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Implementation of Self-Directed Supports for Individuals with  
Intellectual and Developmental Disabilities: A Political Economy Analysis

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of  
Philosophy in Social Work at Virginia Commonwealth University.

by

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## **Abstract**

Self-directed supports, as a method of service delivery, have grown from small pilot programs in a handful of states to at least one program in every state. For individuals with intellectual and developmental disabilities (IDD), self-direction presents unique opportunities to engage in self-determined behavior and shape the services upon which they rely. Although the evidence base for self-direction is relatively robust, there is a significant lack of information on how implementation of self-direction is faring on the national level. The purpose of this study is to understand how the political and economic factors within and across states have impacted the implementation of a self-directed service delivery system.

*Keywords:* self-direction, participant-direction, consumer-direction, intellectual and developmental disabilities, implementation research, political economy, disabilities, Medicaid, home and community-based services

## **Preface**

Connor is a nineteen year-old African-American male who lives with his parents and two sisters in a rural county in the Southeast United States. When he was 8, Connor was diagnosed with Williams Syndrome, a developmental disability that causes cardiac and gastrointestinal problems, higher levels of anxiety, lower intellectual functioning, and a lack of social inhibition. Connor recently graduated from high school and is transitioning into adult services for people with Williams Syndrome, which often includes employment or volunteer work, social activities and functions, as well as exploring independent living. Both Connor and his parents have expressed desires for him to live independently in an apartment in his hometown. It is this goal for greater independence in living arrangement and his life that causes his parents to consider self-directing his supports.

Because of his disability, Connor finds it hard at times to complete everyday tasks, including bathing, cleaning, and cooking. For the past four years he has worked with direct support workers from a local agency who provide assistance with these tasks while providing education on how to complete them independently. The family has expressed some frustration over the turnover in this position over the past few years, though they report being mostly satisfied with the in-home supports provided. Additionally, Connor requires environmental accommodations, such as a chair lift, in his current home due to a severe cardiac event that makes it difficult for him to climb stairs. His parents, who are of low income, have been unable to secure environmental accommodations independently and have also struggled to maintain Connor's dietary needs due to his diagnosis. Finally, due to their location in a rural town, it is often difficult for Connor's family to find service providers who are willing to provide services in their home.

Connor is a relentlessly positive individual with a caring and supportive family. He is socially gifted and makes fast friends with individuals in any situation. Through his school-age years, he has shown a tremendous ability to meet goals he sets for himself and looks at his young adult years as a time for further growth and independence. His family of five has been a strong source of support throughout his life, with both parents and siblings assisting him with care activities.

As Connor is aging out of his existing Medicaid waiver program for children with disabilities and into the adult waiver, he is gaining access to services that are offered to adults in his state—including supported employment, dietary supports, adaptive aids, chore services, transportation services, and home/vehicle modification. He and his family are weighing the option of continuing in traditional services—with a service provider who employs his direct support worker and a case manager from the state Developmental Disabilities Administration directing how Connor’s Medicaid funds will be spent and determining what services are needed—or beginning to self-direct their funds—with Connor and his family making financial decisions about what services will be purchased and from which providers. While Connor and his family are open to the idea of self-direction as a way for Connor to express his self-determined desires about how to live his life, all members of the family have expressed concerns about finding appropriate backup support in emergencies, the desire for slow and predictable transitions, and the benefits of remaining with his existing agency support worker.

## **Chapter 1: Introduction**

### **Home and Community Based Services for Individuals with Intellectual and Developmental Disabilities**

Individuals with Intellectual and Developmental Disabilities (IDD) are a rapidly growing population in the United States that require a unique approach to human services delivery. Early estimates of the prevalence of IDD in the population are comparatively low, estimated at nearly 1.5 individuals per thousand in the United States (Larson, Lakin, Anderson, Lee, Lee & Anderson, 2001). Recent estimates with more inclusive definitions of IDD determine that 13.2%- 15% of the United States population has an intellectual or developmental disability (Boulet, Boyle & Schieve, 2009; Boyle, Boulet, Schieve, Cohen, Blumberg, Yeargin-Aslopp et al., 2011). Studies of IDD often find widely disparate prevalence statistics, depending on the source of data—self/parent report, diagnostic interviews, medical records, or school records—which clouds the ability of researchers to estimate the true prevalence of this group of disorders. For example, parent-reported prevalence of many of the diagnoses in Boyle et al.'s 2011 study on IDD as well as Visser et al.'s 2010 study on Attention Deficit and Hyperactivity Disorder (ADHD) are low in comparison to meta-analyses of multiple data sources as well as diagnostic interviews which reach parents whose children have not been diagnosed yet. The most recent prevalence statistics for IDD diagnoses include 15.5% for ADHD (Rowland et al., 2013), 1.13% for Autism (Centers for Disease Control, 2012), 0.211% for Cerebral Palsy (Oskoui, Coutinho, Dykeman, Jette & Pringsheim, 2013), 0.0827% for Down syndrome (Presson, Partyka, Jensen, Devine, Rasmussen, McCabe & McCabe, 2013), and 7.66% for learning disabilities (Boyle et al., 2011). Independent of methodology, the IDD literature notes an increase in prevalence over the last decade, particularly in ADHD and Autism diagnoses (Boyle et al., 2011). Moreover, 40% of

children with a developmental disability have multiple disabilities, particularly those with blindness or Autism (Boulet et al., 2009).

IDD is a unique class of disability, as it is diagnosed in childhood or adolescence, is a lifelong condition, and presents relatively predictable service needs for consumers. Individuals with IDD have disproportionately higher rates of physical health, mental health, and special education utilization than the general population (Boulet et al., 2009). Policies designed to assist individuals with IDD with their chronic economic, health, and social supports have transitioned over the past decades towards providing services in the community (Braddock, Hemp, Tanis & Rizzolo, 2014; Larson, Salmi, Smith, Anderson & Hewitt, 2013). States are increasingly moving away from providing services in large public institutions and towards home and community-based settings—with nearly 80% of individuals with IDD living in settings of six or fewer people (Braddock et al., 2014; Larson et al., 2013). As more people are diagnosed with IDD, and through advances in medical technology, live longer lives, the existing human services delivery system for IDD will have to adapt to meet the growing demands for services that address diverse and unique needs.

State and federal government initiatives to reduce the unmet service needs of people with IDD have increasingly turned to Home and Community Based Services (HCBS) due to the advocacy of the disabilities community for services in the least restrictive environment. For individuals with IDD, HCBS services have dramatically increased over the past twenty years. In 2012, approximately 70% of Long-Term Support Services (LTSS) for individuals with IDD were provided in community-based settings—up from 30% in 1995—and in a sample of 21 states, over 90% of individuals with IDD received HCBS services in place of institutional services (Eiken et al, 2014; Merryman, Miller, Shockley, Eskow & Chasson, 2015; Ng, Stone &

Harrington., 2015). This dramatic expansion of community-based services for individuals with IDD is a part of a larger trend in HCBS services for people with all classes of disabilities as HCBS spending by state and federal governments has risen 49% from 2005-2010 to \$53 billion (Ng et al., 2015). The impetus behind this growth has come from the Centers for Medicaid and Medicare Services' (CMS) Medicaid waiver program, which allows states the flexibility to experiment with different methodologies of service delivery, provided they remain cost-neutral (Infield, 2005). HCBS waiver expenditures in FY 2013 were 31.4 billion dollars, with an average cost of 45,800 dollars per person (Braddock et al., 2014). As the cost of HCBS services for governments continues to rise and more individuals seek services, states have increasingly relied on cost control policies including waiting lists for access to HCBS services (Ng et al., 2015). It is within this context of growing needs and growing costs that self-direction has come to prominence as a human services delivery model.

Self-direction has become the preferred model of HCBS service delivery to individuals with IDD (Infield, 2005; Putnam & Frieden, 2014). As of November 2011, there were nearly 300 self-directed supports programs serving any type of disability in the United States with at least one program identified in every state (Sciegaj & Selkow, 2011). This figure is double the previous amount measured in 2002 (Doty et al., 2012). Indeed, the majority of self-directed LTSS service options were started in the last decade following the successful and highly impactful “Cash and Counseling” demonstration projects which focused largely on individuals of advanced age, though it included some individuals with disabilities, as well (Sciegaj et al., 2014). Enrollment in self-directed programs is currently 810,000 people—again nearly double the amount from a decade ago (Doty et al., 2012). Although many self-directed programs began as demonstration projects serving a select number of individuals or a limited geographic area within

a state, the growth of self-direction particularly within the Medicaid system is likely to continue the trend of increased enrollment and increased spending (Sciegaj et al., 2014). Although self-direction is not offered to individuals with IDD in every state, self-advocates, family advocates, and the disability rights community have fought for decades for access to self-directed supports as a right for individuals and families with IDD to have greater choice and control in their long-term support needs.

Connor is eighteen years old and is fortunate that he is able to receive services while living in his parents' home. Connor's home state has offered HCBS services to people with IDD since the 1980s, as part of a larger movement to reduce the population of individuals with disabilities in large, state-run institutions. HCBS services, such as those required by Connor, are relatively predictable over time, as Connor's need for dietary, chore, and transportation assistance will likely remain relatively constant throughout his life. Although Connor was able to secure services through a children's HCBS program, many individuals with IDD are placed on waiting lists for services, as states attempt to manage HCBS expenditures. Connor and his family may choose to self-direct their services, which may be both cost-effective for the state and empowering for Connor. Alternately, they may decide to remain in traditional HCBS services, with service providers providing services in the home and receiving reimbursement through the Medicaid program. The opportunity for Connor to self-direct his supports and the ability to receive services in the community are the result of decades-long advocacy of disability rights activists.

### **History of the Self-Directed Services Movement**

The desire for greater control and more meaningful participation in supportive services for individuals with disabilities grew out of the disabilities rights movement and the desire for

greater participation in society. Beginning in the 1960s, younger consumers with disabilities formed the independent living movement and demanded the right to manage their own care, fought to receive care in community settings rather than institutions, and challenged assumptions that individuals with disabilities were vulnerable and needed protection in the form of professional decision-making and management (Doty, Kapser & Litvak, 1996; Nadash & Crisp, 2005; Tilly, 1999). Individuals with developmental disabilities, their advocates, and family members joined the movement for community living, and the self-determination movement grew out of these efforts (Nerney & Shumway, 1996). Administrators in some states, including Massachusetts and Maine, were strongly influenced by the independent living, self-advocacy, and self-determination movements to create the first self-directed programs (Doty et al., 1996; Nadash & Crisp, 2005). Over the next few decades, these policies were enacted largely in community-based programs and covered a small portion of the overall IDD population requiring home and community-based services—due chiefly to a lack of state support for publicly funded self-directed programs and the lack of federal guidance and coordination (Crozier, Muenchberger, Colley & Ehrlich, 2013; Sciegaj et al., 2014).

The growth of self-direction in the provision of home and community based care services was the direct result of the issue framing done by the disabilities rights movements. As services moved from the institution to the home, disabilities advocates needed to develop terminology around what services individuals with disabilities needed. Personal assistant services—also known as personal care services, personal care attendant services, or in-home services—is the term preferred by individuals with disabilities to describe their needs within the home (Doty et al., 1996). These needs are primarily served through employing a direct support worker (DSW) who assists the individual with their Activities of Daily Living (ADLs) (e.g. “bathing, dressing,



transferring from bed to chair, eating, and going to the toilet”) and Instrumental Activities of Daily Living (IADLS) (e.g. “housekeeping, meal preparation, doing laundry, managing money, and making telephone calls”) (Doty, Benjamin, Matthias & Franks, 1999, p. 1). The progress of the disability rights movement in relocating these supports from the restrictive hallways of institutions to small group homes, family homes, or independent consumer homes represents a major achievement towards civil rights, dignity and autonomy, and social inclusion for individuals with disabilities. As services increasingly moved into home and community settings, the supports individuals demanded expanded to align with the goals of greater social inclusion. States increasingly spent money not only on DSWs and residential services, but also employment, family support, transportation, health, respite, and assistive technologies (Rizzolo, Friedman, Lulinski-Norris & Braddock, 2013). Though direct support remains a substantial portion of HCBS waiver spending, the ability of participants to self-direct these additional supports is an integral part of transitioning away from agency-managed services and towards programs that provide for greater participant self-determination.

In the beginning of home and community based services, direct support work was administered by a licensed home care agency under contract with a public financing program, such as Medicaid (Doty et al., 1999). This system continues today and is referred to as traditional services, professionally-managed services, or agency-directed services. In agency-directed services, home care agencies assume responsibility for hiring and management of support workers, retain discretion over honoring participants’ requests for replacing unsatisfactory workers, and may change participants’ workers for administrative reasons. While agencies generally honor participant requests for the same or different support workers to provide services, ultimate authority over what services are provided, how they are provided, and

who provides them resides within the agency. Doty et al. (1999) summarize the arguments for professionally managed services for clients as protecting them from administrative burden, providing staff supervision, recruitment, and training, guarding against incompetent or unreliable help. For DSWs, professionally managed services allows workers to engage in peer consultation, protects workers from unreasonable client demands, and provides opportunities for career advancement.

Although the move towards de-institutionalization and community care represents a watershed moment for disability rights, participants in the community continue to fight with agencies and the state for greater control over supports based on the ideas of autonomy, capability, and individual knowledge. Professionally managed services within home and community settings, while validating the physical autonomy of individuals with disabilities, deny them psychological and spiritual autonomy regarding important aspects of their lives—including control over one’s environment and life (Simon-Rusinowitz & Hofland, 1993; Yamada, 2001). To disability rights advocates, professionally managed services are predicated on the deleterious idea that individuals with disabilities are vulnerable and in need of protection from the important decisions in their lives (Tilly, 1999). Insulation from the decision-making process— a well-intentioned, though paternalistic practice— assumes that individuals with disabilities are likely to be incapable of making important decisions in their own lives or do not possess the knowledge necessary to do so because they lack medical or professional expertise (Doty et al., 1996). Disabilities advocates describe the experience of some professionally managed services as “severely dehumanizing” for the participant as a passive recipient of services (Nadash, 1998, p. 18). Traditional service models afford the agency providing services the power to determine a participant’s daily life experience such as when they would eat and bathe, who may touch their

body, where they would go for the day, and in what activities they might participate (Nadash & Crisp, 2005; Putnam & Frieden, 2014). Although individuals with disabilities are living in the community, their lives were still to a great degree controlled by private agencies as well as the state and federal Medicaid bureaucracies who funded their services.

