a programmatic standpoint:

Many programs limit consumer “choice” to a choice between contracted home care agencies with little or no consumer input regarding the actual types of services or their delivery. Others provide consumers with full autonomy and authority for decisions, but retain control of financial transactions. Only a handful offer consumers full autonomy and authority for services and fiscal responsibility. (p. 9)

However, the expression of participant direction on a continuum is more complex than this simple description implies. Admittedly, there is a continuum at a broad level regarding which components the consumer or surrogate may be allowed choice and control (or autonomy and authority). Yet the concept of a continuum also exists at the individual indicator level.

Each indicator is reflected in one or more continua of choice and control. Generally, the more choice and control afforded to the consumer or their surrogate, the less professional or agency direction is required. For example, the indicator of *provider qualifications* (categorized under the policy component) has three continua that explicate the types of choice and control the consumer or surrogate may have with regard to provider qualifications: (a) using background checks, (b) hiring family and friends, and (c) licensing requirements. Sometimes two levels reflect the continuum of choice. This is the case with the continuum covering use of background checks: (a) participant has a choice of whether to conduct background checks and abuse screenings and (b) participant is required to conduct all state-required background checks and abuse screenings. Other continua, however, may be represented with three levels, such as the continuum regarding hiring of family and friends. The three levels of choice and control regarding hiring family and friends are: (a) no family members – only non-relatives, (b) some family – family member may not be legally responsible (e.g., parent of a minor consumer or spouse of a consumer), and (c) any family member – even legally responsible members - may be hired. Finally, for some indicators, particularly those categorized under *employing* in the *what* construct, the levels of choice and control are much more generic, as in the following:

- consumer or surrogate may choose to be completely responsible;
- consumer or surrogate has some input but is required to share responsibility with a designated professional; and
- designated professional is fully responsible for the activity.

I have detailed this level of analysis in the document analysis tool (see Appendix D), which I used in the focused coding stage. Each continuum representative of the indicators is evidenced through definitions and examples of the degree of choice and control afforded to

consumers and surrogates in programs of participant direction. Each continuum was rank ordered with a 0 representing that the continuum was not addressed in the document, moving up to the least level of choice and control (1) afforded to the consumer or surrogate, up through the greatest level of choice and control possible, rank numbered with the total number of levels in each continuum, which ranged from two to four levels. Each of the indicators and their respective continua of choice and control are discussed in greater detail below in the presentation of the conceptual framework.

Conceptual Framework

The conceptual framework (see Figure 1) consists of a collection of activities and structures that facilitate the exercise of choice and control by the consumer or surrogate over the supports and services received by the consumer. These activities and structures are organized in two theoretical constructs, *what* and *how*.

What

The *what* construct consists of the activities over which the consumer or surrogate decision maker may have some level of choice and control. I categorized indicators of these activities under three components of participant direction programs: (a) planning, (b) budgeting, and (c) employing (see Figure 2 and Table 4). I describe these components and the expression of their respective indicators below.

Figure 2

Components and Indicators Housed in the What Construct

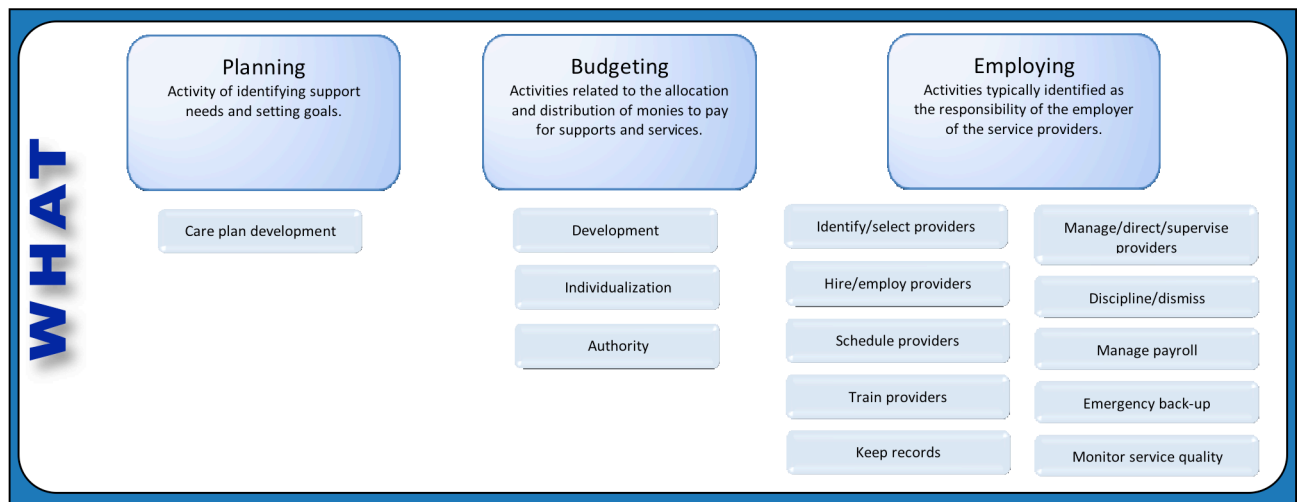


Table 4

Components and Indicators Housed in the What Construct

WHAT		
Components	Indicators	Indicator Definition
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

Planning. Planning refers to the activity of identifying support needs and setting goals. Approximately half of the documents analyzed in this study addressed the component of planning. Although planning was definitely understood to be a common component of participant direction, documents spent little time actually addressing 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 is conducted.

Only one indicator was identified relevant to planning; it was care plan development, which had two continua associated with it. The first continuum reflected the consumer's or surrogate's role in planning. Some programs of participant direction emphasized the consumer's role in directing and "participat[ing] in the development of their own care plan" (Claypool & O'Malley, 2008, p. 2), while others clearly identified the role of the professional in guiding the process. McGaffigan (2008) emphasized the consumer's role, stating "the individual's own identification of existing needs and resources should be paramount in a participant-directed model" (p. 9), while Loughlin et al. (2004) emphasized the role of the professional (e.g., case manager), particularly in Medicaid funded programs.

The second continuum reflected the opportunity for the consumer or surrogate to invite anyone he or she wished to participate in the planning process. No documents explicitly stated that the consumer or surrogate could not invite whomever they desired to participate in planning;

although the small number of documents that did address it generally stated that the team should include “key family and friends chosen by the consumer” (Cloutier, Malloy, Hagner, & Cotton, 2006; Revell & Inge, 2007, p.125).

Budgeting. Budgeting refers to the activities related to the allocation and distribution of monies to pay for the supports and services identified in the consumer’s individualized budget. Monies refer 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 et al., 2006; O’Keefe et al., 2005) allocated to meet the needs of the consumer. Under the component of budgeting, I identified three indicators of activities over which the consumer or surrogate decision maker may have some choice and control: (a) development, (b) individualization, and (c) authority.

Development. The indicator of development presented with two continua: one addressing method of development and the other addressing level of consumer or surrogate participation in the process. Authors addressed the method of development more frequently than the level of consumer or surrogate participation. There are typically three ways in which a consumer’s budget is developed. 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 yet still somewhat individualized approach based budget development on a “statewide uniform assessment process to determine the functions of daily living consumers are unable to perform on their own” (Barnes et al., 2006, p. 5). Typically the results of the assessment determine the quantity of monies allotted annually to fund the consumer’s long-term care

supports and services. The third approach, which offered the least level of consumer individualization, allocated a budget based on a capped spending approach. Under this approach all consumers received the same quantity of monies through the program of participant direction regardless of abilities, needs, or goals. For example, the state may decide that for long-term care supports and services available under a specific program, all eligible consumers will receive “a monthly personal assistance voucher benefit of up to \$250” (Meng, et al., 2006, p. 185) to cover supports and services.

Although the participant has no choice or control over the method of budget development a state uses to determine his or her allocation, each method offers consumers or surrogates differing levels of input or participation in the process. In some programs, the consumer or surrogate does not participate in the activity of budget development (beyond compliance with a required assessment), and a designated professional (e.g., case manager, program director) is solely responsible for developing the budget amount based on a set of state or program guidelines (Barnes et al., 2006). Other participant direction programs allowed the consumer or surrogate 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). Both approaches to budget development are primarily driven by a designated professional with minimal input from the consumer or surrogate.

Individualization. The indicator of individualization presented with multiple continua related to consumer or surrogate choice and control over the creation of the individualized budget, including selection of goods and services and alteration of the individualized budget to meet the consumer’s changing needs. The individualized budget typically identifies the goods or services (e.g., personal assistance care, respite, supported employment) to be purchased, how

much will be purchased (e.g., hours/units of service, quantity of a good), who will provide the goods or services (i.e., name of service provider or business), and over what time period the services will be provided. The level of choice and control the consumer or surrogate is given in the creation and maintenance of the individualized budget ranges from having little input to having “significant flexibility” (Tritz, 2005, p. 33). In some programs, consumers or surrogates are given “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 with participants to determine the type and amount of personal care services they need” (Spillman, Black, & Ormond, 2007, p. 40). While still in others, a professional “assesses how many hours of service you need per month” (Kennedy, 2004, p. 229).

A small number of documents addressed the continuum associated with alteration of the individualized budget to meet the consumer’s changing needs. Programs operating under a Medicaid 1915(c) HCBS Waiver are required by CMS to designate a timeframe for review and update of the individualized budget, which must occur “at least annual[ly] ... or more frequently when necessary” (CMS, 2008, Appendix D-1:2). Such a budget revision may be recommended by the professional responsible for supporting the consumer or by the consumer or surrogate “as they learn new and innovative ways to meet their needs” (McGaffigan, 2008, p 10).

Authority. The indicator of authority involved multiple continua regarding (a) who has the final say on distribution of monies, (b) how payments are made, (c) who determines rate of pay for service providers, (d) from what kind of vendor may goods be purchased, and (e) what may be done with unspent monies. With regard to who has the final say on the distribution of monies and how payments are made, the consumer or surrogate may be “responsible for all

facets of funding” (National Mental Health Association, 2005, p. 2), including provider or vendor payment, and “receive an actual cash budget payment into an individual bank account they control” (Spillman et al., 2007, p. 10). The consumer or surrogate may also use “vouchers to purchase service hours” (Whitlatch & Feinberg, 2006, p. 129) directly from providers. Some programs required that the consumer or surrogate “sign-off on services before providers are paid by a third-party fiscal agent” (O’Brien, Ford, & Malloy, 2005, p. 72), relieving the consumer or surrogate of the financial responsibilities of participant direction yet still allowing some level of control over the funding. Finally, it is also possible that the consumer or surrogate are completely excluded from the payment process and have not been granted any budgeting authority (CMS, 2008).

The consumer or surrogate may also have increased choice and control over payment for services and goods identified in the individualized budget. Concerning payment for services, the consumer or surrogate may be able “to determine how much each worker will be paid” (Claypool & O’Malley, 2008, p. 7). In some programs the consumer or surrogate is allowed “to negotiate provider payment rates” (“Wyoming,” 2004, p. 1); in other programs, the consumer or surrogate may determine pay rates, which must be within certain limits (e.g., minimum/maximum) designated by the state (CMS, 2008). Yet still in other programs, the state, a designated agency or “intermediary service organization ... sets the wages” (Gage, Khatutsky, & Wiener, 2005, p. 10), and the rate of pay is non-negotiable by the consumer (Caldwell, 2007). With regard to 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 consumer or surrogate “to purchase goods and services not available in the traditional system” (Alakeson, 2008; Nadash & Crisp, 2005, p.11), such as online businesses and store

fronts (e.g., Walmart, Lowe's). In some programs, a financial management agency is "considered the provider and would be able to directly pay [nontraditional providers] for consumer purchases without having them sign provider agreements" (O'Keefe et al., 2005, p. 5), increasing consumer or surrogate choice while still leaving control of the payment for goods in the hands of the financial management agency.

Finally, budgeting authority was also revealed to extend to the use of unspent monies. If the consumer or surrogate are efficient managers and are able to meet the consumer's needs at a lesser cost than originally anticipated in the consumer's individualized budget, the consumer or surrogate may be able to use some or all unspent monies for a variety of purposes: (a) to purchase one-time expenses, typically goods, to increase independence or decrease dependence on paid supports (O'Keefe et al., 2005; Department of Health and Human Services in State of North Carolina, 2005); (b) to purchase "additional personal assistance hours" (Clark, Hagglund, & Sherman, 2008, p. 689); or (c) to deposit in a savings account (e.g., a LIFE account) that does not negatively affect eligibility for benefits (Bates, 2007; O'Keefe et al., 2005). Although, 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 to the program agency, then to be put into a risk pool or "development fund" (Research and Training Center on Community Living, 2004, p. 13) for the program.

Employing. The third component in the *what* construct is employing. Employing refers to the activities typically identified as the responsibility of the employer of the service providers. The component of employing was the most commonly described component of participant direction represented in the documents. Under the component of employing, I identified ten indicators of activities over which the consumer or surrogate decision maker may 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) emergency back-up, and (j) monitor service quality. Table 4 defines each of these indicators. Consumer or surrogate choice and control over these indicators is represented by a continuum of three levels:

- consumer or surrogate may choose to be completely responsible;
- consumer or surrogate has some input but is required to share responsibility with a designated professional; and
- designated professional is fully responsible for the activity.

Below I present some ways in which the indicators and this continuum of choice and control were described in the documents.

The general consensus in the field of home and community based long-term care supports and services is that “consumers 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 of participant direction allow the consumer to be 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 the documents to group these employing activities/indicators (i.e., identify/select, train, manage, dismiss) together when discussing the primary responsibilities of the consumer or surrogate in a program of participant direction (e.g., Claypool & O’Malley, 2008; Infeld, 2005; Kitchener, Ng, & Harrington, 2007; Minnesota Department of Human Services, 2004; Scherzer, Wong, & Newcomer, 2007; Surpin, 2007). Documents also frequently included the indicator of scheduling providers as the responsibility of

the consumer or surrogate. They emphasized the importance of the consumer or surrogate having the ability to control when and where services were received. Typically in participant direction programs, the consumer or surrogate may choose to “schedule [providers] during early mornings, nights, and weekends, when other paid help is hard to find” (Kassner, 2006, p. 1). Consumers or surrogates may choose to schedule services to be provided “at home and in other locations” (Topeka Independent Living Center, 2005, p. 1) as appropriate.

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 consumer 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 of participant direction, the consumer is deemed the employer of record and is 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 acts as the employer of record while the consumer acts as 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 assumes the responsibility of employer of record, the agency takes on the payroll management activities of “paying workers, providing workers compensation insurance, and withholding, filing, and paying federal, state, and local income and employment taxes” (“Kansas,” 2004, p. 1). When an agency is responsible for managing payroll activities, “the consumer [or surrogate] is responsible for keeping a record of hours worked ...verifying and signing the provider’s timesheet” (Barnes et

al., 2006, p. 11) as well as “documenting expenditures” (Barnes et al., 2006, p. 67) to be submitted to the agency for payment or reimbursement.

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

Finally, the activity of monitoring service quality was the least addressed of all identified indicators under the employing component. Many programs allow consumers or surrogates to “complete the majority of monitoring that takes place” (McGaffigan, 2008, p.12). Other programs designate it as the primary responsibility of a professional (e.g., case manager, service facilitator, agency; Griffin, 2005; Infeld, 2005), allowing some “consumer input into or direction of program evaluation efforts” (National Council on Disability, 2004, p. 41).

The components and indicators described above represent the *what* construct, the activities over which the consumer or surrogate may have some level of choice and control. In some programs, consumer or surrogate choice and control over activities is substantially limited, while others let the consumer or surrogate decide how “they implement this control and exercise this choice in their daily lives” (Fleming-Castaldy, 2008, p.18), including deciding what activities to participant direct.

How

The *How* category consists of the structures that may be in place to support the consumer or surrogate and facilitate or guide the implementation of participant direction programs. I categorized indicators of such structures under two components of participant direction programs: (a) policy and (b) aid and assistance (see Figure 3 and see Table 5 for definitions). I describe these components and the expression of their respective indicators below.

Figure 3

Components and Indicators Housed in the How Construct

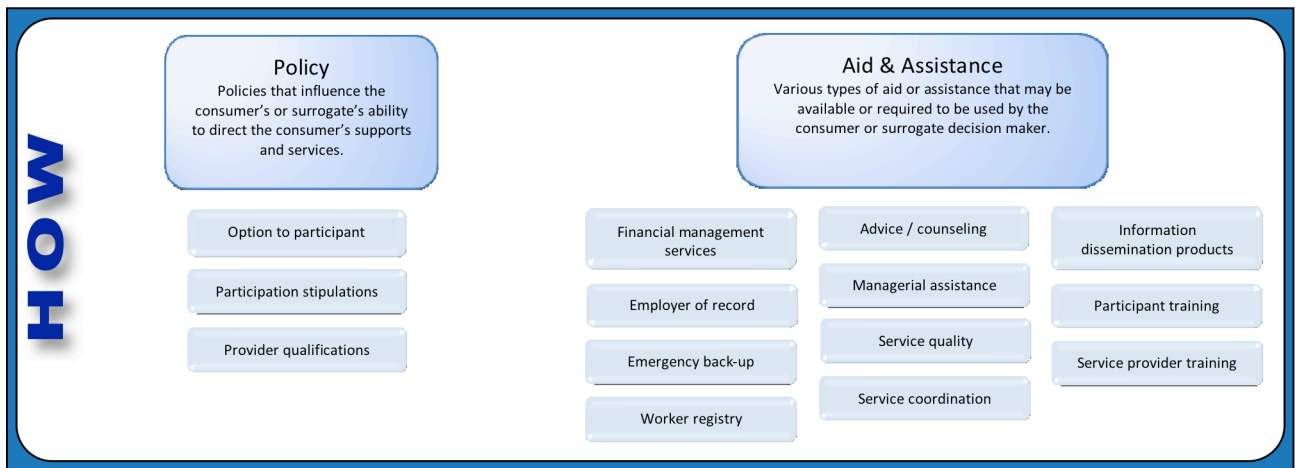


Table 5

Components and Indicators Housed in the How Construct

HOW		
Components	Indicators	Indicator Definition
Policy	Option to participant direct	Election of or choice of the consumer or surrogate to direct the consumer's supports and services
	Participation stipulations	Requirements or limitations regarding participation in programs of participant direction by the consumer or surrogate decision maker
	Provider qualifications	Regulations or practices regarding who may be hired to provide the services outlined in the individualized budget
Aid & Assistance	Financial management services	Assistance with or responsibility for all payroll management (e.g., paychecks, taxes, withholdings) and goods purchasing relative to the plan of care, commonly referred to as a fiscal agent or intermediary
	Emergency back-up	Maintenance of or assistance with the development of a back-up system or plan for when scheduled workers are not available
	Worker registry	Maintenance of or assistance with the development of a registry that lists available and qualified service providers
	Advice/counseling	Assistance provided in the form of advice and counseling regarding things like service options, personal goals, identifying training needs, etc.
	Managerial assistance	Assistance with employer responsibilities related to service providers as described in the <i>what</i> category
	Information dissemination products	Paper, audio, video, web-based products or activities designed with the intent of providing needed information to consumers, surrogates, or service providers regarding participant direction
	Employer of record	Role of legal employer of the service providers
	Service quality monitoring	Assistance with the responsibility of assuring that the services received by the consumer are quality services that meet the consumer's needs
	Service coordination	Assistance with the responsibility of identifying and accessing appropriate and needed services and

	resources in the community
Participant training	Training of consumers or surrogates on the activities associated with participant direction of the consumer's supports and services
Service provider training	Training of service providers that is not consumer specific, such as CPR certification, first aid, and generic care delivery (e.g., transferring, lifting, bathing), and workplace behaviors

Policy. I defined the component of policy as any local, state, or national policies that influenced a consumer's or surrogate's ability to direct the consumer's supports and services. Under the component of policy, I identified three indicators of structures that may influence a consumer's or surrogate decision maker's ability to direct the consumer's supports and services: (a) option to participant direct, (b) participation stipulations, and (c) provider qualifications.