Self-direction is a direct response to the identified issues with professionally managed services—those of autonomy, capability, and expertise. Expanding upon the idea of spiritual and psychological autonomy, advocates demanded that individuals with disabilities have primary control over “the nature of services and who, when, and how services are delivered” (Dinora, 2008, p. 15). Participants with disabilities have a right to control their daily life activities, such as waking, eating, and movement, and the right to autonomy should be instantiated in HCBS programs (Nadash & Crisp, 2005). Supplementing rights-based arguments, advocates contend that services centered around autonomous participants will force service providers to become more responsive to participant need and that these participants will be the best monitors of service quality, particularly when they are trained to do so (Nadash, 1998). Self-direction is also predicated on the idea that individuals with disabilities possess unique, individualized knowledge on their service needs that professional managers can never acquire (Nadash & Crisp, 2005; Yamada, 2001). By acting within the context of self-directed programs, participants are able to develop a package of services that best reflects their preferences, values, and context (Nadash, 1998). In this way, self-direction honors and facilitates the inherent competency and capability of individuals with disabilities to monitor and direct the services upon which they rely. Although individuals may lack medical or professional knowledge, advocates argue that individuals do not need to possess medical certification to understand or manage the basic activities of daily life covered under HCBS services (Doty et al., 1996). In 1996, the National Institute for Consumer-

Directed Long-Term Care Services provided a definition of self-direction, then called consumer-direction, that represents how critiques of professionally managed direct support work coalesced into a comprehensive and politically powerful service delivery model:

“Consumer-direction is a philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choices about the services they receive. They can assess their own needs, determine how and by whom these needs should be met, and monitor the quality of services received. Consumer direction ranges from the individual independently making all decisions and managing services directly, to an individual using a representative to manage needed services. The unifying force in the range of consumer-directed and consumer choice models is that individuals 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.” (as cited in Nadash & Crisp, 2005, p. 10)

### **Components of Self-Direction**

The openness of administrative and legislative systems to self-directed supports reflects a value commitment: that authority, management, and control over service dollars should reside in the participant. In the transition from philosophically questioning the passive role assigned to individuals with IDD and defending their right to self-determination to building a concrete model of service delivery, advocates for self-direction fundamentally altered the traditional roles of state officials and existing service providers, the structure and purpose of the Medicaid program, the outcomes deemed important for program success, and the relationship between support systems in the disability network (Moseley, 2001). The following section will describe how self-

direction functions in the abstract, detailing its component parts and their purposes. It should be noted, however, that the program design decisions made by administrators often deviate significantly from the textbook model of self-direction. As shown in Appendix B, components of self-direction are often altered, limited, or omitted entirely from different implementations based on the needs and preferences of administrators.

Beginning with the “Cash and Counseling” demonstration project in the 1990s, policy experts and disability advocates deconstructed specific parts of agency-directed supports and created a robust system of policy innovations, including individual budgeting, person-centered planning, employer and budget authority, support brokerage, and fiscal intermediaries. In agency-directed supports, an eligible individual with IDD is assigned to an agency that is paid through a government program to provide the services on a treatment plan. Self-direction breaks this service role into its component parts and centers planning and implementation authority over those components with the participant, as described in Figure 1.

Individual Budgeting	Allocations from the state that are based on individually assessed support needs.
Person-Centered Planning	Process in which participant, natural supports, and case manager understand the participant’s life goals and support needs.
Employer Authority	Authority to hire, train, maintain, and dismiss support workers as well as choose from different provider agencies
Budget Authority	Authority to make decisions on what supports will be purchased and how much money to allocate to each support need.
Support Brokerage	An employee of the participant who assists them with employer and budget authority and interfaces with providers and state officials.
Fiscal Intermediary (FMS)	Private entities such as non-profit, for-profit companies, or service agencies that assist the participant in complying with labor and tax laws and track spending for the implementing department.
Representative	A person, usually a family member, the participant authorizes to make decisions on their behalf.

Figure 1: Components of Self-Direction

Self-direction is exercised within an individual budget and support plan approved by the state. The specific benefit determination process varies by state but generally involves an individual assessment of the participant's "needs, preferences, wants, and abilities" carried out by a professional with the intensive participation of the individual and their family members (Crisp, et al., 2010, p. 1-8). While a majority of states use a unique, state-devised "developmental process" based in person-centered planning or implement standardized assessment tools such as the Supports Intensity Scale (SIS), less self-directed states elect use either a pre-determined amount for each program participant or discrete categories with a pre-determined amount assigned based on assessed level of need (Crisp et al., 2010; Gross et al., 2015b; Moseley, 2005). Assessment tools are used alongside future expenditure forecasting based on statistical modeling of the individual's expenditures from previous year, the average expenditure in the state, an assessment of future medical, functional, housing, and behavior needs as well as existing supports, particularly unpaid care (Crisp et al., 2010).

The individual budget should be created through an assessment that includes person-centered planning. Person-centered planning, much like individual budgeting, is a policy innovation that predates self-direction, though it is a vital component of the program design. It identifies the hopes and dreams of the individual and coalesces them under the framework of the state program. Family participation in the person-centered planning process can allow, in some states, the ability to revise the amount determined by the state, increasing opportunities for self-determination. For each participant, the assessment process produces an identification of needs, a service plan to address those needs, an overall budget amount, and a spending plan (Crisp et al., 2010). States provide different avenues for participants to submit adjustments to their

budget amount or spending plan both annually and during the fiscal year for emergency situations.

One of the earliest innovations in self-direction was the creation of employer authority. Employer authority entails hiring, management, and dismissal over service workers—most significantly DSWs—as well as the ability to recruit and refer individuals to become service workers for the participant (Crisp, Doty, Smith & Flanagan, 2010). Although all self-directed programs must include hiring, management, and dismissal of service workers as part of employer authority, there is significant variation between the states on how other aspects of employer authority are implemented (Crisp et al., 2010). Some states require service workers to register with the state, complete mandatory training, or affiliate with an existing service agency. In programs with a greater degree of self-directedness, participants may recruit family members—including intimate family members, legal guardians, or extended family—as well as friends or acquaintances to engage in support work instead of agency-affiliated workers (Crisp et al., 2010). Despite growth in the number of programs and changes to Medicaid waiver regulations that allow family members to provide paid work, only a minority of states allow participants to employ family members as caregivers, many of which prohibit spouses and parents specifically from providing paid care (Gross et al., 2015a; Ng et al., 2015; Sciegaj et al., 2014; Simon-Rusinowitz et al., 2009). These supply-side regulations help determine the pool of workers available from which participants choose, alongside wage limitations imposed by the state due to collective bargaining arrangements, minimum wage laws, and other legal requirements.

The participant's role in employer authority begins with recruiting, interviewing, and hiring a service worker. Most commonly, the worker of greatest importance to the participant is the DSW, who assists the participant with ADLs and IADLs every day (Doty et al., 1999). Once

a worker is recruited, the participant performs the duties of an employer—setting wages, scheduling, training, record-keeping, supervising, and evaluating performance (Crisp et al., 2010; Gross et al., 2015b). Many states offer participants the choice between becoming the common law employer of workers—almost always with a private fiscal intermediary company fulfilling payroll and tax duties—or serving as co-employer with a private or public agency who fulfills payroll or tax duties. These policy innovations were created in response to disability advocates reporting that the paperwork associated with employing workers without assistance is often overwhelming (Scala & Nerney, 2000). There is significant state variability in the maximum and minimum wages allowable for specific goods and services. While the majority of self-directed programs allow participants to determine wage rates, in states with low self-directedness, the wage floor and ceiling have little to no difference, which impedes the ability of the participant to reward or punish workers based on performance and satisfaction (Crisp et al., 2010; Sciegaj et al., 2014). Participants may exercise employer authority for many different types of services included in their service plan such as direct support work, supported employment, respite, skilled nursing, among dozens of others.

In addition to employer authority, other major innovation of self-direction is budget authority which grants the participant authority over all or some of the funds allotted to the participant to purchase specific goods and services that are authorized in their individual plan of care. Budget authority allows individuals to determine how much money will be spent on a given service while also expanding the types of good and services that may be purchased. For example, many programs offering budget authority provide opportunities to purchase assistive technology, home modification, day treatment, among dozens of other services and goods.

Without budget authority, the participant has less flexibility in determining where funds will be



spent in a given year. For individuals with budget authority, they are better able to allocate funds based on unforeseen events, short or long term needs, and personal preference. However, there is considerable variation between states on what goods and services are covered, whether participants need to submit budgetary changes to the state, or predetermined pay rates or limitations for specific goods or services (Gross et al., 2015b; Ng et al., 2015).

To assist with exercising employer and budget authority in most states, the participant engages the services of a support broker (also known as a support counselor) who assists the participant by explaining laws and regulations, helping participants with budget preparation and supervision of employees, and acting as liaison with the fiscal intermediary, service agencies, and the state. Unlike case managers—who are employees of the state or service agencies within agency-directed supports—support broker are employees of the participant and exist in a collaborative relationship focused on providing information and support regarding self-directed tasks (Crisp et al., 2010; Walker, Hewitt, Bogenschutz & Hall-Lande, 2009). Although support brokers provide a necessary service as intermediary between participant and public and private agencies, not all states provide monetary assistance for support brokerage and others do not require the use of a support broker in order to participate in self-direction.

With support brokers providing participants face-to-face assistance with managing budget and employer authority, a fiscal intermediary or financial management service (FMS) provides support on the back-end—ensuring regulatory compliance with tax and labor laws, fiscal accountability with the state IDD department, and payment to service workers and agencies (Murphy, Selkow & Mahoney, 2011). The fiscal intermediary services may be provided by a disability services agency, a government department, or a private financial management service, depending on the state. While the majority of states require participants to

use a fiscal intermediary, states with a higher degree of self-directedness offer participants a choice between fiscal intermediary providers (Sciegaj et al., 2014). Programmatically, fiscal intermediary providers fulfill a dual role—monitoring participant spending on behalf of the state as well as providing instrumental support to participants who would otherwise be burdened with employer paperwork. The creation of a separate fiscal intermediary authority resolves a conflict of interest in agency-directed supports in which an agency is involved in both financial management of individual budgets and service delivery paid through those budgets (Crozier et al., 2013).

It is important to note the family context in which budget and employer authority are exercised. The preceding description of self-directed supports uses the term participant to refer to the unit of authority within support programs, but individuals have the option to designate a representative, or surrogate decision-maker, to assist them with self-directing their supports (Crozier et al., 2013). This policy innovation began in “Cash and Counseling” and opened up the model of early self-directed programs, which only allows applicants with “fully intact cognition,” to participants with more significant cognitive limitations (Doty et al., 2012, p. 33). Participants who appoint representatives may seek their assistance with decisions or authorize the representative to make decisions on their behalf (Crozier et al., 2013). A family member acting as a representative is not permitted to be a paid helper, though there are recent policy changes that may allow it under the 1915c Medicaid waiver authority (Simon-Rusinowitz et al., 2009). The designation of a representative is a vital part of the self-directed model of services for individuals with IDD because of the limitations their diagnosis may place on their ability to exercise employer and budget authority. In accommodating these limitations, self-direction is designed to honor the preferences and participation of individuals with IDD in the decision-

making process, not only the proxy authority granted to representatives. However, proper use of case management and support brokerage is needed to ensure that the voices of a representative or family members do not crowd out those of the participant.

### **Self-Direction in Present-Day Programs**

The preceding description of self-direction represents an idealized view of self-direction. In practice, implementations of self-direction vary widely on critical design features within states and between states. Although self-directed programs across the United States are similar in important respects, many authors concur that self-direction is best conceptualized as “self-directedness,” with individual implementations granting more or less authority on specific components of long-term care services (Gross, Blue-Banning, Turnbull & Francis, 2015a; Gross, Blue-Banning, Turnbull & Francis, 2015b; Kendrick, Petty, Bezanson & Jones, 2006; Nadash, 1998). A program’s self-directedness may be a function of the number of components offered, the degree of authority and control participants have over those components, and the options available to the participant self-directing their funds.

Based on the domains from Gross and colleagues’ (2015a) grounded theory analysis of self-directed Medicaid waivers, Appendix B describes the many aspects in which self-directed programs may vary in their design. Across the planning, budgeting, and employing aspects of self-direction, policymakers and public administrators make decisions about program features that influence the service delivery system that participants experience. The purpose of this investigation is to understand how the institutional environment influences the decisions about program features.

## **Self-Direction and Connor's Family**

In the preface of this manuscript, Connor and his family were considering whether to remain in traditional agency-directed supports or to self-direct their funds within a Medicaid waiver for individuals with IDD. In both models, Connor would be assessed by the Developmental Disabilities Administration (DDA) in his state and a services budget would be estimated for the coming year. If Connor's family chose to remain in traditional services, those funds would remain with the DDA until they are requisitioned by the various agencies and individuals providing services to Connor—including employment specialists, direct support workers, contractors making home modifications, and dieticians—as long as these services were covered under his plan of care. While Connor and his family could request different workers from agencies providing these services as well as suggest the best hours for service delivery, the agencies providing services are not obligated to accommodate those requests. Workers in traditional services are paid according to a pay schedule set by the DDA, and Connor's family would not be able to negotiate lower rates or pay higher rates depending on their satisfaction. Connor would be assigned a case manager who provides oversight for the state, performing periodic assessments, and assisting Connor and his family with understanding their service options. Traditional services would provide Connor and his family the necessary supports he would need while retaining the administrative activities of employing and paying service workers with the DDA. It may also assist with assuring continuity of service with his existing personal support worker and may be a predictable and easier transition between the child and adult waivers.

Although there are benefits to remaining in a traditional service delivery model, Connor's family may also find some benefits from self-directing his supports. Connor's family would,

similar to traditional services, participate in an assessment with the DDA to determine Connor's services budget for the year. A support coordinator would work with Connor and his family to develop a person-centered plan of care based on Connor's understanding of what supports he requires, how he feels those supports should be provided, personal goals or life dreams, and what community activities he would like to engage in during the year. Based on that plan of care, Connor or a representative of his choosing would engage in hiring and paying support workers for treatments covered under Connor's plan of care. The support broker also functions as an intermediary between Connor's family and providers. His case history indicates that direct support, supported employment, and dietician services will likely be a part of his plan of care. Connor and his family would be able to choose which providers will be performing these duties and determine—within limits set by the state—how much money each provider will be paid. The spending flexibility within self-direction also allows Connor and his family to reassign money based on unforeseen circumstances. Service workers who are providing unsatisfactory or unresponsive services, perhaps by arriving late or not attending to Connor's needs well, can be dismissed and new workers may be hired. This is particularly important for Connor's direct support worker, as Connor lives in a rural area which is often underserved by in-home care agencies. Connor may choose a family member to act as his DSW, and that family member can receive payment through Connor's plan of care. Should Connor wish to remain with his existing DSW, he will be able to do so depending on the consent of the worker's support agency and can even pay that provider more money to support the longevity of that support relationship. Any payments to service workers must be approved by Connor or his family—usually through timesheets or work orders—and are then sent to a fiscal intermediary that handles tax

withholding and payment disbursement to the provider. Connor is also assigned a case manager who provides similar monitoring functions as in traditional services.

The day-to-day experience of traditional services and self-directed services for individuals with IDD are quite similar. Services related to the plan of care are carried out under the supervision of Connor's family, a case manager, and the DDA. However, the small differences between traditional and self-directed models of care are particularly meaningful for participants and families and may be meaningful to Connor's family. Though many of the same services are likely to be available using traditional or self-directed supports, Connor and his family will have greater control over when and by whom services are provided if they choose to self-direct their supports. If the family is satisfied with existing provider arrangements and wishes to maintain them, this may not be a meaningful difference. Indeed, the family may not wish to engage in recruiting and hiring employees, approving timesheets, and negotiating payment. If Connor's family wants to increase their level of control over their existing supports or make existing arrangements more flexible, then self-direction may be an attractive alternative to the traditional services they currently receive.

## **Preferences and the Policy Environment of Developmental Disabilities Program**

### **Administrators**

Self-direction represents a significant shift from previous agency-directed models of service. As self-direction has grown exponentially over the past few decades, developmental disabilities program administrators (DDPAs) are entrusted with translating the philosophical impetus for greater choice, control, and autonomy into concrete service delivery systems. Using Ostrom's (1989) model of public administration, the following section details a methodologically

individualistic approach to understanding the preferences and contexts of public administrators. Ostrom proposes a model of public administrators as rational, self-interested, and law-abiding actors in an uncertain political environment that engage in a utility maximization strategy based on their individual perception of rewards and costs. Public administrators also act within an institutional environment of formal and informal rules, organizations, and historical contexts. The institutional environment is subdivided in this analysis into state and federal contexts, as each has a unique impact on the actions of public administrators.

**Preferences of administrators.** Preferences are defined as the wants and desires of the acting individual, and in accordance with the political economy literature, these preferences are largely modeled as self-interested. The maxim of behavioral symmetry in public choice theory posits that these preferences are largely self-interested (Niskanen, 2002), though the interests of administrators and the target populations of their programs often overlap as in any effective principal-agent relationship (Tullock, Seldon & Brady, 2002).

**Reducing cost.** Due to the significant increases in long-term care and other medical spending on the state level, there is a distinct preference demonstrated in the literature for service delivery models that will be less costly to the state government (Braddock, 2007; Hall-Lande, Hewitt, Bogenschutz & LaLiberte, 2012; Walker, Hewitt, Bogenschutz & Hall-Lande, 2009; Yamada, 2001). Self-direction presents numerous opportunities for cost savings versus traditional agency-directed services. Agency-directed services are often more expensive on a per unit basis, as they include administrative and supervisory activities that are provided gratis by the participant in self-directed services (Doty et al., 1996). The lower cost per unit of self-direction is seen as a way to address increased demand for HCBS services without expanding traditional agency-directed waiver services (Kitchener, Carrillo & Harrington, 2003; Litvak & Kennedy,

1991; Mahoney & Simon-Rusinowitz, 1997). Moreover, although early studies of self-direction indicated that wage rates and fringe benefits for care providers in self-directed service options are lower than agency-directed options, providing additional cost savings (Simon-Rusinowitz & Hofland, 1993; Yamada, 2001), more recent findings indicate that higher wages but fewer benefits is the more accurate representation of worker compensation in self-direction (Bogenschutz, Hewitt, Hall-Lande & LaLiberte, 2010). Program administrators in previous studies describe the choice to engage in self-directed services as an effort towards reducing overall administrative and oversight costs in their agencies, reducing overspending on case management services for individuals with disabilities, reducing “guesswork” in budget expenses, and ensuring accountability (Litvak & Kennedy, 1991; Mahoney & Simon-Rusinowitz, 1997; Schmitz, Luxenberg & Eustis, 2005, p. 6; Stone, 2006). In the longer term, DDPAs describe self-direction as strengthening participant’s support systems and keeping them in their own homes, thereby reducing long-term spending on nursing homes, emergency rooms, and other expensive service options (Crozier et al., 2013; Doty et al., 1999; Infield, 2005).

***Improving service delivery and meeting participant need.*** At the same time states are trying to reduce costs, the demand for community-based disability services has significantly increased, leaving some participants without access to adequate support services. Program administrators have reported perceived gaps in service delivery and increased participant demand as some of the most important reasons to offer a self-directed service option (Infield, 2005; Schmitz et al., 2005). In particular, DDPAs identified rural and non-traditional participants as facing inequities in service delivery that are better addressed through self-direction. Rural participants are often faced with a lack of available service providers in their area, and by allowing them to hire friends or family members in self-direction, these gaps can be closed and



more services can be provided (Infield, 2005). Self-direction also provides the flexibility in spending that is important for participants with low-incidence diagnoses or those that require specialized goods and services such as special diets (Hall-Lande et al., 2012). Participants from diverse ethnic and racial backgrounds may also be more comfortable relying on family members or care providers that share their culture, and DDPAs are sensitive to the need for culturally competent services (Hall-Lande et al., 2012; Infield, 2005). In addition to reducing unmet need, DDPAs demonstrate a preference for high quality services that lead to increased participant satisfaction and quality of life (Hall-Lande et al., 2012). DDPAs implementing self-direction noted the importance of building consistent, high quality helping relationships that reduce family and provider issues in assessing the success of self-directed programs (Hall-Lande et al., 2012). In this way, DDPAs demonstrate a strong preference for self-directed service options because they promote higher quality service, greater equity across participants, and expanded access to services (Cubanski & Kline, 2003; Schmitz et al., 2005).

***Philosophical agreement.*** Although cost and service gaps are important issues for DDPAs, the transition to self-directed models of service often entails deeper philosophical, ideological, and political commitments that drive implementation. Program administrators report that offering a self-directed service option was “the right thing to do” for their participants (Infield, 2005, p. xii). Self-direction, according to DDPAs “is all about the person [whereas] traditional services are all about the service provider,” noting that the shift in roles that self-direction brings is often welcomed by DDPAs (Hall-Lande et al., 2012, p. 250). In offering a self-directed service option, administrators report a commitment to individual and family empowerment, participant choice, community inclusion, workforce participation, and strengthening informal support systems (Doty et al., 1999; Infield, 2005; Simon-Rusionwitz et

al., 2002). General awareness of the success of other states' self-directed service options, especially the positive results from "Cash and Counseling" demonstration projects, as well as peer-facilitated learning about other states was shown to be effective in DDPA's understanding, accepting, and promoting self-direction (Doty et al., 2012; Infield, 2005;)

***Dissatisfaction with existing programs.*** Agreement with self-direction often entails a reconsideration of traditional views of participants with disabilities (Hall-Lande et al., 2012; Yamada, 2001). Some administrators report dissatisfaction with the inflexible and paternalistic medical model of care traditionally provided in agency-directed services (Simon-Rusinowiz et al., 2002; Tritz, 2004; Walker et al., 2009). Through offering self-direction, administrators demonstrate a strong preference for models of service that are responsive to diverse participant needs and accommodate those needs in the least restrictive environment (Putnam & Frieden, 2014; Tritz, 2004). Relatedly, administrators are also using self-direction to continue their efforts at de-institutionalizing the IDD population in their state by providing individualized and community-based services (Doty et al., 1996). While acknowledging the sometimes substantial waiting lists for services resulting from de-institutionalization, DDPA's may conceptualize self-direction as the driving component behind a new approach to working with disabled population (Maryland Department of Health and Mental Hygiene, n.d.). Self-direction is also seen as a way to reduce "dependency" on government for individuals with disabilities and foster an "ownership society" (Dinora, 2008, p. 39; Friedland, 2005, p. 8; Yamada, 2001). However, philosophical agreement is counterbalanced by policymakers who express concern at paying family members for informal care they should provide as part of their family obligation (Doty et al., 1999; Infield, 2005). As a result of these conflicting ideas, implementing self-directed supports is subject to ideological pushback.

***Avoiding scandal, fraud, and abuse.*** Preferences and opinions about self-direction are not always positive. Many DDPAs also express concerns about aspects of self-direction that impact their administration of IDD services. Primary among these concerns is the potential for fraud or misuse of funds and the desire to avoid public scandal (Infield, 2005; Nadash, 1998; Mahoney & Simon-Rusinowitz, 1997; Simon-Rusinowitz et al., 2009). Program administrators may fear that by creating more flexible and liberal benefit programs, self-direction may tempt low-income participants to divert money away from medically necessary supports and toward unapproved uses (Sciegaj et al., 2008). As Simon-Rusinowitz et al. (2002) state, “even if fraud and abuse are very rare, one single case can cause so much damage” (p. 108). Though there is some debate in the literature as to how much these concerns materialize in practice (Infield, 2005), Nadash (1998) reports that these concerns significantly impact program design by creating limits on services and budgets—ultimately leading to “a lack of competition, participants who have to ‘take what they can get,’ and service providers that are not responsive to participant needs” (p. 16). This sensitivity towards even small instances of fraud and misuse is an important component to understand the actions of DDPAs (Simon-Rusinowitz et al., 2002).

***Limiting state liability.*** Similarly, DDPAs seek to minimize the potential legal liability of state governments, particularly in cases of negligence, exploitation, and abuse. In traditional agency-directed models of service delivery, the state was protected from abuse and fraud claims by transferring liability to home care agencies (Litvak & Kennedy, 1991). Self-directed services allow participants to recruit support workers independent of home care agencies, including family and friends who do not have formal healthcare training (Infield, 2005). DDPAs are sensitive to the potential for neglect when these workers are unable to serve the participant due to illness or emergency, and lacking a formal agency attachment, there is no backup support worker

to help the participant with their needs (Simon-Rusinowitz et al., 2002). By eliminating the home care agency as an intermediary in some cases, the state increases its potential liability for abuse of participants by support workers as well as abuse of support workers by participants (Sciegaj et al., 2008). DDPAs report that assessing the competence of individuals and families to manage their own funds and their own supports is difficult, and that any negative repercussions will reflect poorly on the state (Simon-Rusinowitz et al., 2002). Some administrators report not starting self-directed service options because of the concern that bad decisions by participants or support workers would increase liability (Infield, 2005).

**The state policy environment.** Political economy models of administrative behavior propose that the context within which a person acts is important for understanding their behavior. Contextual elements create positive or negative incentives that may influence how an administrator orders and expresses their preferences.

***Socioeconomic factors.*** There are significant state-level issues that impact the administration of self-directed service options. DDPAs are significantly influenced by the prevalence of specific disabilities in their state as part of the decision-making process for beginning new programs or expanding service offerings (Merryman et al., 2015). States with a greater percentage of their population over age 85, in metropolitan areas, fewer minority races and ethnicities, and at higher per capita income are more likely to spend more on HCBS services (Kitchener, Carrillo & Harrington, 2003). Similarly, those with more nursing homes and fewer home health agencies and users are also less likely to spend more on HCBS services (Kitchener, Carrillo & Harrington, 2003). Having established relationships with service providers experienced with self-direction, such as support brokers and fiscal intermediary providers, make it more likely DDPAs will support self-direction (Simon-Rusinowitz et al., 2014). Other

institutional supports, including advocacy and expertise from the research community, state DD councils, and University Centers for Excellence in Developmental Disabilities (UCEDD) centers, have been instrumental in advocating for self-direction (Bogenschutz, 2010; Merryman et al., 2015).

***Budget constraints.*** In an era of state budget shortfalls, of particular concern is the rapid increase in medical spending in the states and the corresponding drain on fiscal resources (Cubanski & Kline, 2003; Kitchener, Carrillo & Harrington, 2003). The growth of Medicaid-induced budget shortfalls has also occurred during an increase in political pressure for state tax cuts, difficulty limiting cost in Medicaid managed care, and federal cuts to safety-net programs (Cubanski & Kline, 2003; Holahan, Weiner & Lutzky, 2002). DDPAAs report that new administrations vary in their approach to budgetary matters, with some focusing largely on maintaining or reducing existing spending levels on HCBS services and others looking to expand or reconfigure service offerings (Walker et al., 2009). Building supportive and collaborative relationships with legislators, particularly in fiscally conservative policy environments, is also important in initiating, expanding, and maintaining self-directed programs (Walker et al., 2009). The pressure to find budget economies in the state has been found to impact DDPA decision-making around self-direction, particularly in New York where implementation of “Cash and Counseling” was derailed by risk-averse program administrators reeling from “years of substantial budget retrenchment” (Sciegaj et al., 2008, p. 90). Uncertainties about funding caused New York to not implement its “Cash and Counseling” program, and implementation analyses of other programs report that inconsistent funding created understaffing, froze enrollment, extended waiting lists, and reduced benefit amounts (Bachman et al., 2012; Simon-Rusinowitz et al., 2014).

***Legal constraints.*** In addition to the monetary constraints faced by political actors, there are unique legal issues within each state that affect the implementation of self-direction. Throughout the history of self-direction, there have been legal concerns about who is considered the employer of record and how withholding, workers compensation, and labor laws would impact service (Litvak & Kennedy, 1991; Infield, 2005). Some states have required care workers to participate in a worker registry or attain state licensure or certification in order to comply with existing health professional laws (Infield, 2005). Additionally, the application of certificate of need laws to HCBS service providers may diminish the supply of formal workers in the system (Kitchener et al., 2003). DDPAs have demonstrated concern about how these regulations may adversely impact implementation of a key feature of self-direction, the recruitment of unlicensed family caregivers as DSWs (Infield, 2005).

***Shortage of direct support workers.*** Compounding the legal issues surrounding employment, there is a long-standing and worsening shortage of direct support workers for individuals with disabilities (Tritz, 2004). There are numerous reasons for the decline in available direct support providers including the growth of community inclusion and deinstitutionalization, potentially lower wages or fewer benefits, high turnover rates, longer life expectancy of long-term care recipients, few opportunities for career advancement, the demanding and often unpleasant nature of direct support, and unhealthy organizational culture at home care agencies (Hewitt et al., 2008; Holahan et al. , 2002; Lakin, Polister & Prouty, 2003; Larson, Hewitt & Knoblauch, 2005). DDPAs have demonstrated sensitivity to these concerns through exploring self-directed service options which expand the potential pool of caregivers and have the potential to reach those who would not ordinarily be served by a traditional home care agency (Heller, Arnold, van Heumen, McBride & Factor, 2012a; Tritz, 2004).

***Participant advocacy.*** Within the state policy context, there is significant pressure brought by interest groups to introduce or expand self-directed service options. DDPAAs report hearing from participants who have trouble obtaining services, are unhappy with agency-directed services, or have no control over negligent or callous workers who negatively impact their health (Infield, 2005). Participant advocacy was instrumental in creating the first self-directed programs, and it has been influential in expanding access to self-directed models of service delivery over the past few decades (Litvak & Kennedy, 1991). Input of family members in the policy process—including quality control, evaluation, forms, and formal procedures—was identified by program administrators as a key to the success of the “Cash and Counseling” demonstration project (Mahoney, Fishman, Doty & Squillace, 2007; Merryman et al., 2015; Simon-Rusinowitz et al., 2014). As these programs expanded, formal advocacy by disabilities organizations and non-profits transitioned into instrumental assistance with program administration and implementation (Mahoney et al., 2007). Overall, grassroots advocacy has led to growing acceptance of self-directed models of service, and where there is “not total acceptance yet, ‘the door is opening’” (Infield, 2005, p. 45).