Option to participant direct. This indicator presented with one continuum associated with when and how the option of participant direction was made available to the consumer or surrogate. On the least restrictive end of the continuum, some documents identified that "after meeting eligibility requirements" consumers were given "a choice about what kind of services to receive: facility or residential services, provider directed services in the home, or if available, consumer-directed services in the home" (DHHS of NC, 2005, CDS1-p.17). For some consumers, however, the option to participant-direct was more limited and became available to the consumer or surrogate once he or she became "dissatisfied" (Kennedy, 2004, p. 229) with the traditional agency-directed model. Other authors explained that it was only an option for consumers living in a designated part of the state for which the program was developed (CMS, 2008; Koyangi et al., 2008). In the entire representation of programs in the documents, there was only one state, California, in which participant direction was the default option for those

determined eligible for long-term care supports and services (Barnes et al., 2006; Claypool & O'Malley, 2008; Tritz, 2005).

Participation stipulations. The indicator of participation stipulations addresses the eligibility of the consumer or surrogate to participant-direct the consumer's supports and services. This indicator presented with two continua, one addressing the determination of the consumer's capacity to participant-direct and the other addressing whether a surrogate may assist a consumer in participant direction of his or her supports and services.

The first continuum addresses the consumer's capacity to direct his or her own supports and services. Many programs do not require any capacity test of the consumer; merely an expression of interest to participant-direct was all that was needed, regardless of need for a surrogate decision maker (Flanagan, 2005; Squillace & Firman, 2005). In these programs, "program administrators tend to think of the 'consumer' as a dyad consisting of both the individual and his or her family" (Jamison Rissi, 2007, p. 8). Although recognition of the dyad participant (consumer and family) was common, a few programs required the formality of a physician's letter (Claypool & O'Malley, 2008) or a "nurse's medical assessment" (Bates, 2006, p. 4) that indicated that the consumer was capable or had a surrogate to act on his or her behalf. Still other programs were much more stringent regarding assurances of consumer capacity and required that the consumer pass a test, training course, and/or assessment or evaluation of the consumer's capacity to participant direct prior to allowing the consumer to participate in a participant direction program (Claypool & O'Malley, 2008; Flanagan, 2005; Griffin, 2005; Tritz, 2005).

The second continuum reflective of participation stipulations concerned whether the consumer is even allowed to have a surrogate decision maker if he or she is unable to

independently direct his or her supports and services. Some programs required that the consumer be capable of independently handling all responsibilities associated with participant direction (Griffin, 2005; Spillman et al., 2007). Other programs allowed consumers to receive support with the financial aspects but expected the consumer to be capable of directing his or her own care (O’Keefe et al., 2005). Still others allowed “people with cognitive impairments ... to choose a representative to administer the [individualized budget] on his or her behalf” (Topeka Independent Living Resource Center Inc., 2005, p. 1).

In addition to the continua presented above regarding participation, several documents also addressed characteristics of the consumer and surrogate that may prohibit their participation. For example, if the consumer required 24-hour care (Claypool & O’Malley, 2008), lived in congregate housing (such as a nursing home, ICF/MR, or group home; Griffin, 2005), had an intellectual disability (Griffin, 2005), or had or needed a guardian or conservator (O’Keefe et al., 2005), the consumer was not allowed to participant direct. Similarly, some documents identified criteria regarding who could act as a surrogate decision maker for a consumer. Examples of criteria regarding the surrogate’s ability to participant-direct a consumer’s supports and services included the following:

- The surrogate may not be a paid service provider for the consumer.
- The surrogate must “be at least 18 years old.”
- The surrogate must be available to both the consumer and his or her service providers.
- The surrogate must “monitor care at least once a week” (Minnesota Department of Human Services, 2004, p. 7).

Additionally, some programs allowed the surrogate decision maker to also be a guardian or person with power-of-attorney for the consumer, while other programs prohibited that relationship “to avoid conflict of interest” (McGaffigan, 2008, p. 14; O’Keefe et al., 2005).

Provider qualifications. The indicator of provider qualifications has three continua that explicate the types of choice and control the consumer or surrogate may have with regard to provider qualifications: (a) using background checks, (b) hiring family and friends, and (c) licensing requirements.

One common qualification was that the provider must pass background checks, typically including criminal background and abuse registry screenings. This continuum reflected two levels of choice regarding the use of background checks: (a) participant has a choice of whether to conduct criminal background checks and abuse screenings, and (b) participant is required to conduct all state-required background checks and abuse screenings. If this qualification was required, it was typically dictated by state policy, regardless of the type of service model (agency direction versus participant direction), and was required for all service providers in the state (“Kansas,” 2004). However, some programs allowed more discretion with regard to this requirement, recommending that the consumer or surrogate “seriously consider doing a criminal background check” (The ARC of Tennessee, 2004, p. 60), but leaving the decision of whether or not to conduct the background check up to the consumer or surrogate (Griffin, 2005).

Another provider qualification that the authors repeatedly addressed was whether family and friends could be hired to provide services to the consumer. The rules and regulations governing the funding source for the services generally dictated this provider qualification. Some programs had no restrictions regarding who could be hired, allowing consumers to “hire legally responsible individuals” (McGaffigan, 2008, p. 4), such as a spouse or legally responsible parent.

Other programs “prohibit[ed] spouses and parents (of minors) from being paid workers” (Doty, 2004, p. 6; Kim et al., 2006), but allowed other family members (e.g., daughter, grandson) to be paid service providers (Squillace & Firman, 2005). Finally, on the most restrictive end, is the requirement that no family members may be hired, only non-relatives (Flanagan, 2005; Kassner, 2006; Meng et al., 2006).

The last provider qualification identified was whether the service provider must be licensed, certified, approved, contracted, or enrolled (hereafter “licensed” in reference to any of the aforementioned means of provider qualification designation) by a designated state agency (e.g., state Medicaid agency). This qualification also appeared to be governed by the rules and regulations of the funding source for the services. In some programs, the service provider was legally employed by the consumer or surrogate and had no requirement for licensure with the state (Gage et al., 2005; The ARC of Tennessee, 2004). These programs allowed the consumer to “choose virtually any provider ... whether a private nonprofit organization or for-profit corporation or an individual” (Breihan, 2007, p. 366). Other programs simply required that the service provider be under the supervision of or employed by a licensed service provider, allowing the consumer or surrogate to “find a [personal assistant] ... and then have that person hired by an agency” (The ARC of Tennessee, 2004, p. 2). Finally, some programs required that anyone providing services be licensed; thus, “workers in many consumer-directed programs are ‘independent providers’ and may be categorized as support service employees of the [consumer]” (Scherzer et al., 2007, p. 30). This approach was used in some programs to facilitate family and friends of the consumer to meet state licensure requirements or qualifications and become an independent service provider for the consumer. Other programs had more restrictive regulations regarding licensure and required all licensed service providers to be an agency (e.g.,

a home health agency), requiring the consumer or surrogate to “register as a personal care agency solely for the purpose of directing [the consumer’s] care” (Griffin, 2008, p. 13).

Aid and assistance. Aid and assistance refers to the various types of aid or assistance provided by the state or its agent that may be made available or required to be used by consumers or surrogate decision makers choosing to direct the consumer’s supports and services. As with many aspects of participant direction, different words and terms are used to identify similar structures. Accordingly, it became essential to try to identify the function of the aid and assistance as distinguished from the label or role (e.g., support broker, case manager, service facilitator) designated by the program design. Under the component of aid and assistance, I identified 11 indicators of structures that may be available or required to be used by a consumer or surrogate choosing participant direction: (a) financial management services, (b) employer of record, (c) emergency back-up, (d) worker registry, (e) advice/counseling, (f) managerial assistance, (g) information dissemination products, (h) service quality monitoring, (i) service coordination, (j) participant training, and (k) provider training. Similar to the employing component, the continuum of choice and control in the aid and assistance component is simple. Choice is a matter of whether the aid and assistance is available to anyone choosing participant direction, and control is a matter of whether the aid and assistance is required to be used by anyone choosing participant direction. Below I describe the indicators of aid and assistance in more detail.

Financial management services. Financial management services were the most frequently available and required form of aid and assistance. Financial management services “provide the support to individuals with a disability and their person-centered planning team in handling the business aspects of being an employer” (Blue-Banning, 2007, p. 62) of service

providers. Most programs, because of the policy requirements of the funding source, used a financial management service to ensure accountability for funds and employer payroll responsibilities, disallowing the consumer or surrogate to assume responsibility for the activity of payroll management (Cloutier et al., 2006; Infeld, 2005). In these programs, a fiscal intermediary may contract with the state or its agent to perform such functions as “tracking and monitoring budgets, performing payroll services, and handling billing and documentation” (Massachusetts Department of Mental Retardation, 2007, p. 10) for all consumers in the participant direction program, making this form of aid and assistance both available and required. Other programs made financial management services available but allowed the consumer or surrogate to “choose how much help [they] need and with which aspect of [the] program” (The ARC of Tennessee, 2004, p. 97).