***Traditional service provider advocacy.*** Opposing the advocacy efforts of individuals and families with disabilities, traditional direct support agencies, nursing homes, and labor unions seek to conserve traditional agency-directed service models. Direct support agencies feel threatened about losing clients to self-directed options and fear a loss of business from independent workers or family members (Simon-Rusinowitz et al., 2009; Tritz, 2004). This fear materializes as political advocacy emphasizing potential issues with quality of care or neglect/abuse, increasing home care costs, and sharing negative anecdotes about self-directed services (Infield, 2005; Mahoney et al., 2007). Labor unions also face some potential losses of

monetary and employment privileges earned through collective bargaining. In the New York “Cash and Counseling” demonstration project, representatives from the Service Employee International Union expressed fears that under self-direction wage rates would decrease, there would be no mechanism for filing work-related grievances, and the potential for an exploitative work environment would increase (Sciegaj et al., 2008). DDPAAs are sensitive to these concerns in implementing self-direction, as according to Sparer (2004), “long-term care reform is a complex activity that requires consultation and consensus building. There is a pluralistic cast of characters that all have significant political power, and any effort to enact comprehensive reform overnight ... is likely to run into determined and effective opposition” (p. 289).

***Intraorganizational issues.*** In addition to the external influences on the policy process, the actions of DDPAAs are impacted by their organizational context (Hasenfeld & Brock, 1991). Implementation of a new service delivery model is a difficult process, and confusion or difficulties in administration can lead to delays, resistance to self-directed options, or deviations from state policy (Schmitz et al., 2005). DDPAAs have identified a lack of clear policies, leadership, and training opportunities as important factors in confusion about or opposition to self-direction (Hall-Lande et al., 2012). The confusion created by inconsistent administrative guidance and support has been shown to create disparities in the size and quality of self-directed options between counties (Hall-Lande et al., 2012). Administrators identify the following as influential in program administration: previous experience with Medicaid waivers, realistic implementation plans, commitment of senior leadership, and clarity in communication with local staff (Mahoney et al., 2007; Schmitz et al., 2005). Although resistance from within the DDPA’s own agency or department was not identified as a major issue (Infield, 2005), support from lower administrators and front-line service workers has been shown to significantly impact the



implementation of self-direction, particularly in states with a decentralized approach to service delivery (Sciegaj et al., 2008). Although local administrators may agree with the theory and philosophy of self-direction, DDPAAs need to commit significant technological, administrative, and financial resources to the new program, include local administrators in program planning and design, and provide instrumental support when questions arise (Sciegaj et al., 2008; Simon-Rusinowitz et al., 2014).

In addition to hierarchical coordination, the experience gained through existing or previous self-directed programs significantly impacts the actions of DDPAAs. States that participated in Robert Wood Johnson's Self-Determination Grants, Cash and Counseling, and other self-direction initiatives were identified by DDPAAs as instrumental in building a successful, permanent self-directed program (Walker et al., 2009). Although knowledge gained in previous programs is valuable, the existing service programs may also act as a barrier to program implementation. State HCBS programs often present a fragmented approach with multiple programs and disparities in access, funding, and services (Kaye, 2014). DDPAAs attempting to revise existing programs or initiate new self-directed programs are necessarily impacted by the existing HCBS offerings in the state.

**Federal Context.** In addition to the myriad state issues that impact implementation of self-directed supports for individuals with IDD, DDPAAs are also impacted by issues on the national level. The federal government has acted to expand access to self-direction, beginning with the creation of HCBS waiver services as part of the Omnibus Budget and Reconciliation Act of 1981. Additionally, the lawsuits settled in federal courts have mandated increased access to HCBS services as well as timely and responsive service provision. Federal issues are particularly important for understanding the implementation of self-direction, as self-direction is

primarily funded through Medicaid waivers overseen by the Centers for Medicare and Medicaid Services (CMS). As part of the executive branch, CMS has prioritized the increased utilization of HCBS and self-direction in particular by state governments serving individuals with IDD. Together, the legal, executive, and legislative context enable DDPA actions in implementing self-direction.

***Litigation.*** DPAs implementing self-direction operate within a contentious historical and legal environment. The landmark 1970 case of *Wyatt v. Stickney* gave legal voice to individuals within state institutions who demanded adequate and appropriate services, and subsequent litigation increasingly focused on the adequacy of state resources in the community (Smith, 2006). The Supreme Court's 1999 *Olmstead* decision expanded Title II of the Americans with Disabilities Act (ADA) to require a state to furnish integrated community-based services for participants who do not require institutional care in a manner consistent with the participant's preference (Smith, 2006; Tritz, 2004). *Olmstead* was a watershed moment in the disability rights movement. Under this new interpretation of the ADA, states were required to place "institutionalized persons with disabilities in community settings when: (a) the state's treating professionals have determined that a community placement is appropriate; (b) the transfer from an institution to a more integrated setting is not opposed by the affected individual; and (c) the placement can be reasonably accommodated, taking into account the resources available to the state along with meeting the needs of other persons" (Smith, 2006, p. 35). The decision spurred further litigation to ensure that people with disabilities had prompt access to community services and reduce the use of institutionalization as an intervention for people with disabilities. As a result of the *Olmstead* decision, administrators operate within an institutional environment in which litigation about HCBS services can lead to significant structural change in

the IDD service delivery system. Moreover, each state is currently required to maintain a plan for how it maintains compliance with the *Olmstead* decision (Kitchener, Wilmott, Wong & Harrington, 2008). DDPAAs have, in part, responded to the requirements for HCBS services through Medicaid waiver programs which provide federal dollars to defray the cost of *Olmstead* mandates (Ng et al., 2015; Tritz, 2004). Self-direction is also consonant with the philosophy and value system undergirding *Olmstead*—that individuals with IDD are capable of living integrated lives in community-based settings (Bogenschutz, 2010)

Disability advocates have continued to litigate based on the *Olmstead* decision to address issues with access to services, adequacy of services, and establishing entitlement to services (Holahan et al., 2002). One branch of lawsuits aims to establish an entitlement within Medicaid to community services on equal footing with institutional services which may greatly expand state obligations (Smith, 2006). Within state programs, litigants in Colorado—*Mandy R. et al. v. Owens et al.*—are seeking to create precedent for establishing sufficient payment rates to field a healthy pool of DSW or other support workers for HCBS participants, as otherwise, they would be forced to reside and receive services in an institution (Smith, 2006). Litigation also addresses state funding priorities, addressing state policies that direct disproportionate money towards institutional settings and away from community services (Smith, 2006). Finally, the last decade saw a large number of lawsuits to address increasingly lengthy waiting lists caused by a lack of available intermediate care facility beds and HCBS waiver slots including *Makin v. Hawaii*, *Fisher v. Oklahoma*, *Boulet v. Cellucci* and *Doe v. Chiles* (Bogenschutz, 2010; Smith, 2006). More information on important *Olmstead*-related rulings can be found in Appendix G.

As states accrete legal obligations through federal and state lawsuits, DDPAAs often expand HCBS services and self-direction in particular to comply with unfavorable decisions

(Braddock, 2004; Smith, 2006). For example, Oregon implemented its self-directed waiver as a result of a settlement agreement reached in the case of *Staley et al. v. Kulongski et al.* (Smith, 2007). *Staley* was a successful lawsuit that challenged Oregon's failure to furnish long-term care services for eligible individuals with IDD in a timely manner. The litigants succeeded in raising the expenditure for HCBS services by \$350 million, mandating services be offered to participants in crisis, and increasing the available slots in HCBS programs on an annual basis.

***Legislative initiatives.*** Similar to the historical roots of IDD litigation, legislation related to self-directed service options dates back to the 1970s and the Intermediate Care Facilities for Individuals with Mental Retardation amendment which provisioned federal reimbursement for services for individuals with IDD (Braddock, 2007). In 1981, this program was expanded by creating the legislative authority for HCBS services through a state-based waiver to traditional Medicaid programming (Braddock, 2007). The flexibility afforded within the new HCBS Medicaid programs granted states the authority to experiment with different models of service delivery. Although this policy environment fostered the development of self-direction, implementation of HCBS services varies significantly between states as a result of the flexibility of Medicaid HCBS waivers. Since its passage, the HCBS waiver program has accelerated the transition away from large institutions towards community settings by allowing states to target specific geographical areas, populations, and medical conditions as well as introduce new services not covered under traditional Medicaid, such as home modifications (Kitchener et al., 2003). Under the Deficit Reduction Act of 2005, states will be able to build these increasingly robust HCBS services into their state plans rather than relying solely on Medicaid waivers which require periodic renewal (Cohen et al., 2007; Mahoney et al., 2007). Taken together, these legislative proposals provide the bedrock for state experimentation with self-direction and HCBS

services. Indeed, a majority of program administrators listed federal initiatives as a significant factor for beginning or expanding self-directed service options (Infield, 2005).

***Executive initiatives.*** In addition to legislative actions, CMS, the Department of Health and Human Services, and other federal executive agencies influence the environment in which DDPAAs act through utilizing funding opportunities to shape state HCBS programs (Kaye, 2014). Beginning with the Self-determination National Projects and the Money Follows the Person demonstration program, the federal government demonstrated a commitment to increasing HCBS services through grant funding of state experimentation (Yuskauskas, 2005; Cohen, Scully, Bockweg, Richardson & Goolsby, 2007). Extended through 2016 as part of the Affordable Care Act, the Money Follows the Person demonstration provides increased federal funding to forty-six states to assist with transitioning individuals out of long-term residential institutions (O'Malley Watts, Musumeci & Reaves, 2013; Kaye, 2014). In addition, the Real Choice Systems Change initiative and New Freedom Initiative provided a foundation of support and administrative competence in building HCBS services (Spillman, Black & Ormond, 2006). Although the New Freedom Initiative has been criticized as insufficiently impactful, it nevertheless raised the profile of self-direction as a service delivery model (Putnam & Frieden, 2014).

The success of federal demonstration projects led to the Independence Plus Initiative, which encouraged all states to use 1115 or 1915c waiver authority to expand self-directed service options in HCBS services, particularly through individual budgeting and employer authority (Spillman et al., 2006; Yuskauskas, 2005). Independence Plus provided technical assistance on key features of self-direction as well as established a set of design elements that state self-directed programs must have to gain CMS approval: “a person-centered planning process, an

individualized budget, fiscal intermediary services, a support broker who serves at the direction of the participant, a quality assurance and quality improvement system, and participant protections such as an emergency back-up system and an incident management system” (Tritz, 2004, p. 15). These features are now included on all Medicaid waiver applications, encouraging states to consider self-direction as an option for participants with IDD. Indeed, state administrators report that federal agencies view self-direction as the “new model of best practice in long-term care” (Infield, 2005, p. xi).

This trend of growing self-direction through federal initiatives is likely to increase after the establishment of the Community First Choice state plan (1915k) as part of the Affordable Care Act (Doty et al., 2012; Ng et al., 2015). The Community First Choice state plan option provides increased funding for states to provide HCBS services to those who would otherwise need an institutional level of care (O’Malley Watts et al., 2013). In addition to funding, states that participate are mandated to include opportunities for self-direction and are able to cover additional services, such as transitional housing costs. At the same time as the Community First Choice option, the expansion of the 1915i state plan option allows states more flexibility to target state plans to specific groups, disabilities, or age groups and allow states to expand eligibility for HCBS services. Additionally, by transitioning existing 1915 and 1115 programs to this new authority, they will no longer be subject to the limitations of waiver or demonstration projects, for example, around services states may potentially offer participants.

***Medicaid administration.*** The Medicaid administrative context deserves special attention, as nearly all self-directed service options are funded through Medicaid waivers. Moreover, Medicaid’s interactions with states have fostered the development and growth of self-direction, and the recent CMS Final Rule on Community Living pushes states to further expand

self-directed programs. Medicaid is an attractive funding option for states, as it allows some of the service cost to be shifted onto the federal government and provides oversight and guidance in program development. The Medicaid waiver program also affords significant flexibility to DDPAAs designing or implementing a self-directed program. Through the use of 1115 or 1915 waiver programs, states are given options in developing HCBS service programs so they may address local needs and reach diverse populations (Cubanski & Kline, 2003; Holahan et al. 2002; Spillman et al., 2006;). Although there is wide variation in HCBS service coverage between states, all states must abide by federal Medicaid regulations, most significantly that all services must be based on a participant's individual plan of care (Moseley, 2005; Yuskas, 2005).

Despite the structure and flexibility offered by Medicaid, many program administrators report that “federal rules and regulations are seen as barriers to implementation and expansion” of self-direction (Infield, 2005, p. x). In particular, the approval process for waivers and waiver amendments were identified as excessively long, and confusion over fiscal intermediaries and employers of record persist even in states that participated in the “Cash and Counseling” demonstration projects (Infield, 2005). Given that Medicaid structures the environment for almost all self-directed service options, the actions of DDPAAs occur in a context of uncertainty and inconsistent support.

### **Summary of Theoretical Frame of Analysis: Hasenfeld & Brock's Political Economy Model of Implementation**

Hasenfeld and Brock's (1991) model of policy implementation uses an iterative approach to understand how policies are created, formed, and reformed by individuals and driving forces in the political arena. They theorize six components of policy implementation—policymaking,

policy instruments, critical actors, driving forces, service delivery system, and policy output—which mutually inform one another as a policy moves from the legislature, to administrators, to street-level bureaucrats. The greater the degree of cooperation and mutual accommodation within the system, the more likely that the policy output will correspond to participant needs in the community. This analysis will seek to understand how each state’s policy components impact the service delivery system that implements self-directed supports. By drawing connections from the service delivery system up through previous components in the model, the present investigation will illuminate the feedback loops that are salient to DDPAs in administering self-direction.

### **Research Questions**

Aim 1: Assess the utility of Hasenfeld & Brock’s Political Economy Model of Implementation.

RQ1: To what extent are the components and relationships proposed by Hasenfeld and Brock found in the responses of DDPAs?

RQ2: What new components and relationships are important to DDPAs in administering self-direction?

Aim 2: Describe the enacting of self-direction by DDPAs.

RQ1: (exploratory): For DDPAs, what are the important features of service delivery systems implementing self-direction?

RQ2: In what ways do these features reinforce or challenge the literature on best practices in self-direction, specifically limitations on budget and employer authority?



Aim 3: Describe the institutional forces, program features, and critical actors that influence DDPA's in the process of administering self-directed service options.

RQ1: What do DDPA's describe as the salient forces impacting implementation of self-direction?

RQ2: What effect do these forces have on the service delivery system implementing self-direction?

Aim 4: Describe DDPA perspectives on policy output and the degree to which participant needs are being met by self-directed programs.

RQ1: What concepts are important for DDPA's in assessing success in self-directed programs?

RQ2: What innovations would DDPA's propose to improve policy output?

## **Chapter 2: Empirical and Theoretical Literature Review**

### **Outcomes in Self-Directed Programs**

The following section will review the major outcomes associated with participating in self-direction for individuals with IDD and their families. A special case of when family members provide paid support work will also be considered. Although the evidence presented in favor of self-direction as a service delivery model is strong, it is important to emphasize that self-direction is not available to all individuals and families with IDD. While forty-one states provide self-direction in some form to individuals with IDD, individuals may be excluded due to income eligibility requirements or lengthy waiting lists for HCBS enrollment that total over 400,000 people nationwide (Ng, Harrington, Musumeci & Reaves, 2015). For individuals with IDD applying for any Medicaid waiver, including those that offer self-direction, the average length of time on the waiting list is just under four years (Ng et al., 2015). The studies reviewed below represent both pilot programs within states as well as the large-scale “Cash and Counseling” demonstration projects that included participants with IDD. As self-direction continues to expand availability, newer studies probing outcomes for participants and families may present a more complex and nuanced picture of how these programs impact people with disabilities.

**Outcomes for participants.** Self-direction, as a model of human services delivery, has built a significant body of evidence over the past few decades for its positive impact on participants and families. The most significant finding through the years has been the increase in satisfaction with services that accompanies participation in self-direction. The “Cash and Counseling” demonstration projects, a large-scale trial by the Robert Wood Johnson (RWJ) Foundation, found that participants regardless of state or age reported higher satisfaction with the

paid care they received as well as their relationship to the paid caregiver (Carlson, Foster, Dale & Brown, 2007). Although “Cash and Counseling” demonstrations were mainly focused on individuals of advanced age, the results from these projects are an important part of the self-direction literature. Increases in satisfaction also accompany other program components including fiscal intermediary, education and counseling on employment and budget issues, flexibility of caregiver schedules, and ability or authority to control services (Beatty, Richmond, Tepper & DeJong, 1998; Foster, Brown, Carlson, Phillips & Schore, 2002; Foster, Brown, Carlson, Phillips & Schore, 2003; Mirza & Hammel, 2009; Schore, Foster & Phillips, 2007; Young & Sikma, 2003). Although increased satisfaction is a common outcome in self-direction, it remains a problematic construct to measure for individuals with IDD. Many of the studies above provided satisfaction information from self-direction participants who have other long-term care needs or belonged to other long-term care populations, such as elderly participants or individuals with physical disabilities. Additionally, individual studies of self-direction often use unstandardized measures of satisfaction and proxy response by caregivers or family members which makes any generalizations problematic (Copeland, Luckasson & Shauger, 2014).

Satisfaction is intrinsically linked with the quality of supports, and national measures of quality often incorporate measures of satisfaction in a more systematic manner. The National Core Indicators (NCI) project, which tracks outcomes for individuals with IDD in thirty-nine states, uses a five element test of quality and satisfaction. NCI measures quality as the proportion of participants who want to live in their current location, make choices about their everyday lives, are provided options about their daily activities, participate in integrated community activities, and have a job in the community (Musumeci, 2015). An alternative approach is offered by the Council on Quality and Leadership (CQL) and the Personal Outcome

Measures assessment tool (CQL, n.d.). The CQL assessment tool uses a person-centered approach to understanding the quality of services, assessing the degree to which people are: connected to natural supports and intimate relationships, safe, in good health, able to exercise rights, fairly treated, free of abuse and neglect, able to experience continuity and security, and able to decide when to share personal information. These elements are part of the personal domain, that which governs the self and close relationships. The next domain level assesses community integration asking if participants choose where and with whom they live, choose where they work, use their environments, live in integrated environments, interact with other community members, perform different social roles, and choose services. Finally, the dreams domain asks about the participant's future orientation including choice of personal goals, realization of personal goals, community life and participation, friendships, and respect. For both the NCI and CQL measures, satisfaction is subsumed under the heading of quality and the outcomes from standardized measures of quality further supports the finding in more limited surveys of individual programs that self-direction increases participant satisfaction (Human Services Research Institute, 2015).

At minimum, self-directed services are designed to provide individuals with greater choice, control, and self-determination. The impetus behind employer authority in self-direction was to increase the ability of participants to dismiss DSWs if they were providing unsatisfactory services. Results from the “Cash and Counseling” demonstration project provide significant evidence that self-direction participants were able to choose their own workers, manage them, and in some cases even fire them if they were providing unsatisfactory services—including relatives providing paid support (Foster et al., 2003). Most participants reported that they were able to receive the unique supports they required which in turn fostered better helping

relationships (Foster, Brown, Phillips & Carlson, 2005). Other demonstration projects, such as those in Washington state, found that participants experienced “improved autonomy, self-determination, and choice” through participation in the self-direction (Neely-Barnes, Marcenko & Weber, 2008; Young & Sikma, 2003, p. 188). Across programs, participants understood their engagement with the process of self-direction as an opportunity for greater independence and control in their lives (Hewitt, Agosta, Heller, Williams & Reinke, 2013; Mahoney, Simon-Rusinowitz, Loughlin, Desmond & Squillace, 2004).

Self-direction is also successful at keeping participants in their own homes, close to family members and their community. Across multiple studies, individuals using self-direction are found to be less likely to require out-of-home placement at an institution or nursing home (Heller & Caldwell, 2005; Young & Sikma, 2003). For those that do require nursing home placement, discharge may occur more quickly because of their self-directed care arrangements (Young & Sikma, 2003). Through the provision of services in the home that can be controlled by the individual and their family, caregiver stress and burden is reduced, allowing participants to stay in the community for as long as possible (Schore et al., 2007). Participants who live at home, even those with severe disabilities, report higher rates of community involvement, such as attending clubs and community events, that is sustained over time (Caldwell & Heller, 2003; Caldwell & Heller, 2007; Gross et al., 2013; Neely-Barnes et al., 2008).

Increases in satisfaction, community inclusion, and self-determination are natural outgrowths of the flexible and supportive structure of the self-directed model. Case studies from the “Cash and Counseling” demonstration project relate how participants are able to customize a plan of care with goods and services to suit their unique needs (San Antonio et al., 2007; Foster et al., 2002). Participant authority over services also empowers participants in their

communication and coordination with DSWs to provide feedback, with “good care” being a process that develops through communication between equals (San Antonio et al., 2007). Within this newly empowered relationship, workers were described as developing expertise with care recipients and satisfaction with services increased (San Antonio et al., 2007). Other studies of “Cash and Counseling” states showed that self-direction produced more positive care experiences, punctuality and reliability, and higher ratings for quality of care accompanied by a significant reduction in poor performance ratings or incomplete care tasks (Carlson et al., 2007; Foster et al., 2003). Participants in self-directed programs related being grateful for more reliable support workers, as many recalled stories of agency workers who did not complete necessary care tasks during visits and would sometimes miss appointments (Foster et al., 2003). Other studies of self-direction report fewer reported instances of neglect, disrespectful interactions, abuse, fraud, and theft by paid caregivers (Carlson et al., 2007; Schore et al., 2007).

Participants using self-direction also report fewer unmet needs as a result of their enrollment (Foster et al., 2003; Carlson et al., 2007). With “Cash and Counseling” states, some of the reduction in unmet need was due to self-directed participants actually receiving services while the control group was still waiting for services to begin (Carlson et al., 2007). However, other “Cash and Counseling” studies indicate that the reduction in unmet needs was a result of obtaining higher quality care, necessary care supplies, and more flexible and responsive care (Foster et al., 2002). Participants in self-direction reported the greatest decrease in unmet need for social/recreational services, vocational services, dental care, and advocacy (Caldwell & Heller, 2007). Self-direction has also been shown to increase self-reported participant performance towards treatment goals, even in aging disabled populations whose performance level is usually stable at later stages of human development (Mirza & Hammel, 2009).

Accompanying the reductions in need, self-direction participants also report positive physical and mental health outcomes. Participants report better medication management, oral health, dietary health, and general health status as well as fewer reported health problems and disability-related adverse events (Carlson et al., 2007; Foster et al., 2003; Gross et al., 2013; Young & Sikma, 2003). Successes in physical health are also demonstrated by decreased rates of hospitalization and institutional long-term care and greater use of ambulatory care services (Fox & Kim, 2004). Respondents with severe IDD were observed as having an increase in overall happiness and a reduction in challenging behaviors (Gross et al., 2013). Overall, participants reported higher rates of life satisfaction as a result of their participation in self-direction, with most saying it improved their lives a “great deal” (Foster et al., 2002; Schore et al., 2007, p. 446).

**Outcomes for families.** Intellectual and developmental disabilities not only impact participants but the entire family system. One of the most important goals of the self-directed services model is to produce better outcomes for families than traditional agency-directed care. Most studies of families find very high satisfaction with self-directed services as a whole (e.g. Caldwell & Heller, 2003; Foster et al., 2005) as well as satisfaction with particular program features such as care provided, relationship with care worker, scheduling, and household tasks performed by caregiver (Simon-Rusinowitz et al., 2005). The substantial satisfaction with the program is likely the result of greater flexibility and control which allows families to select and supervise someone who meaningfully cares for their care recipient.

Families transitioning from agency-directed services to self-directed services describe the empowering experience of transitioning from a large agency offering only one type of program to figuring out and adjusting an individual plan of care to fit the exact needs of the participant

(Gross et al., 2013; Vinton, 2010). Instead of seeking approval for each decision from provider agencies, case managers, and state administrators, parents report an experience of engaging with these individuals only when needed (Vinton, 2010). As needs or preferences of participants change, whether gradually or in emergency situations, families can adapt by adjusting the type or level of support offered (Gross et al., 2013). Similarly, as family members' abilities and preferences change over time, for example due to health problems, they report self-direction allowed them to have a "Plan B" and "peace of mind" knowing they could shape services to meet new challenges (Vinton, 2010, p. 220-221).

Akin to flexibility and customization, families of individuals also report that control over self-directed budgets and paid workers was instrumental in their satisfaction with the program (Gross et al., 2013). Families emphasize that it is not only the greater choice, control, and access to needed services that is important but how those activities are performed. In self-direction, families report paid support workers are more responsive to the care recipient's needs and listen to their wants and desires ((Timberlake, Leutz, Warfield & Chiri, 2013). Parents describe the setting of direct support work services in particular as intimate, as it is provided in the home, making interpersonal characteristics between family and worker more important (Timberlake et al., 2013). As one parent explained, "I offered it [direct support position] to the ladies from the preschool... I trust them because they know the boys...it made me feel more like a mom versus services from the school where they dictate" (Timberlake et al., 2013, p. 909). Working with an individual with disabilities, for family members, requires someone who would build a relationship with the individual and family unit (Gross et al., 2013).

The ability to select support workers who truly care for their loved one is a vital component of self-direction. Many families report experiences with agency-directed support



workers who were incompetent and unreliable, and families used self-direction to hire family members, friends, or paid caregivers who viewed care as “more than just a job” (Gross et al., 2013 p. 94). Many families choose individuals who have long-standing professional or personal relationships with participants, who display personality traits and attitudes congruent with parent expectations, and who know how to connect with and help their children (Bogenschutz et al., 2010; Gross et al., 2013; Timerlake et al., 2013). For families who are not well-informed about the professional dimension of support work, they felt competent to assess the interpersonal dynamics between DSW and participant which improved in self-directed services (Foster et al., 2005; Timberlake et al., 2013). As a result of the DSW selection process, families reported greater self-efficacy in employee management and significantly less turnover of staff members (Timerlake et al., 2013; Gross et al., 2013).

**Outcomes for families when relatives or friends provide paid support.** In some states, self-direction allows for family members who control individual budgets to employ themselves, close relatives, or friends for a limited number of hours. Many empirical studies have sought to understand how the use of family support workers, friend support workers, and agency-based support workers create different outcomes within self-directed programs. The effect of hiring family and friends on participant satisfaction with care is usually positive (Bogenschutz et al., 2010; Hewitt et al., 2013; Simon-Rusinowitz, Mahoney, Loughlin & Sadler, 2005). In particular, participants reported greater satisfaction with interpersonal dynamics, choice and control, feeling secure with support provider, not feeling at risk, and overall quality of care (Matthias & Benjamin, 2008). These subjective feelings of well-being are buttressed by reports of positive health outcomes for participants, including fewer respiratory infections, sores, and falls with paid family support workers (Heller, Arnold, McBride & Factor, 2012b; Simon-Rusinowitz et al.,

2005). Participants also report receiving more support, particularly during non-traditional hours and more stability in services as a result of hiring family members (Foster et al., 2005; Matthias & Benjamin, 2008; Simon-Rusinowitz et al., 2005). With participants reporting less unmet personal support needs as a result of hiring family members or friends, self-direction provides families of individuals with disabilities options to improve participant and family functioning (Simon-Rusinowitz et al., 2005).

In addition to positive outcomes for participants, using family or friends to provide paid support is also associated with benefits for the family system. Families who utilize this option report greater feelings of self-efficacy and self-determination in managing services for the care recipient (Heller et al., 2012a). Low-income families reported that the ability to get paid for limited hours of care was essential to the family by providing an additional source of income (Heller et al., 2012b). Mental health of family members was reported to be the highest when family or friends provided services and least when agency-affiliated staff provided services (Heller et al., 2012a). Family members who provided paid care themselves reported less emotional strain, better physical health, greater life satisfaction, and improved caregiving relationships with participants (Foster et al., 2005).

## **Introduction to Theoretical Literature Review**

Building on the empirical support for self-direction, this section will provide a theoretical approach to understanding how self-direction functions and how its implementation can be studied. Self-determination theory explores the ecological systems that empower individuals with disabilities to express their desires and make choices about areas of their lives they consider important (Abery & Stancliffe, 2003). Hasenfeld and Brock's (1991) political economy model

of implementation seeks to understand how the service delivery system in self-direction is impacted by driving forces, critical actors, and policy instruments during implementation. Together, both theories illuminate how ideas around self-direction are formed into concrete service delivery systems by DDPAs.

## **Self-Determination Theory**

**History of self-determination theory.** Self-determination theory is an outgrowth of previous philosophical inquiry in the disabilities literature, beginning with the principle of normalization. Nirje's (1969) classic article on the normalization principle advocates for service delivery systems that bring everyday life for individuals with disabilities as close as possible to the routines and patterns of individuals without disabilities throughout the lifespan. Normalization accompanied and arguably drove the increasing push for deinstitutionalization for individuals with disabilities, particularly those diagnosed with IDD, and for community-based alternatives for services (Bogenschutz, 2010). Although normalization is critiqued on the grounds that it privileges the dominant culture in establishing what an individual's life should look like, Nirje's conception of normalization explicitly addresses the need for disability services to honor the self-determination of individuals by allowing them greater control over their supports (Culham, 2003; Nirje, 1969).