Employer of record. If a program required the use of a financial management service to ensure accountability for funds, then it was also common for the agency assuming this role to act as the employer of record (Clark et al., 2008; Colorado Department of Health Care Policy and Financing, 2007; “Kansas,” 2004), assuming the legal responsibility of hiring the service providers. Other programs “provide[d] supports to enable the participant to be the ‘employer of record’” (DHHS of NC, 2005, CDS1-p. 51).

Emergency back-up. Only about one quarter of the documents addressed the indicator of emergency back-up. Depending on the responsibilities agreed upon by the consumer or surrogate and any agency acting as the employer of record, the agency may “arrange for adequate backup support,” or the consumer or surrogate may need to “arrange for their own backup” (Rosenberg et al., 2005, p. 15).

Worker registry. Like all the indicators of aid and assistance, the availability of the structure depends entirely on the design of the program (Claypool & O'Malley, 2008). As with emergency back-up, only about one quarter of the documents addressed the establishment or maintenance of a work registry. In California, the public authority in charge of the participant direction program "maintains a registry of providers who are interested in working for [participant direction] consumers" (Barnes et al., 2006, p. 6). In other programs, a designated professional or agency may be "responsible for compiling a registry of potential direct care workers" (Claypool & O'Malley, 2008, p. 11) with little follow-up regarding ensuring the list is current (Surpin, 2007). Most participant direction programs, however, do not offer a worker registry to assist participants (Griffin, 2005).

Advice/counseling. As is characteristic of the Cash and Counseling participant direction programs, advice/counseling was often considered essential to the successful direction of the consumer's supports and services (Bradshaw et al., 2006). A designated professional, such as a "support broker" (Massachusetts Department of Mental Retardation, 2007, p. 4), "service facilitator" (Caldwell, 2007, p. 551), or "peer specialist" (Revel & Inge, 2007, p. 126), may provide advice/counseling on things such as benefits, plan development, and individualized budget creation.

Managerial assistance. Managerial assistance, another frequently cited structure under aid and assistance, focused on supporting consumers or surrogates as they engaged in their employer responsibilities. Similar to advice/counseling, professionals (Bates, 2006) or peers may provide this support (i.e., other consumers or surrogates experienced with using participant direction; Claypool & O'Malley, 2008). The consumer or surrogate may receive support with

employing activities like scheduling, recruiting, and supervising providers, creating a backup system, and interacting with the financial management service agency.

Information dissemination products. Information dissemination products are “materials that [are] widely distributed and posted on state and agency websites that [are intended to] assist consumers and their families in understanding self-direction” (Massachusetts Department of Mental Retardation, 2007, p. 23). These products may include PowerPoint presentations (DHHS of NC, 2005), handbooks or manuals (Bradshaw et al., 2006; Minnesota Department of Human Services, 2004), or resource binders “containing educational materials” (Masters, 2006, p. 586). The purpose of these products is “to support informed decision making about services, delivery approaches, and strategies for navigating systems” (Kendrick et al., 2006, p. 10).

Service quality monitoring. Service quality monitoring is a structure not often addressed in documents. Although when it was addressed, in reference to programs where Medicaid was the funding source, “the state Medicaid agency maintain[ed] responsibility for monitoring service delivery” (Tritz, 2005, p. CRS-11). Some programs allowed the consumer to “monitor the quality of the services received,” while other programs designated a professional to remain “‘at the helm’ for quality assurance” (Infeld, 2005, p. 10).

Service coordination. Service coordination was often provided in tandem with other structures such as advice/counseling and managerial assistance. Service coordination consisted of “disability care management” (Surpin, 2007, p. 58) and the coordination of personal care needs with medical care needs. In addition, a professional providing service coordination may assist the consumer or surrogate “to identify resources to achieve [the consumer’s] goals” (Cloutier et al., 2006, p. 5) as identified in the consumer’s care plan (DHHS of NC, 2005). In

some programs, assistance with service coordination was required while, in others, a professional assists only “when requested” (Masters, 2006, p. 384).

Participant training. The indicator of participant training typically included training to assist the consumer or surrogate with the “roles and responsibilities of [participants] in terms of recruiting, hiring, and supervising their personal assistants” (Surpin, 2007, p. 58). Other topics consumers or surrogates may receive training on included “personal advocacy and self-management” (Fleming-Castaldy, 2008, p. 17) and “seeking emergency support through local organizations” (McGaffigan, 2008, p. 12). Although in some programs participant training was a choice, other programs required successful completion of a training program on the “fiscal and legal responsibilities of employment” (Griffin, 2005, p. 14) prior to participant-directing the consumer’s supports and services (Doty, 2004).

Provider training. The indicator of provider training under the component of aid and assistance differs from provider training under the component of employing. Under aid and assistance, provider training is not consumer specific, and providers may be required to “undergo the same training as traditional agency workers” (O’Keefe et al., 2005, p. 39), such as CPR certification, first aid, and nursing care delivery (McGaffigan, 2008).

The components and indicators described above represent the *how* construct, the structures that may be in place to support the consumer or surrogate and facilitate or guide the implementation of participant direction programs. The indicators I described in the *how* theoretical construct substantially influence the design and implementation of participant direction programs as they varied the most out of all the indicators identified in the conceptual framework (see Figure 1). While it was common for consumers or surrogates to be allowed a substantial level of choice and control over employing activities, particularly

identifying/selecting, training, scheduling, managing/directing/supervising, and disciplining/dismissing of service providers, it was uncommon for consumers or surrogates to have significant choice or control over policy or aid and assistance. In Chapter Four, I will discuss the findings and their implications for policy and research.

CHAPTER FOUR: DISCUSSION

Summary

The design of programs of participant direction varies significantly. Because each program is designed for a specific disability population and according to the rules and regulations of its funding source, design elements (e.g., who is allowed to participate, what services the participant is allowed to direct, and what sort of aid and assistance may be provided to support the consumer's or surrogate's participation) are inconsistent from program to program. In addition to this variation in design, programs also vary regarding the level of choice and control afforded to the consumer or his or her surrogate in the direction of the consumer's supports and services. This study sought to analyze the designs of various programs of participant direction across disability and funding sources in order to identify and define the range of components and indicators available in U.S. long-term care programs. The findings of this study 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).

I implemented this study using qualitative methods to analyze 53 documents. These documents reflected one non-specific and seven specific disability categories (see Appendix A) and 10 different document types (see Appendix B). A grounded theory approach, using constant comparative data analysis, facilitated the development of a theory of program design and a conceptual framework representing an ideal type of program of participant direction.

The resulting theory of design and conceptual framework describe programs of participant direction and categorize the identified components and indicators under two broad

theoretical constructs, *what* and *how*, which may be applied to all programs of participant direction (see Figure 1). Components and indicators housed in the *what* construct refer to the activities over which the consumer of surrogate may, under the program design, have some level of choice and control. Components and indicators housed in the *how* construct refer to the structures that may, under the program design, be available to guide or facilitate the implementation of the program of participant direction. The design elements in any program of participant direction may be housed in either the *what* or *how* construct, and every program of participant direction has design elements in both constructs, for it is improbable that one construct will be represented without having some design element(s) in the other; what happens (a substantive construct) interacts with how the what happens (a procedural construct), and vice versa.

The presence or absence of any one of the components or indicators, in either construct, does not necessarily indicate the effectiveness of the program nor does it denote a judgment on a program's consumer "friendliness." Rather, the ideal type I developed reflects a standard of comparison, a coherent taxonomy, with clearly defined and categorized components and indicators. This standard of comparison has significant implications for the construction of meaningful and rigorous studies and for the development of effective and comparable programs of participant direction.

I discuss below the implications of my findings for (a) future research and (b) policy context and development.

Implications

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 be overcome in conducting rigorous, comparative research on programs with such varied designs and organizational structures, especially with regard to implementation and outcomes for participants. The results of this dissertation study are the first step in a research agenda to directly address the concern of “best practices,” allowing for advances in research and a standard of comparison for policy discussions and development.

Future Research

I foresee two stages of research following this dissertation study: (a) the development of a tool to assess a participant’s level of choice and control over the direction of the consumer’s supports and services and (b) the use of that tool in outcomes-based cross-program research to assess which components and indicators, or combination of components and indicators, are necessary or sufficient to lead to positive and desirable outcomes for consumers in programs of participant direction.

Tool development. In the first stage of research following this dissertation, I intend to develop an innovative tool to assess participants’ levels of choice and control over the various components and indicators of participant direction programs. Research to date has assessed only outcomes for consumers or family caregivers in specific programs of participant direction. Due to the significant variability in the design of these programs, it is impossible to attribute outcomes to specific causal variables (e.g., the individual components and indicators that comprise programs of participant direction). The development of a tool that could assess an individual’s level of choice and control over the various components and indicators of participant direction would facilitate much needed cross-program research and translate to effective and efficient program development and design.

The conceptual framework (see Figure 1) as well as the document analysis tool (see Appendix D) developed in the course of this dissertation research will form the basis for this innovative tool. The ideal type of participant direction program developed in this study is comprised of a collection of activities (i.e., components and indicators under the *what* construct) and structures (i.e., components and indicators under the *how* construct) that facilitate the exercise of choice and control by the consumer or surrogate over the supports and services received by the consumer. The tool to be developed will assess participants' experiences and perceptions about which individual components and indicators are in place in their specific participant direction program and the degree to which the consumer or his or her surrogate exercises choice and control with regard to each component and indicator.

The development of this assessment tool embarks down a research road that has yet to be tested despite several decades' history of and research on participant direction. The most rigorous research conducted in the field of participant direction to date has been on the Cash and Counseling demonstration programs, although all of that research has been program specific. Existing research on Cash and Counseling as well as other program designs (e.g., agency with choice, participant employer of record) has yielded positive outcomes for the consumer and family caregivers in addition to some cost savings to the states. However, there is no research to support the inclusion or exclusion of various components and indicators in a program of participant direction. There is considerable debate whether the consumer or surrogate should have budget authority (Stone, 2006), whether family members should be paid service providers (Groger, 2006), and whether individuals with intellectual disabilities or other cognitive impairments should be allowed to participate or have a surrogate decision maker (Kapp, 2000; Stone, 2006). However, the discussions marking these issues are backed by only conjecture and

personal or state sense of moral judgment and individual/familial responsibility. An innovative assessment tool, such as the one I propose to develop, would change current approaches to research of participant direction programs, allowing cross-program research to occur and data to emerge to support the effectiveness of tough policy decisions regarding program design.

Cross-program research. After developing the tool, I will pilot it 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 its feasibility for use in cross-program research of participant direction. Once appropriate outcomes measures have been identified, cross-program research into the influence of the various components and indicators, or combinations of components and indicators, on consumer or family caregiver outcomes may be conducted. Considering that cross-program research will focus on the organizational configurations of participant direction programs, which are directly influenced by the policy guiding their implementation, set-theoretic methods that aim to understand organizational configurations in context are most appropriate for this second stage of research (Friss, 2009).

Set-theoretic methods allow researchers to study empirically evident cases as opposed to hypothesizing about theoretical configurations that may or may not exist in present day organizations. Simply stated, there exists limited diversity in naturally occurring organizational structures (Ragin, 2008). Although the five components of participant direction identified in the ideal type have a total of 28 indicators that could feasibly present with 2^{28} (over 268 million) different organizational configurations, it is highly unlikely that such various social phenomena actually exist empirically in the field of participant direction. As discussed in the findings, the various rules and regulations (i.e., national, state, and local policy) governing participant

direction impose certain organizational configurations (i.e., require the presence or absence of certain indicators) that naturally result in limited diversity in the occurrence of the 268 million possible configurations of participant direction programs. Set-theoretic, case-based methods allow the researcher to study the actual occurrences of organizational configurations (i.e., program designs) and their causal relations with desired outcomes for consumers or family caregivers.

Another benefit to the use of set-theoretic methods at this second stage of research is the ability to address equifinality of different organizational configurations (Friss, 2007; Friss, 2009; Ragin, 2008). Equifinality is the idea that different configurations may be “alternate causal paths or ‘recipes’ for the outcome” (Ragin, 2008, p. 54). As discussed in the literature review, multiple program designs have yielded similar outcomes for the consumer or family caregiver; therefore, it is possible that there are multiple recipes for participant direction programs that will yield positive and desirable outcomes. By examining the different recipes (i.e., designs) of participant direction programs using set-theoretic methods, I will be able to identify the various indicators, or combinations of indicators, that are necessary or sufficient for achieving positive and desirable outcomes for participants.

There is no research addressing the effectiveness of various participant direction program designs in causing specific participant outcomes. Therefore, cross-program research is an essential step to providing data to support the inclusion or exclusion of various components and indicators in participant direction program development. With the evidence based-data resulting from cross-program research using the assessment tool, outcomes measures, and set-theoretic methods, states can be confident in their decisions to design, develop, and expand programs of participant direction.

Policy Context and Development

In this section I address the implications of this study's findings and future research relative to policy context and development. I discuss the (a) relevance of disability policy core concepts, (b) value of the ideal type, (c) use of cross-program research, and (d) urgent need for long-term care in the coming years in relation to the development of effective and efficient programs of participant direction.

Relevance of disability policy core concepts. As I stated in chapter 1, the premise of participant direction is to allow consumers or surrogates some level of choice and control over the consumer's long-term care supports and services. Choice and control are intricately intertwined. As Griffin (2005) notes, "Consumer control is premised upon the availability of consumer choice. At the same time, the existence of consumer control can minimize the need for some types of choice" (p. 43).

The ideas of choice and control are reflective of two core concepts that have driven disability policy for at least the last two decades (Turnbull, Beegle, & Stowe, 2001). Choice, as defined in this study, is the act of making a selection from a range of options (e.g., service options, levels of participation, degree of control). In order for choice to exist, there must be a range of options from which to choose. The more limited the range, the more limited the choice. Choice also includes the option to give up control. Choice may be equated with the disability policy core concept of "Autonomy" (Turnbull, Beegle, & Stowe, 2001, p. 138), which refers to the act of consenting. Control, as defined in this study, refers to the consumer or surrogate making substantive decisions regarding and taking responsibility for the consumer's supports and services. Control is represented by the disability policy core concept of "Empowerment/Participatory Decision-Making" (Turnbull, Beegle, & Stowe, 2001, p. 138),

which refers to shared decision-making power and responsibility among the professional/service provider and the consumer or surrogate. These two core concepts drive the guiding philosophy of participant direction and represent the constitutional principle of liberty, which is the “freedom to carry on the pursuits of life without undue interference from others” (Turnbull & Stowe, 2001, p. 182).

Although the core concepts of autonomy and empowerment/participatory decision-making form the philosophical basis of participant direction, this analysis of participant direction program designs revealed evidence of additional disability policy core concepts. Three more core concepts, under the category of administrative principles, became evident.

First, the component of planning, which is the activity of identifying support needs and setting goals, and its indicator of care plan development, is reflective of the core concept of individualized and appropriate services. Individualized and appropriate services “must be based on the person’s capacities, needs, and preferences” (Turnbull, Beegle, & Stowe, 2001, p. 137). This is the purpose of the development of a care plan through a person-centered process in programs of participant direction.

Second, the component of budgeting includes the development of the amount of monies to be allotted to the consumer, the allocation of the monies for the purchase of goods and services, and the authority and responsibility for the distribution of the monies accordingly. The component of budgeting is reflective of some of the possible activities associated with the core concept of accountability (Turnbull, Beegle, & Stowe, 2001). Accountability refers to all actors (i.e., policy makers, policy implementers, service providers, individuals with disabilities and their families) in the implementation of disability policies and services. Accountability is a core

concept of great concern in programs of participant direction that allow consumer or surrogate choice and control over budgeting.

Third, the component of aid and assistance includes the various types of aid and assistance that may be made available or required to be used by the consumer or surrogate choosing to participant direct the consumer's supports and services. As mentioned in the findings, the state or its agent, which includes various entities contracted to perform specific functions, typically provides for the various indicators of aid and assistance. These indicators (see Figure 3 and Table 5) serve the purpose of capacity building, both for the systems that support participant direction and for the individuals (e.g., service providers, consumers, surrogates) engaged in implementing the necessary functions or activities (under the *what* construct) of participant direction programs.

The application of the core concept taxonomy of disability policy to this dissertation gives operational meaning to and advance the core concepts present in the policy and implementation of participant direction programs.

Value of the ideal type. The development of the ideal type has three values in the realm of policy development. First, the ideal type provides an organizational framework, offering five components to be considered in the planning and development of programs of participant direction. By addressing each of the conceptual framework's five components in the planning and development of programs of participant direction, administrators of federal and state agencies can be assured of targeting the most commonly addressed aspects of participant direction and minimizing the effect of local leaders and disability culture on the implementation of participant direction. Second, the ideal type also clearly lays out 28 individual indicators showing the existing range of extension or implementation of each component. Policy makers

may use these indicators as a frame of reference for consideration of the activities over which to allow consumer or surrogate choice and control and what structures to put in place to support their participation in the program. Third, the ideal type provides a common nomenclature with clearly defined terms that will facilitate the development of both policy and research. As the broad term participant direction is also known by several other terms (e.g., consumer control, consumer direction, self-direction, self-determination), so too is the vocabulary used to describe the various components and their indicators. Using the ideal type developed in this study, a common nomenclature can be established in the field allowing the development of more comparable programs and facilitating cross-program research of newly created programs.

Use of cross-program research. As mentioned in the implications for research, the information derived from this study will be used to develop an innovative tool to assess participants' levels of choice and control over the various components and indicators of participant direction programs. This tool will facilitate much needed cross-program research into the influence of the various components and indicators, or combinations of components and indicators, on consumer or family caregiver outcomes. The results of outcomes-based, cross-program research will provide an empirical basis for the inclusion or exclusion of various indicators, as well as the participant's level of choice and control over those indicators, in a program of participant direction. The use of case-based, set-theoretic methods in cross-program research allow the researcher to identify the multiple recipes or paths (i.e., various combinations of indicators) that lead to desired outcomes. Such results would provide policymakers with much needed data identifying the indicators that are necessary or sufficient (Ragin, 2008) in a program of participant direction to cause certain participant outcomes for individuals receiving long-term

care supports and services. Knowing the recipe for a successful program would directly transfer research findings into policy and program development.

Urgent need for long-term care. The rising prevalence of individuals with autism (Kogan et al., 2009; Newschaffer, Falb, & Gurney, 2005) as well as the impending aging and retirement of the baby boom generation (Allen, 2005) is anticipated to create an intense need for long-term care home and community based supports and services in the coming years. Also spending estimates on long-term care for individuals who are elderly alone are projected to quadruple between 2000 and 2050 (Allen, 2005). Therefore, budget shortfalls and the shortage of direct care service providers will significantly impact the availability of long-term care supports and services for both elderly and non-elderly populations in the future. As the need for long-term care increases in the next few decades, the development of long-term care policy will have to respond with more efficient and effective means to meet the growing need. An increase in the number of participant direction programs could alleviate some of the pressure from this burgeoning long-term care need by providing more cost effective supports and services and increasing the overall pool of service providers.