Normalization was also critiqued and reformulated by Wolfensberger (1983) into social role valorization, which focuses on individuals with disabilities occupying socially valued roles in society. Social role valorization focuses its efforts on changing how society understands individuals with disabilities and providing opportunities for individuals to fulfill roles that confer positive things from other people (Wolfensberger, 2002). Though Wolfensberger (2002; 2011)

critiques the ideas of self-determination as a “power ideology,” self-determination theory has significantly benefitted from the theory’s focus on changing the perceptions of disability and furthering the discussion on accommodation and inclusion for individuals with disabilities (Bogenschutz, 2010).

**Defining self-determination.** Building on philosophies that drove the historical shift in service delivery from large, secluded institutions to independent living, self-determination theory provided the intellectual ammunition for reforming how individuals with disabilities receive services and supports. Self-determination marks a conceptual break from models of service delivery that focus on changing or reforming the individual to work within a system and towards models that promote systemic changes to accommodate and adapt to diversity in participant needs (Dinora, 2008). This evolution in service delivery brought about the policy innovations integral to the self-directed model of care.

Within self-determination theory, there are many different definitions of the concept of self-determination. Indeed, a major criticism of self-determination theory is its lack of clear, consistent definitions (Simpson, 1996). The mainline of self-determination theory proposes that self-determination is a “characteristic, quality, trait, or...dispositional characteristic” of an individual (Wehmeyer, 2005, p. 114). Earlier formulations of self-determination theory focused on the degree to which actions incorporated four essential characteristics: autonomy, self-regulation, psychological empowerment, and self-realization (Wehmeyer, Kelchner & Richards, 1996). To classify a person as acting autonomously, they must be the “primary causal agent” in their life, “free from undue external influence or interference” (Wehmeyer et al., 1996, p. 24). A self-determined individual is one who reflectively takes in information about their environment and incorporates it into their actions through self-regulation.

The addition of human action is conceptually significant as it distinguishes self-determination as a dispositional trait from self-determined behavior—or actions that flow from an individual's sense of self-determination. By engaging in self-determined behavior, individuals perceive they can influence their environment and engage in behaviors that will result in outcomes that are valuable to the individual, i.e. psychological empowerment. Wehmeyer (1999) elaborates that self-determination is not merely the ability to engage in decision-making, control, or goal-setting but is intertwined with the desire to actively engage in a personally meaningful life or self-realization. Thus, while self-direction does allow for self-determined behavior to occur, the true nature of self-determination is much deeper and reflects the dreams and hopes of an individual, rather than just simple decision-making.

Although this more action-oriented definition helps to elucidate what classifies an action as self-determined, it remains challenging to ascertain from afar whether or not an individual's actions are to a degree self-determined. An unknowing observer may perceive an individual who decides to cede decision-making authority to a parent, guardian, or representative to be less self-determined than another who makes those decisions independently. Ecological self-determination theory builds on Wehmeyer's conceptualization and clarifies that to act in a self-determined manner, an individual exercises the degree of control they desire to the extent it is important for them to do so for all aspects of their life (Abery & Stancliffe, 2003). On a spectrum from total control to no control, the desired level of control is usually in the middle of that continuum; furthermore, with a focus on interdependence rather than autonomy, ecological self-determination theory attends to how social context enables or constrains decision-making and control (Abery & Stancliffe, 2003). In this way, both individuals who make nearly every decision for themselves and those who choose to have others make decisions for them can

embody the characteristic of self-determination—provided that their level of control is aligned with their desires and preferences. This conceptual definition accords well with participants' definitions of self-determination which rested on speaking out about their wants and intentions as well as being in charge of making decisions for themselves (Nonnemacher & Bambara, 2011).

Self-determined behavior, and self-determination theory, is necessarily ecological and social in orientation. Individual competencies and characteristics shape the degree to which an individual can engage in self-determined behavior—including skills such as goal setting and decision-making, knowledge of resources and self, and attitudes such as self-confidence and determination—among many others (Abery & Stancliffe, 2003). These personal characteristics only have the ability to express themselves through self-determined behavior if their environment provides opportunities to do so. Within the microsphere, Abery and Stancliffe (2003) argue that self-determination is impacted by basic needs, respect and acceptance, opportunities for self-determination, positive reinforcement for exercising self-determination, participation and inclusion, role models, and individualized supports. This philosophical analysis is supported by the experiences of participants who describe how support staff impede self-determination by making decisions for them, controlling spending money, being unapproachable, not following through with plans, or vetoing their decisions; additionally, participants state that support staff encourage self-determination by presenting options for choice-making, making themselves or supervisors accessible, building supportive helping relationships, listening and respecting their decisions, and providing needed assistance once their decision had been reached (Nonnemacher & Bambara, 2011). Additionally, self-determination has been found to be higher in individuals who live and work in independent, community-based, nonsegregated environments which self-direction is designed to facilitate (Nonnemacher &

Bambara, 2011; Stancliffe, Abery & Smith, 2000). These environments, unfortunately, are not available to all individuals with disabilities and the degree to which self-determination is integrated and supported within support services—including vocational, residential, and personal care—varies significantly (Walker et al., 2011).

**Self-determination theory and self-direction.** The integration of self-determination on the microsphere level has led to a number of clinical innovations in working with individuals with disabilities that are not the focus of this analysis; however, the integration of self-determination theory in the exosphere has transformed human services delivery models and created the policy innovations that underlie the self-directed model of care. Nerney and Shumway (1996) highlight several value propositions within self-determination theory that impacted the transition to self-directed models of care including: the freedom to plan with family and/or friends a life with necessary support, the authority to control the budgeting and purchasing of supports, the arranging of resources and personnel that provide assistive services, the responsibility of accounting for spending of service dollars, and participation in the development and implementation of self-determination policies. These propositions underscore that self-determination on an individual scale is only meaningful when an individual's environment provides supportive opportunities to engage in self-determined behavior.

Beginning with the first Robert Wood Johnson Foundation Self-Determination grant projects, implementing self-determination on an exosystem level required the creation of new policy innovations including individual budgeting, support brokerage, and fiscal intermediaries as well as the integration of person-centered planning, a previously existing policy innovation (Moseley, 2001; Turnbull & Turnbull, 2006). Together these innovations made concrete the recommendations of self-advocates for greater opportunities to make important choices, define

their own needs and preferences, choose from a wider range of service options, control their own services budget, and experience greater satisfaction with services (Turnbull & Turnbull, 2006).

In both agency-directed and self-directed HCBS services, an individual is provided with a services budget based on an assessment of their level of need for a given fiscal year. Whereas in agency-directed models, individuals engage in relationships with service providers based on the state's assessment of their needs and goals, self-direction uses budget authority to grant the individual with disabilities control over which service providers will be selected, whether to allocate money towards one service or another, and how much money to spend on a given service. In this way, budget authority facilitates the ability of the participant to determine the role a service provider will play in their life (Turnbull & Turnbull, 2006). Individuals with disabilities may decide to exert a higher or lower degree of control over their budget—some may even designate a representative to make some decisions for them—all of which are consistent with Abery and Stancliffe's (2003) model of self-determination emphasizing the individual's desired degree of control in important areas of a person's life.

Budget authority necessitates the creation of a number of new “planning, operating, and financial structures” to support an individual's budgeting authority (Turnbull & Turnbull, 2006, p. 3). Foremost among these is the person-centered planning process in which the individual is prompted through equitable, respectful, and constructive dialogue to reflect on what community opportunities will enrich their life (O'Brien & Lovett, 1992). Based on the individual's experiences in the pursuit of their life goals, the person-centered planning process serves as a reflection point so new community opportunities can be opened. Person-centered planning emerged in opposition to traditional approaches to disability service delivery, which advocates critiqued as insufficiently respectful of the person with a disability and not focused to fostering



change within the community. The results of the person-centered planning process are then formalized into a plan of care that encompasses the services, goods, and supports necessary to meet an individual's goals (Obrien & Lovett, 1992; Powers, 2005). The person-centered plan, while not synonymous with self-determination, is its best evidentiary depiction as it documents the aspirations and experiences of an individual across time, the community context in which it occurs, and their service needs, preferences, and existing supports.

The service plan that emerges as part of the person-centered planning process is created with the assistance of a support broker, an agent employed by the individual who assists them with gathering information about supports. The support broker also acts as a liaison between the individual, service providers, and the state government department funding the program. In providing the instrumental knowledge in the service planning process, service brokers facilitate the process of self-determination and help individuals to articulate their desires in a formal manner. Because the support broker is an employee of the individual, individuals who are dissatisfied with their service may choose to employ other support brokers.

The final policy innovation necessitated by budget authority is the fiscal intermediary, an independent accounting entity that assists individuals in complying with labor laws as employers—withholding taxes and ensuring accountability of funds for state governments. As individuals in early self-direction programs often complained of the employer paperwork required to engage in self-determination (San Antonio et al., 2007), fiscal intermediaries represent a response to this demand by allowing individuals to exercise authority over the parts of the employer relationship they deemed to be important—managing, hiring, dismissing, training—and grant other aspects such as tax and labor law compliance to someone else. The management of support workers as an employer, termed employer authority in self-direction,

provides another opportunity to exercise self-determination, as individuals are able to choose from an array of service agencies and/or independent providers as well as recruit family members or friends as support workers. By removing barriers to exiting an unsatisfactory care relationship with a provider and widening the available pool of potential support workers, employer authority encourages self-determined behavior.

Although each of the policy innovations in self-direction—individual budgeting, person-centered planning, support brokerage, fiscal intermediaries, and employer authority—provides ecological accommodation for individuals with disabilities to engage in self-determined behavior, self-direction and self-determination are not synonymous. Many self-determination theorists, scholars, and advocates (e.g. Powers, 2005; Nerney, 2005; Wehmeyer, 2005) express frustration with the conflation of the two terms, as practitioners working with individuals with disabilities may refer to implementing self-direction or its components as engaging in self-determination. As the National Resource Center for Participant-Directed Services states:

Self-determination is a grass roots movement for individuals with disabilities, which promotes independence in the community, authority over public resources, supports that are life-enhancing and meaningful, responsibility to ensure resources are expended wisely, and confirmation of participants' role as self-advocates. The use of the term is much broader than self-direction and refers to an approach to manage all aspects of their lives, not just their services (Crisp et al., 2010)

### **Hasenfeld & Brock's (1991) Political Economy Model of Implementation**

The following section of the paper will present Hasenfeld and Brock's (1991) Political Economy Model of Implementation as a theoretical frame of analysis for understanding the

administration of self-directed supports by DDPA's. At its core, the Hasenfeld and Brock model takes an iterative understanding of policy implementation that emphasizes the reciprocal relationships throughout an administrative system that create and reformulate policies over time. Each of the six components—policymaking, policy instruments, critical actors, driving forces, service delivery system, and policy output—affects one another in a linear fashion, yet there are feedback loops that link back to chronologically prior components as well as with the general socio-political environment. These relationships are depicted in Appendix A.

The Hasenfeld and Brock model is particularly appropriate to the research questions in the present investigation. In the terminology of this theoretical model, the focus of the analysis will be the service delivery system. Aim 2 and its attendant questions raise issues of how DDPA's conceptualize self-direction as a service delivery system. How do DDPA's conceptualize the technical core of self-direction—the policy components that provide the mechanism by which participants and administrators enact self-direction? How does the DDPA's conceptualization impact the interorganizational network and control/monitoring mechanisms within the service delivery system? These are the questions that Hasenfeld and Brock's model provide theoretical context for interpreting. Moreover, Aim 3 and its attendant questions seek to develop conceptual links from the service delivery system explored in Aim 2 to other implementation domains—specifically the policymaking, policy instruments, critical actors, and driving forces. Hasenfeld and Brock term these conceptual links feedback loops, and they provide a theoretical structure for understanding each implementation domain and their interrelationships.

In the original Hasenfeld and Brock model, the dependent variable is the policy output—specifically the degree to which a program meets participant need and is accessible to all who

need it, also known as the correspondence index. Because of the limitations in the data used in this study, there is little information related to participant outcomes that would inform an assessment of the correspondence index. However, the concept of the policy output significantly impacts the actions of the DDPAs as they implement self-direction. Aim 4 and its sub-questions address how DDPAs conceptualize the policy output and how their conceptualization impacts their choices as they implement self-direction. Finally, Aim 1 seeks to critically engage with Hasenfeld and Brock's theory using the deductive content analysis method which seeks to verify, revise, or extend the model's theoretical classifications. Through the use of the Hasenfeld and Brock model, this investigation will address the utility of the theory in understanding the actions of the DDPAs as well as suggest new concepts and relationships to be used in future studies of program implementation.

### **Six components of Hasenfeld & Brock's model.**

***Policymaking.*** The first component in the Political Economy Model is policymaking. Hasenfeld and Brock's model of policymaking is adapted largely from Cohen, March and Olsen's (1972) garbage can model of organizational choice, which understands organizational decision-making as an organized anarchy, as well as Kingdon's (1984) adaptation which proposes three policy streams in policymaking—problems, solutions, and the political environment. Both models describe policymaking as a contentious process containing pre-existing problems and solutions without any coherent organization. The organizational structure of the legislature can negatively or positively impact policy entrepreneurs by affecting the timing of when problems, solutions, and choice opportunities arise (Cohen et al., 1972). Policymaking is enacted by policy entrepreneurs who invest personal resources to take problems that are loosely connected or entirely independent of solutions and join them together into a policy that

will pass the legislature in the existing political environment (Kingdon, 1984). Of particular importance to Hasenfeld and Brock is the influence of political conflict which can create unstable or incoherent policies (Ryan, 1995). As a result, Hasenfeld and Brock's model emphasizes the importance of stability in the political environment in creating a coherent and clear policy with adequate resources.

***Policy instruments.*** The policy that emerges from the policymaking component is broken down into three policy instruments—authority, program design, and resources. Authority refers to the power of the department administering the program to elicit compliance via their legal authority. A clear and consistent program design, the second component, will provide specifications on target populations, needs to be addressed, and services to be provided by the department. Hasenfeld and Brock base this subdomain on the work of Sabatier and Maxamania (1979). Sabatier and Maxamania sought to understand how programs can achieve their objectives. Well-designed programs specify an end-state for the target group and the means by which compliance can be attained. The program design rests on a statute that ranks objectives and provides financial resources for implementation. Program objectives may include regulations, plans, or projects that are at a greater degree of specificity than policy, which contains broader goals (Alexander, 1985). Hasenfeld and Brock expand this notion of resources to include personnel, expertise, skills, facilities, and inducements/incentives that support the department implementing the program. These resources, similar to Sabatier and Maxamania, will attract stakeholders by offering resources in exchange for partnership in the interorganizational network implementing the policy. Policies that lack resources or have unstable resources incentivize agencies to minimize their interaction with the program.