The majority of individuals needing long-term care in community settings receive unpaid help, primarily provided by family members, with only 13% receiving some form of paid supports and services (Kaye et al., 2010). In the next few decades, the need for paid long-term care will undoubtedly increase as the worker-to-retiree ratio reverses, leaving fewer elderly and individuals with a disability with available family members to fill the need for unpaid caregiving (Allen, 2005; National Disability Council, 2004). With the majority of long-term care funded through Medicaid, it is now essential that our government reconsider the allocation and distribution of these funds in order to meet the burgeoning need in our elderly and disabled

populations. Participant direction has proven to be a cost effective way to provide services, cheaper than institutional care (Braddock, Hemp, & Rizzolo, 2008) and cheaper than agency directed care (Feinberg & Whitlatch, 1998; Head & Conroy, 2005). Feinberg and Whitlatch (1998) found that participant directed services were less costly per service hour than agency directed services, allowing the consumer to receive more hours of respite care than their agency directed counterparts.

When allowed, individuals choosing participant direction often hire family and friends. Research has shown that family members tend to provide many hours of unpaid services, even when they are officially a paid provider (Benjamin & Matthias, 2000; Benjamin & Matthias, 2004; O’Keefe et al., 2005; Whitlatch & Feinberg, 2006). Family members also are more likely to perform services that are outside of the general job description or allowable services that may be provided under agency-directed programs (Dale et al., 2003a), leading to increased general satisfaction and fewer unmet needs. Therefore, consumers who are allowed to hire whomever they choose (including family members) get more services per dollar spent than consumers who are not allowed that freedom of choice (Feinberg & Whitlatch, 1998). In addition, allowing participants to hire family members or friends increases the pool of direct care service providers (Feinberg & Newman, 2005), even if a participant’s family and friends do not enter the system or provide services to anyone else.

Conclusion

Participant direction is both a young and broad field of study, in its adolescence and in need of some organization. The grounded theory and conceptual framework developed in the course of this study provides that much needed organizational structure, with a frame of reference and clearly defined 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 an individual'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 consumers in programs of participant direction. In the development of policy, there is much to be considered, particularly with regard to how to best address the growing need for long-term care supports and services and how to best design programs of participant direction to meet that need. Participant direction, while a desirable option for some, may not be an appropriate model of service delivery for all consumers due to the increase of personal responsibility. However, just like the continuum of services available to individuals with disabilities in the school system, participant direction should be one option on a continuum of adult services available to all consumers with long-term care needs. In the development of long-term care policy, there are a number of considerations to be made in the decision to implement a program of participant direction. The findings of this study are the first step in the development of truly evidence-based practice with regard to program design.

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APPENDIX A

Disability Categories as Described in Data

Elderly- included individuals typically aged 65 or older who needed assistance with activities of daily living

Intellectual and/or Developmental (ID) - included Down syndrome, intellectual disabilities, “functional disabilities,” cognitive impairments

Mental Illness - included Alzheimer’s, psychosocial

Non-Specific - author did not specifically state or identify the disability of the individuals referenced

Other Health - included chronic conditions and diseases such as A.I.D.S.

Physical - included paralysis, cerebral palsy

Sensory- included vision or hearing impairments

Traumatic Brain Injury (TBI)

APPENDIX B

Document Categories

Dissertation

What: non-published, research study including a literature review, qualitative or quantitative research study, and followed by policy implications or “next steps”

Who: doctoral candidate

Why: to demonstrate research skills and deep knowledge in a topic area as a requirement for completion of a doctoral degree

Where: available through university library databases

Forum

What: opinions, editorials, personal stories, or recommendations for policy change; typically state or program specific

Who: parent, service provider, academic, individual with a disability, or advocate

Why: to inform general population (including consumers, family members, service providers, advocates)

Where: published in a journal, magazine, or agency newsletter

Handbook

What: explanations of state-specific program(s) and policies with concrete examples; a “training manual” or “guidebook”

Who: agency, often university centers or State Department of Health or Human Services

Why: to inform and guide program participants (consumer or surrogate) in the management and direction of the consumer’s supports and services

Where: found on the website of the authoring body or public service agency implementing the program; freely available for download as PDF

Informative, Non Peer-Reviewed

What: facts and information about program(s)/agency; reports trends; may be state or program specific

Who: researchers, academics, or agencies

Why: to inform consumers, family members, service providers, advocates, and academics

Where: published by a public service agency, advocacy organization, or university-affiliated center

Informative, Peer-Reviewed

What: facts, information about a program(s)/agency, reports trends; may be state or program specific

Who: researchers, academics, or agencies

Why: to inform consumers, family members, service providers, advocates, and academics

Where: published in a peer-reviewed journal

Presentation

What: PowerPoint (PPT) presentation describing aspects of existing state participant direction programs

Who: State Department of Health or Human Services agency

Why: to disseminate knowledge of state or local program(s) to a group of people, including consumers, surrogates, family members, or service providers

Where: found on the website of the authoring body; freely available for download as PDF or PPT

Qualitative Research, Peer-Reviewed

What: research study including literature review, an analysis of qualitative data from interviews or surveys, and a discussion, typically with policy recommendations

Who: researcher(s) affiliated with an agency or university

Why: to inform service providers, academics, researchers and policy makers

Where: published in peer-reviewed journal

Quantitative Research, Peer-Reviewed

What: research study including literature review, an analysis of quantitative data from surveys or other measures, and a discussion, typically with policy recommendations

Who: researcher(s) affiliated with an agency or university

Why: to inform service providers, academics, researchers, and policy makers

Where: published in peer-reviewed journal

Report

What: digests of current policy, research, trends and/or current practices and programs; may include independent literature review, non peer reviewed qualitative or quantitative research; typically includes policy recommendations; may be an overview of multiple programs or be state program specific

Who: individual or team affiliated with a university, federal agency or advocacy agency; typically funded by a grant

Why: to inform academics and policy makers and make recommendations.

Where: found on the website of the authoring body and/or funding agency; freely available for download as PDF

Waiver Application

What: form for state Medicaid agencies to complete to request Centers for Medicare & Medicaid Services (CMS) approval for a state Medicaid waiver

Who: federal agency; CMS

Why: to facilitate the establishment of new or renewal of existing state Medicaid waivers

Where: CMS website

APPENDIX C

Reference List of 12 Documents in Initial Coding Stage

- Alakeson, V. (2008). Self-directed care for adults with serious mental illness: The barriers to progress. *Psychiatric Services, 59*(7), 792-794.
- Blue-Banning, M. (2007). A Journey Toward Participant Direction. *The Exceptional Parent, 37*(10), 61-63.
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APPENDIX D

Document Analysis Tool

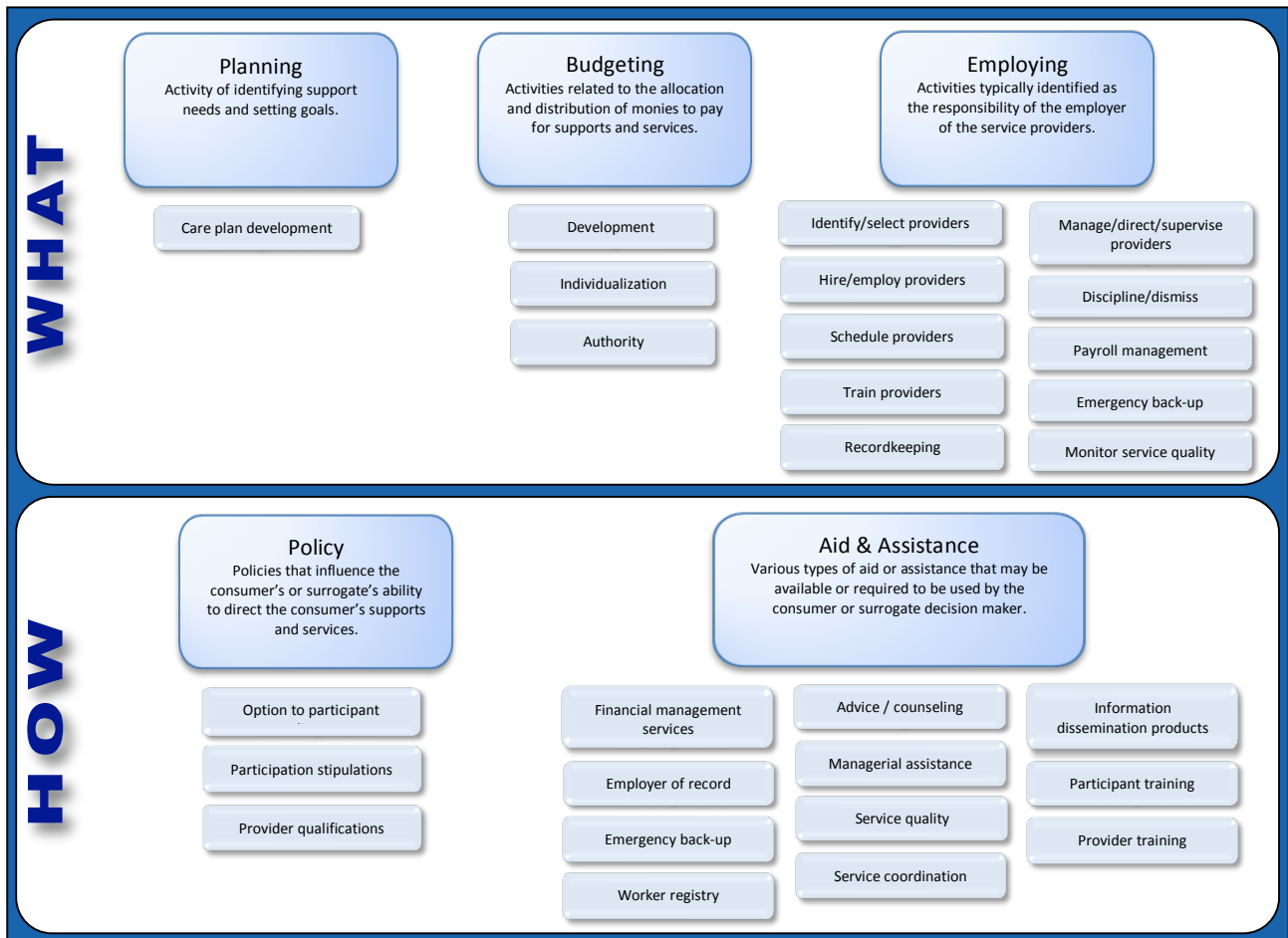
Date: _____
 Document Reference: _____

Reviewer Name: _____

“Components and indicators of participant direction” are a collection of activities and structures that facilitate the exercise of choice and control by the consumer or surrogate over the supports and services received by the consumer.