**Critical actors.** Policy instruments have unique effects on different critical actors in the political field. All three policy instruments impact the implementing department, as its behavior is circumscribed and enabled by the authority, design, and resources provided by the legislature. Hasenfeld and Brock emphasize the importance of centralized control, hierarchical structure, and consensus within the implementing department. A diffuse internal structure beset with conflict between dominant and non-dominant coalitions creates coordination problems during implementation, and lower-level bureaucrats will be less able to achieve fidelity to program design. Additionally, key resources such as skills and expertise are important for the implementing department in creating a coherent service delivery system. Stakeholders are the other set of critical actors highlighted by Hasenfeld and Brock's model. The relative position of the stakeholders to the implementing agency is impacted by the commodities that each stakeholder controls, the number of stakeholders, and the degree to which stakeholders are organized in their efforts. The bargaining power of stakeholders is increased when they are organized in their efforts to define problems, control solutions, or advocate against disfavored policies. Stakeholders with unaligned interests complicate the implementation process for the implementing department, as negotiations and bargaining decrease the technical rationality and coherence of a policy. Both the implementing agency and stakeholders determine how a policy will be implemented and the greater the degree of cooperation between these actors, the more coherent and effective a policy will be.

**Driving forces.** Hasenfeld and Brock identify three driving forces that affect policy implementation throughout the lifespan of a policy—technological core, economic considerations, and power relations. The authors argue that these driving forces are so powerful that when each is met perfectly, the question of implementation becomes a non-issue—the policy

will implement itself. Technological specifications have their origin in the policymaking process but are augmented and reconfigured by the implementing department. The department should, according to the theory, be specific in how program components will be assembled. By creating a uniform implementation system, implementation will remain robust against the ideological, fiscal, and policy considerations of lower-level administrators as well as the lobbying of interest groups and outside stakeholders (Browning, Marshall & Tabb, 1980). This is referred to in the implementation literature as strong statute or statutory coherence. Hasenfeld and Brock reconfigure many of the elements of statutory coherence into other parts of the implementation model but single out the theory of change as a key concept for technological specifications. The theory of change specifies how each component should be arranged, and its coherence is impacted by funding as well as conflict or support among critical actors (McFarlane, 1989).

In addition to the technical core, implementation is driven by economic considerations—namely, cost. The availability of resources and the elasticity of supply and demand of goods and services needed by the program can create imbalances of power should one stakeholder control necessary resources whose demand or supply is inelastic. Additionally, there are production costs, opportunity costs, and transaction costs in implementing a program that can be minimized through effective coordination in the administering department. The role of the implementing department is key, as centralized control over decision making minimizes transaction costs (Calista, 1987). When implementing departments can control information, create confidence through hierarchy, and an orderly appearance of work relationships, the costs of implementation will decrease.

Economic considerations determine, in part, the power relations within policy implementation. Power is defined using Astley and Sachdeva's (1984) definition of the capacity

of actors to overcome resistance of other actors based on their unique objectives. The critical actors—stakeholders and the implementing department—engage in bargaining based on their particular values and interests. Power can be concentrated within the implementing department by instantiating hierarchical authority, control over resources, and network centrality. Given the department's goals of rational administration and monitoring, the concentration of power in the implementing department will likely lead to better outcomes for participants. However, implementation usually requires the use of an interorganizational network to achieve outcomes (Benson, 1975). Stakeholders also act to monopolize critical resources and seek to reorganize the interorganizational network and place themselves at the center. For both stakeholders and the implementing department, power is gained through competition, bargaining, and coalition-building. Control over resources is deemed by Hasenfeld and Brock to be equally as important as the availability of resources (Ryan, 1996). Ultimately, power relations will reach an equilibrium when consensus is reached about the role and scope of the implementing agency, the appropriate approaches to implementation tasks, positive evaluation of other critical actors, and coordination of work effort (Benson, 1975). This process mirrors the description of Lindblom (1965) on partisan mutual adjustment in which coordination emerges without rules that specify the relations between individuals.

***Service delivery system.*** The three driving forces—technological, economic, and power relations—shape the service delivery system created in policy implementation. That is, the greater the degree of technological certainty, economic stability, and power concentration within the administering department, the stronger the technical core, interorganizational network, and control or monitoring mechanisms will be. The technical core of the service delivery system refers to the program component that directly achieves client outcomes and is impacted by the



driving forces. Hasenfeld (1983) specifies five types of technology that are part of the technical core—those that govern client attributes, intervention techniques, interaction patterns, client control, and staff operations. Additionally, relationships between stakeholders create an interorganizational network whose coordination and cooperation impacts program implementation. The relationships between components in the interorganizational network are subject to the forces of power relations and may fall into disequilibrium or imbalance (Benson, 1975). The flow of resources, power, and autonomy throughout the network impacts how each component will interact with the next. Finally, the control mechanisms imposed on the intraorganizational network and technical core can be broken down into structure, process, and outcome measures. These measures gauge how effective the program is at achieving its outcomes. Moreover, the salience of each of the measures of control is affected by the driving forces, particularly technological or economic uncertainty.

***Policy output.*** The five components of policy implementation explicated above are designed to explain the policy output, or what is actually implemented with participants. Hasenfeld and Brock propose a measure of policy output termed the correspondence index which measures the degree to which needs and services correspond to one another as well as the eligible, processed, and served populations under the policy. Without data specific to client outcomes in this analysis, knowledge about the correspondence index will be limited. Finally, the components of policy implementation are all impacted by exogenous shocks to the system as well as the internal adjustments of policymakers or critical actors.

**Hasenfeld and Brock's model in the field.** Hasenfeld and Brock's model has been used previously to understand the implementation of self-direction. Sciegaj, Mahoney and Simone (2008) adapt the model to understand the problems faced by the state of New York in

implementing their “Cash and Counseling” demonstration program. In the analysis, the authors argue that the decentralized structure of the implementing department, coupled with a lack of financial resources, a rationale for implementing a new self-directed program, and support from stakeholders created the conditions for failure in implementation. Hasenfeld and Brock’s model was used to understand the driving forces, critical actors, and policy instruments that created the unfavorable outcome. Further support for the use of Hasenfeld and Brock’s model comes from the social work literature, in which Nakashima et al. (2005) use the driving forces to understand the successful expansion of services at a Veterans Administration hospital system. The authors argue the success of the program rests on leveraging existing technological and economic resources and centralized control by the implementing department over the stakeholder agencies who provided services in the program. Other applications by Ryan (1995, 1996) support the explanatory power of Hasenfeld and Brock’s model in understanding the implementation process.

One critical study of Hasenfeld and Brock’s model is McGrath’s (2009) study of implementation of the State Children’s Health Insurance Program in three states. The author concludes that the only driving force that explains the implementation experiences of the states he examined was the pursuit of rationality and that state-level capacity and previous programmatic experiences explained more of the implementation process. This analysis, however, relies on a different conception of driving forces than is found in the final model presented by Hasenfeld and Brock. Instead of examining the three driving forces in the political economy model—technological, economic, and power relations—McGrath’s analysis uses five driving forces that Hasenfeld and Brock proposed during a separate, though related, inductive review of the implementation literature to date (1991). These categories were reshaped into a

more coherent final model, as presented above, and McGrath's use of pre-theoretical driving forces rather than the driving forces included in the final model limits the explanatory power of his critique.

**Hasenfeld and Brock's model and self-direction.** Self-direction, as a nationwide experiment in human services delivery, provides an interesting case study for the application of Hasenfeld and Brock's model. The six components of Hasenfeld and Brock's political economy model of implementation provide a list of constructs and relationships that DDPA's experience in the process of administering self-direction. By studying how DDPA's conceptualize and understand self-direction and its implementation, the present investigation seeks to first address the two central components—the service delivery system and driving forces—and build conceptual links to critical actors, policy instruments, policymaking, and policy output components through the insights of DDPA's. Hasenfeld and Brock's model accounts for both bottom-up and top-down processes and emphasizes the formulation and reformulation of policies during implementation. Through examining each of the six components in the model, this investigation will explore whether the state policy environments are able to create stable implementation environments based on mutual accommodation and consensus—a key predictor of policies with a high correspondence index, according to Hasenfeld and Brock. Moreover, it will seek to validate and extend the model based on a comprehensive case study of all self-directed programs in the United States.

## **Chapter 3: Methods**

### **Introduction**

This section will review the methodology, data set, and data analysis plan to be used in the present inquiry. The data used in the study was a sub-analysis of a larger QUAL+quant dataset of DDPAs implementing self-direction on the state level. Using the qualitative data from this study, a directed content analysis was performed using the Hasenfeld and Brock model of implementation in order to best understand the service delivery system that provides self-direction to individuals with IDD. Furthermore, the directed content analysis provided an opportunity to critically engage with the Hasenfeld and Brock model and suggest revisions or extensions of existing theoretical concepts and relationships. To facilitate this process, an initial categorization matrix is offered based on the theoretical categories in Hasenfeld and Brock, categories from Abery and Stancliffe's Ecological Theory of Self-Determination, as well as the literature on the preferences and institutions influencing DDPAs. Finally, this section will review information related to the protection of human subjects.

### **Directed Content Analysis: An Overview**

Directed content analysis—also known as deductive content analysis or deductive case analysis—is an approach to analyzing qualitative data for the purposes of testing, refining, or extending an existing theory or body of research on a given topic (Hsieh & Shannon, 2005; Elo & Kyngas, 2008). Existing theoretical models and/or concepts gleaned from a review of the empirical literature are used to determine a priori (or initial) categories before analysis takes place (Elo & Kyngas, 2008). Each category is operationally defined using the theoretical model used to create them (Hsieh & Shannon, 2005). The directed or deductive approach to content

analysis is contrasted with the inductive approach in which categories are determined based on an analysis of the data and refined over time, only afterwards being contextualized in light of existing research and theory (Elo & Kyngas, 2008). Directed content analysis begins with predetermined categories and sorts units of data into a categorization matrix in which units are matched with their most appropriate category or are sorted inductively into new categories (Elo & Kyngas, 2008). Once all units of data have been sorted, results are described based on the contents of the categories with particular attention to the explanatory power of subcategories and the interrelationships between categories (Hsieh & Shannon, 2005). The results are recontextualized within the original theoretical model and offer supporting or disconfirming evidence for a theory (Hsieh & Shannon, 2005).

In using deductive logic to test previous theoretical and empirical constructs, directed content analysis is situated within the post-positivist paradigm of social research. Indeed, directed content analysis has been critiqued by qualitative researchers from the naturalistic and interpretivist paradigms based on its use of a priori categories (Hsieh & Shannon, 2005). According to critics, researchers using a priori categories may be influenced by confirmation bias and interpret data in a way that confirms preexisting biases or causes them to discount important contextual aspects of a phenomenon. Additionally, a priori categories may bias interview participants by cueing them to answer in a way that agrees with or seeks to refute what they believe the researcher's preconceptions are about the topic. Hsieh and Shannon (2005) argue that these critiques are misunderstandings of a strength of directed content analysis—that it accepts that existing research and theory will naturally influence a researcher and that the naïve perspective favored by the naturalistic paradigm is likely unattainable. While directed content analysis can be performed in an overly restrictive way that biases results, it is, when properly

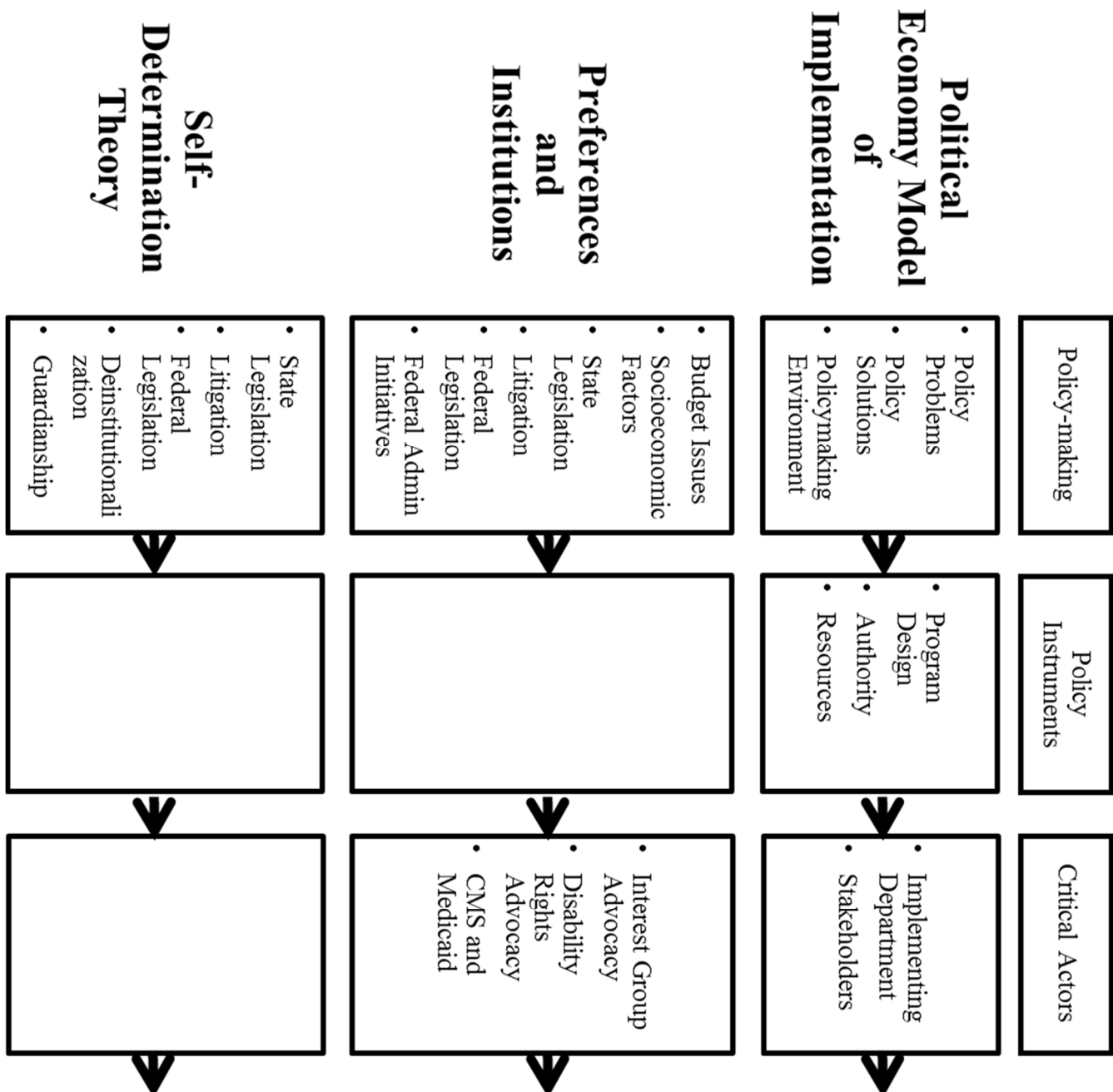
implemented, a flexible approach to data analysis that incorporates both inductive and deductive processes in an iterative manner to support, challenge, or extend existing theory.