The initial coding of 12 documents about participant direction revealed two broad theoretical categories that organize the components and indicators of participant direction: What and How. The “What” category consists of the activities in which the consumer or surrogate may participate and have some level of choice and control. Such activities may be categorized under the components of (a) Planning, (b) Budgeting, and (c) Employing. The “How” theoretical category consists of the structures that may be in place to guide or facilitate the implementation of programs of participant direction. Such structures may be categorized under the components of (a) Policy and (b) Aid & Assistance.

Conceptual Framework of the Components and Indicators of Participant Direction



WHAT: Planning

Planning includes the activity of identifying support needs and setting goals. The planning component includes the indicator of care plan development.

WHAT: Planning: Care plan development

The care plan is sometimes identified as a “person-centered plan.” It typically addresses the consumer’s preferences, capacities, needed supports, and desired outcomes/life goals. This plan is developed within state guidelines.

The consumer’s and/or surrogate decision maker’s level of participation in the care plan development can best be described as:

- 3 The consumer and/or surrogate decision maker directs or may choose to direct the development of the care plan.
- 2 The consumer and/or surrogate assist with directing and have some input into the care plan development with required assistance directing the process provided by a professional (e.g., case manager, social worker, service facilitator).
- 1 The consumer and/or surrogate do not participate in the development of the care plan. It is directed and developed by a professional (e.g., case manager, social worker, service facilitator).
- 0 Not addressed / discussed in this document.

Can the consumer and/or surrogate decision maker invite anyone they want to participate in the planning process?

- 2 Yes
- 1 No
- 0 Not addressed / discussed in this document.

Illustrative quote:

New indicator measure?

WHAT: Budgeting

Budgeting concerns activities related to the allocation and distribution of monies (e.g., cash, vouchers, hours of service) to pay for supports and services identified in the service plan. The budgeting component includes the indicators of: (a) development, (b) individualization, and (c) authority.

WHAT: Budgeting: Development

Development refers to the process by which the amount of money (e.g., cash or vouchers) or quantity (e.g., hours) of supports and services a person will receive is determined (who determines how much is allocated and how it is done).

The budget amount determined is based on:

- 3 the amount of service required to meet individual needs and goals identified in the care plan.
- 2 the results of a state-required/designated assessment (e.g., standardized, criterion) of the consumer's abilities and support needs.
- 1 a capped spending limit (e.g., everybody who qualifies gets \$400 a month).
- 0 Not addressed / discussed in this document.

The consumer's and/or surrogate decision maker's level of participation in determining the amount of money or quantity of service hours that will be received can best be described as:

- 3 The consumer and/or surrogate decision maker fully develop the budget amount.
- 2 The consumer and/or surrogate have some input (in addition to responses required by an assessment process) into the development of the budget amount with required assistance provided by a professional (e.g., case manager, social worker, service facilitator).
- 1 The consumer and/or surrogate do not participate in the development of the budget amount. The professional does this using designated state procedures.
- 0 Not addressed / discussed in this document.

Illustrative quote:

New indicator measure?

WHAT: Budgeting: Individualization

Individualization refers to the “individualized budget,” which outlines how the monies will be allocated for the specific services and goods needed to implement the care plan, and to what extent it can be altered as a person’s needs change. The individualized budget identifies the specific services or goods to be purchased (e.g., personal assistance services, respite, day services, supported employment), how much (e.g., hours/units of the service, quantity of a good) will be purchased, who will provide needed services (i.e., identifies specific service providers) and over what time period (e.g., from June 2009-June 2010).

The consumer’s or surrogate decision-maker’s level of participation in the development and ongoing maintenance of the individualized budget can best be described as:

- 3 The consumer and/or surrogate decision-maker can choose to fully develop the individualized budget.
- 2 The consumer and/or surrogate have some input into the development of the individualized budget with required assistance provided by a professional (e.g., case manager, social worker, service facilitator).
- 1 The consumer and/or surrogate do not participate in the development of the service plan.
- 0 Not addressed / discussed in this document.

The individualized budget can be modified to meet the consumer’s changing needs:

- 3 whenever the consumer and/or surrogate decision-maker desires (as often as needed).
- 2 more often than once a year – no more than once a month.
- 1 only once a year.
- 0 Not addressed / discussed in this document.

****NOTE**** This question specifically addresses how often the individualized budget *may* be altered. Typically it is required to be reviewed / revised annually, but this question addresses how often it *may* be changed.

Who decides when an individualized budget needs to be changed/altered to meet the consumer’s changing needs?

- 2 Consumer and/or surrogate decision-maker
- 1 Professional (e.g., case manager, service facilitator, care advisor)
- 0 Not addressed / discussed in this document.

The consumer and/or surrogate decision-maker:

- 2 may choose which services (of those he/she is eligible for) to participant direct.
- 1 is only allowed to direct specific services (of those he/she is eligible for) as identified by the state agency or regulations.
- 0 Not addressed / discussed in this document.

The consumer and/or surrogate decision maker:

- 3 may select all services needed to implement the care plan.
- 2 have some input into the service selection with required assistance provided by a professional (e.g., case manager, social worker, service facilitator).
- 1 do not participate in service selection.
- 0 Not addressed / discussed in this document.

The consumer and/or surrogate decision maker:

- 3 may decide what goods to purchase to support the implementation of the care plan.
- 2 have some input into the goods selection and purchase with required assistance provided by a professional (e.g., case manager, financial management service/intermediary).
- 1 do not participate in goods selection and purchase.
- 0 Not addressed / discussed in this document.

Illustrative quote:

New indicator measure?

WHAT: Budgeting: Authority

Authority refers to who has choice and control over the distribution of monies (e.g., cash, vouchers, hours of service) provided to meet the consumer's needs and goals identified in the care plan.

The consumer and/or surrogate decision maker:

- 3 has the final say on the distribution of monies regarding the purchase of supports and services such as service provider hours, goods, home modifications, etc.
- 2 has some input into the distribution of monies with required assistance provided by a professional (e.g., case manager, financial management service/intermediary, service facilitator).
- 1 do not participate in the distribution of the allocated funds. The professional makes all decisions regarding how and on what all monies (i.e., cash, vouchers, service hours) are spent.
- 0 Not addressed / discussed in this document.

Payments are made for goods and services:

- 3 by the consumer or surrogate decision maker who is typically provided with a monthly cash allotment determined in the budget development.
- 2 by the consumer or surrogate decision maker using a voucher.
- 1 by a designated financial management service/intermediary or state agency.
- 0 Not addressed / discussed in this document.

The rate of pay for service providers is:

- 3 set by / negotiated by the consumer or surrogate decision maker.
- 2 determined by the consumer or surrogate decision maker but must be within certain limits designated by the state.
- 1 set by the state or designated agency and is non-negotiable by the consumer.
- 0 Not addressed / discussed in this document.

The consumer and/or surrogate decision maker may purchase durable or nondurable goods/items through:

- 3 both traditional (i.e., state contracted/approved organizations) and nontraditional (e.g., Walmart) vendors using cash.
- 2 both traditional (i.e., state contracted agencies or businesses) and nontraditional (e.g., Walmart) vendors via a financial management service/ intermediary who processes the payment.
- 1 only traditional vendors contracted with the state to provide goods.
- 0 Not addressed / discussed in this document.

When the consumer and/or surrogate decision maker are efficient managers and are able to meet their needs at a lesser cost than originally identified in the budget plan, the consumer and/or surrogate decision maker:

- 3 may use all unspent monies (e.g., cash, vouchers, hours of service).
 - 2 may use half of unspent monies (e.g., cash, vouchers, hours of service) and return the other half to the designated state agency.
 - 1 must return unspent monies (e.g., cash, vouchers, hours of service) to state agency.
- Examples of what may happen to returned monies include: putting monies into a risk pool for consumers or calculating a reduced budget for the next year based on savings.
- 0 Not addressed / discussed in this document.

If the consumer and/or surrogate decision maker are allowed to use unspent funds (i.e., a 3 or 2 was marked on previous question), then they

- 3 may save unspent monies (e.g., cash, vouchers, hours of service) in a savings account that does not impact eligibility for benefits (e.g., a LIFE account).
- 2 may use unspent monies (e.g., cash, vouchers, hours of service) to purchase additional service hours.
- 1 may use unspent monies (e.g., cash, vouchers, hours of service) to purchase one-time expenses, typically goods, to increase independence or decrease dependence on paid supports.
- 0 Not addressed / discussed in this document (or marked a 1 or 0 on previous question).

Illustrative quote:

New indicator measure?

WHAT: Employing

Employing refers to activities typically identified as being the responsibility of the individual or agency considered the employer of the service providers. Such activities include the indicators listed in the table and defined below.

In the table below, select the box that best describes who takes responsibility for each of the employer responsibilities listed.

	The consumer and/or surrogate decision maker is or may choose to be responsible for these	The consumer and/or surrogate have some input and are required to share responsibility with	The professional (e.g., case manager, service facilitator, financial management service /	Not addressed / discussed in this document.
Identify / select providers	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
Hire / employ providers	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
Schedule providers	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
Train providers	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
Manage / direct / supervise providers	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
Discipline / dismiss providers	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
Payroll management	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
Emergency back-up	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
Recordkeeping	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
Monitor service quality	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0

Identify / select providers refers to who chooses the service providers. The choice may be that the consumer may choose anyone (including family) or the choice may be more limited in that the consumer must choose from a list of Medicaid contracted providers. The indicator is about who makes the choice (whatever its scope).

Hire / employ providers refers to who legally hires/employs the service provider.

Schedule providers refers to who determines the schedule of service providers, when to provide services and where.

Train providers refers to who trains or makes training available to service providers in how to provide consumer-specific supports and services.

Manage / direct / supervise providers refers to who is responsible for the direct management or supervision of the day-to-day activities of the service provider, including determining specific tasks to be performed and providing feedback on performance.

Discipline / dismiss providers refers to who is responsible for the discipline (reprimand or correction of) and dismissal of service providers.

Payroll management refers to who assumes financial responsibility for payroll functions such as payment for services, worker's comp, deductions, etc.

Emergency back-up refers to who assumes responsibility for the development and implementation of a back-up plan for when the regularly scheduled worker is unable to work.

Recordkeeping refers to who is responsible for recordkeeping (e.g., maintaining timesheets, saving receipts) regarding goods purchase and service provision.

Monitor service quality refers to who is responsible for determining what constitutes quality and monitoring the services provided to the consumer.

Illustrative quote:

New indicator measure?

HOW: Policy

Policy refers to any local, state, or national policies that influence a consumer’s and/or surrogate decision maker’s ability to direct the consumer’s supports and services. The policy component includes the indicators of (a) option to participant direct, (b) participation stipulations, and (c) provider qualifications.

HOW: Policy: Option to participant direct

The option to participant direct refers to the election of or choice of the consumer and/or surrogate decision maker to direct the consumer’s supports and services.

The consumer or surrogate decision maker is provided with the option to participant direct supports and services:

- 4 when the consumer is determined to be eligible to receive services in the home or community.
- 3 when the consumer and/or surrogate decision maker becomes dissatisfied with the traditional agency-based service system.
- 2 participant direction is the default service system option for consumers receiving home or community based services.
- 1 only when living in an area of the state allowing participant direction.
- 0 Not addressed / discussed in this document.

Illustrative quote:

New indicator measure?

HOW: Policy: Participation stipulations

Participation stipulations refer to the requirements or limitations regarding participation in programs of participant direction by the consumer and/or surrogate decision maker.

If the consumer is not capable of independently directing all his/her supports and services:

- 3 the consumer may still participate with the assistance of a surrogate decision maker. The surrogate may assume all responsibilities.
- 2 the consumer must be able to direct his/her own care in order to participant direct, but may receive support with financial aspects and responsibilities (e.g., perhaps from a financial management service/intermediary or other professional).
- 1 the consumer may not participant direct his/her supports and services.
- 0 Not addressed / discussed in this document.

In order to determine whether or not a consumer is capable of directing his/her supports and services:

- 3 the consumer or surrogate decision maker must simply express an interest – no capacity determination is needed.
- 2 a physician must provide a letter/statement indicating that the consumer is capable or has a surrogate decision maker to act on his/her behalf.
- 1 the consumer must pass a test, training course, and/or assessment or evaluation of the consumer’s capacity to participant direct.
- 0 Not addressed / discussed in this document.

Some characteristics of the consumer may *prohibit* them from participating in a program of participant direction of supports and services. Check each characteristic of the consumer below that is identified in the document as prohibiting their participation in the program of participant direction. If needed, use the blank spaces to add additional characteristics found in the document but not listed below.

- Consumer requires 24-hour care.
- Consumer lives in congregate housing, such as a nursing home or group home.
- Consumer needs / has a guardian or conservator.
- Consumer _____
- Consumer _____
- Not addressed / discussed in this document.

Some programs have certain limitations on who make act as a *surrogate decision maker* for a consumer participating in a program of participant direction of supports and services. Check each limitation described below that is identified in the document. If needed, use the blank spaces to add additional characteristics found in the document but not listed below.

The surrogate decision maker (i.e., authorized representative):

- must be freely chosen by the consumer.
- may not be paid to be a surrogate.
- cannot be hired as a service provider.
- may be a (circle one) family member, friend, legally appointed guardian, power of attorney.
- must be 18 years or older.
- must not be convicted of abuse, exploitation, or assault.
- must not have a condition that may result in harm to the client.
- must accept the consumer's participant direction responsibilities.
- Surrogate _____
- Surrogate _____
- Not addressed / discussed in this document.

Illustrative quote:

New indicator measure?

HOW: Policy: Provider qualifications

Provider qualifications refer to the regulations or practices regarding who may be hired to provide the services outlined in the individualized budget.

Regarding basic, commonly state-required, qualifications such as conducting criminal background checks and abuse registry screenings:

- 2 the consumer and/or surrogate decision maker may make the choice of whether or not to require such checks and screenings for their chosen service providers.
- 1 the consumer and/or surrogate decision maker must abide by all state-required qualifications for their service providers, including such basic checks and screenings as previously mentioned.
- 0 Not addressed / discussed in this document.

With regard to whether or not family may be hired to provide paid services for the consumer, the following applies.

- 3 anyone may be hired – family members may include spouse, legally-responsible parent, siblings, in-laws, extended family, etc.
- 2 some family may be hired – any family member BUT legally-responsible members such as the consumer’s spouse or the parent of a dependent consumer.
- 1 no family members (immediate or extended) may be hired to provide services – only non-relatives.
- 0 Not addressed / discussed in this document.

Service providers providing services to a consumer:

- 3 may be employed by the consumer and/or surrogate decision maker. The service provider does *not* have to be licensed / certified / approved / enrolled by a designated state agency or have a contract with the state.
- 2 must be under the supervision of or employed by a licensed / certified / approved / enrolled service provider.
- 1 must be licensed / certified / approved / enrolled by a designated state agency (e.g., state Medicaid agency) as a service provider.
- 0 Not addressed / discussed in this document.

Service providers that are required to be licensed / certified / approved / enrolled by a designated state agency:

2 may be independent providers not affiliated with an agency. Family or friends of the consumer that meet state licensure requirements or qualifications may become independent service providers.

1 must be an agency (e.g., a home health agency) – organization consisting of more than one provider.

0 Not addressed / discussed in this document.

Illustrative quote:

New indicator measure?

HOW: Aid & Assistance

Aid & assistance refers to the various types of aid or assistance provided by the state or its agent that may be made available to or required to be used by consumers or surrogate decision makers choosing to direct the consumer’s supports and services. Such activities include the indicators listed in the table and defined below.

In the table below, select the box for each type of aid and assistance that best describes its availability and use by consumers on the program of participant direction.

	Availability? The aid or assistance is <i>available</i> to anyone choosing participant direction.			Required Use? The aid or assistance is <i>required</i> to be used by anyone choosing participant direction.		
	Yes It is available.	No Not available.	Not addressed or discussed.	Yes Use is required.	No Use is voluntary.	Not addressed or discussed.
Financial management services	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 0
Emergency back-up	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 0
Worker registry	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 0
Advice / counseling	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 0
Managerial assistance	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 0
Information dissemination products	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 0
Service coordinator	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 0
Employer of record	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 0
Service quality monitoring	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 0
Participant training	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 0
Service provider training	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 0

**If under availability, the answer is “No – not available”, then the default response for required use is “Not addressed or discussed.”

Financial management services refer to the financial agent, or financial intermediary, that provides assistance with or assumes responsibility for all payroll management (e.g., taxes, withholdings, service provider payments) and goods purchasing.

Emergency back-up refers to the maintenance of or assistance with the development of a back-up system or plan for when scheduled workers are not available.

Worker registry refers to the maintenance of or assistance with the development of a registry that lists available and qualified service providers.

Advice / counseling refers to assistance provided in the form of advice and counseling regarding things like service options, personal goals, accessing resources, identifying training needs, etc.

Managerial assistance refers to assistance with employer responsibilities related to service providers as described in the *WHAT* construct. Peers (i.e., other consumers using participant direction) or professionals may provide this assistance.

Information dissemination products refer to any paper, audio, video, web-based products or activities designed with the intent of providing needed information to consumer and service providers regarding participant direction.

Service coordination refers assistance with identifying and accessing appropriate and needed services and resources in the community.

Employer of record refers to the role of legal employer of the service providers. The individual or agency assuming this role may also provide assistance with employer responsibilities (e.g., recordkeeping, payroll management).

Service quality monitoring refers to assistance with the responsibility of assuring that the services received by the consumer are quality services that meet the consumer's needs.

Participant training refers to training of consumers or surrogates on the activities associated with participant direction of the consumer's supports and services, such as selecting qualified workers, communicating needs and preferences, supervising workers, disciplining/dismissing workers, and payroll management.

Service provider training refers to training of service providers that is not consumer specific, such as CPR certification, first aid, and generic care delivery (e.g., transferring, lifting, bathing), and workplace behaviors. This does *not* refer to service provider training provided by the consumer as a part of the consumer's employer responsibilities.

Illustrative quote:

New indicator measure?