Directed content analysis was uniquely suited to answering the research aims and question in this study. Hasenfeld and Brock's political economy model of implementation provided a general model of how implementation of self-direction may be performed by DDPAs, but its real-world applicability had been called into question by recent research (McGrath, 2009), and previous investigations using Hasenfeld and Brock's model left out key categories in their analysis (Sciegaj et al., 2008; Nakashima et al., 2005). Most importantly for understanding self-direction, the service delivery system had been an understudied component of program implementation. Directed content analysis, through its use of existing theory, allowed the researcher to test the utility of each category and relationship within a theoretical model. Moreover, it used an inductive process to edit and augment existing theoretical models with new categories and relationships grounded in empirical data. Because the research questions in the present investigation sought to critically engage with categories based in an existing theory, directed content analysis was the necessary choice.

### **Categorization Matrix: Tentative A Priori Categories and Subcategories**

In the present investigation, the a priori categories were derived from the Hasenfeld and Brock (1991) political economy model of implementation as well as Abery and Stancliffe's (2003) self-determination theory. Additionally, tentative subcategories were offered based on the preferences and institutions subsections in Part 1 of this manuscript. This categorization was tentative and was subject to iterative change based on the categories emergent in the data—including revisions to existing a priori categories or the creation of new categories. The figure

below describes the a priori categories and subcategories that were used to investigate the implementation of self-direction.



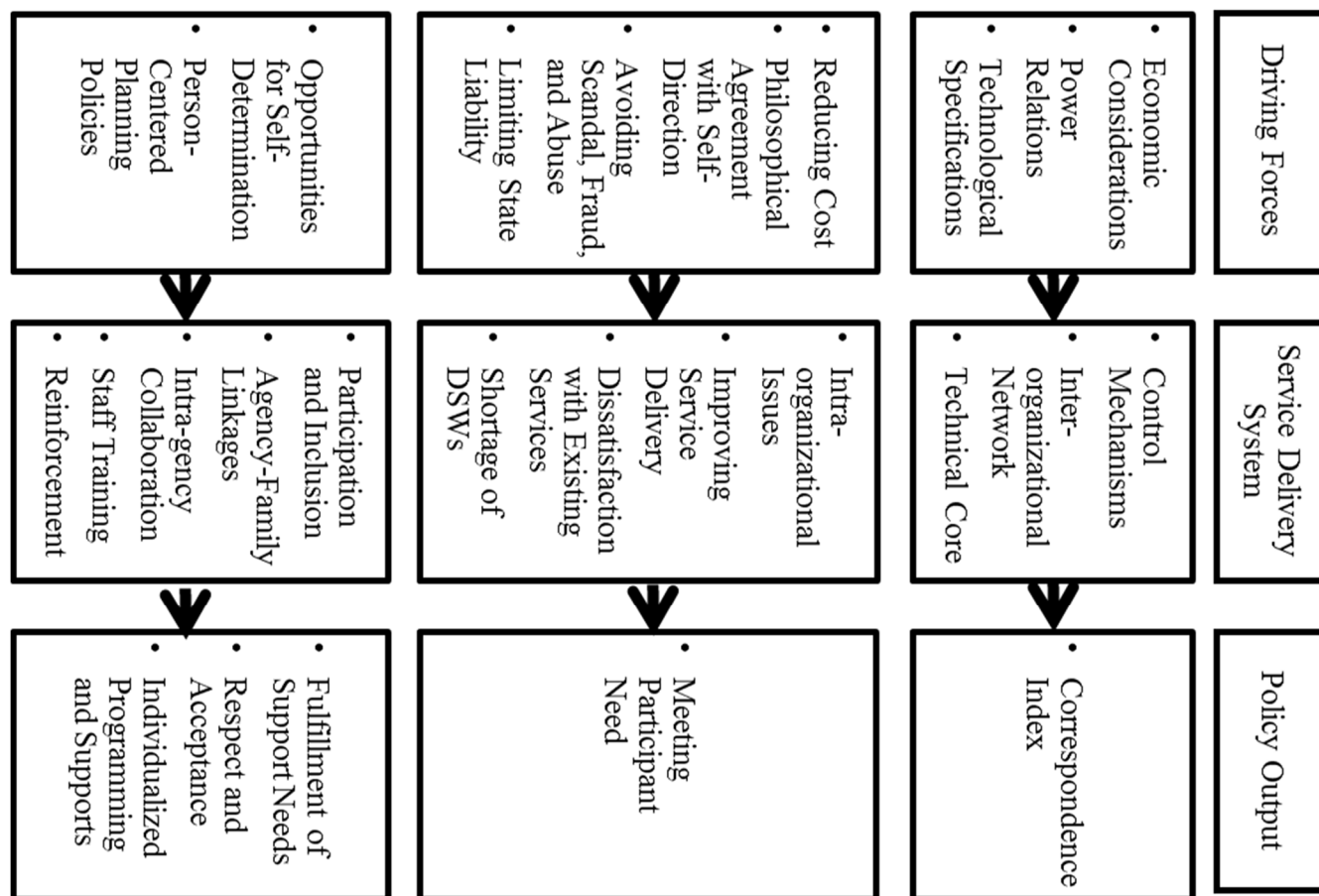


Figure 2: Original Coding Matrix

### Larger Research Project: State of the States

This research project was a sub-analysis of a larger project investigating the implementation of self-direction for individuals with IDD. The overall study, titled State of the States in Self-Direction for People with Intellectual and Developmental Disabilities, was conducted by this researcher in collaboration with a research team from the Virginia Commonwealth University School of Social Work and the University of Minnesota's Institute on Community Integration. In the State of the States project, the aim was to understand the current landscape of self-directed supports for individuals with Intellectual and Developmental Disabilities and Autism within the United States.



The State of the States study began by contacting Developmental Disabilities program directors and commissioners in all 50 states and the District of Columbia. Using the publicly available list of DDPAAs on the National Association of State Directors of Developmental Disabilities Services (NASDDDS) website, the researchers compiled a list of program directors and waiver managers from each state. An introductory email explained the nature of the research and asked directors—or someone in the department who the director designates as the most knowledgeable person on self-direction—to complete a short questionnaire detailing basic information about the size, scope, and components of self-directed service options in their state. If the director was unavailable or did not respond to the first inquiry, an inquiry was made to the waiver manager from that state. The results of the pre-interview questionnaire provided additional background on programs that could not be ascertained from reading the state’s waiver approval documentation available on the CMS database or program materials posted publicly on the state developmental disabilities department’s website. Interviews were conducted via phone with the individual or group of individuals the director designated as the most knowledgeable about self-direction. States that reported not offering self-direction—defined as offering employer or budget authority to individuals for at least one service to individuals with IDD—were excluded from this analysis. All other states that offered self-direction were given the opportunity to participate, though only thirty-three states completed the final interview out of a total of forty-one states offering self-direction for individuals with IDD. The thirty-three states participated in this project are listed in Appendix D.

The first aim of the larger study was to inform participants, scholars, and policy advocates about the size, scope, and composition of self-directed support programs in the United States. Results from the pre-interview questionnaire, the document review, and some interview

questions elucidated the first aim. Additionally, qualitative questions were included to explore how DDPAs conceptualized program strengths, challenges, best practices, and future directions for self-direction. These qualitative questions informed the secondary aim of the larger research project, designed to replicate Walker et al.'s (2009) study, exploring DDPA implementation of self-direction. The research team endeavored to update these earlier findings as the number of individuals on self-direction and the number of self-directed programs for individuals with IDD had grown significantly in the intervening years.

Data from the third research aim is the focus of the present sub-analysis—exploring the institutional environment in which DDPAs implement self-direction. The research team developed questions that probed key decisions that DDPAs made during implementation in order to understand the intraorganizational and external influences on those actions, and how these decisions affected the service delivery system. The interview protocol included a number of questions that phrased according to Hsieh and Shannon's (2005) suggested formatting for directed content analysis—an open-ended question followed by targeted questions addressing a priori categories. Phrasing questions in this manner allowed participants to explore concepts related to program implementation openly with follow up prompts based on a priori categories [see Appendix C, Questions 1, 5, 7, 10, 11, 12, and 14]. Specifically, questions explored the service delivery system in detail—for example, how individual budgets are determined, employing family members, available goods and services. These questions were followed up with prompts that delved deeper into the decision-making process for why these features of the service delivery system were created—including feedback from stakeholders, intraorganizational issues during implementation, and conceptualization of important outcomes for participants. Following the Hasenfeld and Brock model, these more in-depth questions probed for information

related to each of the six domains of implementation and sought to explore the relationships between those domains. In this way, this sub-analysis provides a more detailed and granular understanding of the implementation process, building off of the more general inquiry into program implementation in the first two aims. After the conclusion of this investigation, results from the qualitative analysis were shared with the entire research team and were used to contextualize findings related to the first two aims of the overall research project.

### **Human Subjects Protection**

The present investigation was submitted and approved through the Virginia Commonwealth University expedited Institutional Review Board process. Participants in this study were recruited via publicly available contact sheets on the NASDDDS website. An informed consent document explaining the purpose of the study, sponsoring organizations, voluntary participation, intent to record the interview, and any benefits or risks of participation were provided to all participants in the introductory email. The informed consent document did not require a signature, as the research project did not require any procedures for which written consent is normally required outside of the research context, and the research presented no more than minimal risk of harm to participants. Before beginning each phone interview, this researcher reviewed the contents of the informed consent sheet with the participant and received verbal confirmation that the participant consented to participate and did not have any questions or reservations about their participation.

Each interview was transcribed using the state name only and omitted information related to the participants in the interview. The key document matching state names to participant names was stored in a password-protected, encrypted computer folder shared among the research

team and backed up on a private, encrypted cloud storage service by this researcher. Voice recordings containing identifying information were deleted no more than one month after the transcription process was completed. Transcriptions were completed through a contractor at the University of Minnesota who was given read-only access to the voice recordings folder.

Confidentiality were maintained in this report by omitting the state name for data units related to individual states and instead referring to the general geographic region of the United States from which the information was gathered. No monetary or non-monetary inducements were offered to the participants, though a copy of research products was offered to participants to facilitate state-to-state learning, as requested by the participants. No dual relationships, conflicts of interest, or deception were involved in the research process.

### **Data Analysis Plan**

Data from the thirty-three state interviews were entered into Atlas.ti version 7.5.7. As a first step in data categorization, the proposed categorization matrix was tested on a subsample of five interviews. Test coding promoted consistency in category definitions and assisted with the creation of coding rules (Zhang & Wildemuth, 2009). A peer reviewer engaged with the researcher during the test coding process to provide feedback on coding consistency and advise on coding rules which need to be clarified, added, or further developed. Specifically, the peer reviewer used Elo and colleagues' (2014) method of checking coding consistency. After the initial coding of the five test states was completed by the researcher, the peer reviewer was provided with the a priori categorization matrix, any new categories that emerge inductively, descriptions of all categories, methodological journal entries, and the preliminary analysis of the data. After independently reviewing the analysis, the peer reviewer did not have any suggested

revisions to the categorization matrix. The researcher then proceeded with coding the entirety of the data set

At the conclusion of the first round of coding the researcher and peer reviewer conferenced. The peer reviewer was provided the new categorization matrix, a sample of coded interviews, and methodological journal entries. After examining the new matrix, the peer reviewer did not suggest any changes to the coding matrix. They provided confirmation that the coding matrix had internal logic and emphasized the importance of self-determination theory. Subsequently, a second round of coding was completed, and the peer reviewer was provided with the same materials as during test coding—categorization matrix, methodological journal entries, and coded transcripts. The peer reviewer and this researcher again verified that changes emerging from the inductive processes were grounded in the data. The final pass of coding was conducted by the researcher to ensure consistency with the coding matrix finalized during the second round of coding.

Constant comparison was used to examine each unit of data with the best possible match within the appropriate a priori category. For data units that did not fit into a priori categories or represented a revision of an a priori category, units were analyzed inductively and provisionally categorized with new labels which were subject to change as more data units were added to the analysis. Possible new categories and suggested revisions to a priori categories were documented in a methodological journal and discussed during peer review to help ensure trustworthiness.

After all data units were evaluated using constant comparison, the revised categorization matrix was compared with the original categorization matrix. Throughout the data analysis

process, the researcher focused on identifying observed relationships in the data that may explain aspects of the service delivery system in self-direction by assessing the direct and indirect impact of other implementation domains from Hasenfeld and Brock (i.e. policymaking, policy instruments, critical actors, driving forces, and policy output). As a result of the directed content analysis, a new categorization scheme was created that extended both the Hasenfeld and Brock and Aberly and Stancliffe models.

### **Trustworthiness**

In qualitative research, analytic rigor is defined by the trustworthiness of the research process and the research product. Trustworthiness was ensured through triangulation of multiple data sources, test coding and checking coding consistency, formal peer review, and external auditing. As a whole, these processes helped to ensure a trustworthy research product grounded in the responses of participants.

Triangulation of the data was accomplished through gathering multiple data sources. A thorough document review of all self-directed waiver documents on the CMS database was conducted for each state. Additionally, every state's developmental disabilities administration website was searched for any documentary materials relevant to self-direction program implementation, including rules and regulations, manuals for participants and support workers, satisfaction surveys, internal memos, and advocacy briefs. Qualitative interview responses indicating support for existing categories or potential new categories were analyzed in light of the documentary evidence.

To further ensure trustworthiness, the researcher also used a peer reviewer who evaluated the methods and interpretations employed by the researcher as well as the methodological

decisions in the methodological journal. The peer reviewer was a member of the research team who is knowledgeable about self-direction and qualitative data analysis but did not have previous exposure to the interview transcripts in this data set. A coding consistency plan, described above, was established with the peer reviewer. The peer review process helped to ensure dependability and confirmability of the results and reduced the potential for bias on the part of the researcher (Creswell, 2013; Hsieh & Shannon, 2005).

Additionally, an auditor was used to ensure trustworthiness of the final product. An experienced qualitative researcher who was affiliated with the research team, though not a contributor on this project, conducted a partial audit of coded transcripts after the third round of coding. The goals of the auditing process were to ensure that the final categorization was grounded in the words and experiences of the participants and was applied consistently across participants. At the completion of the study, the results were provided to the research team in a debriefing session. No changes were suggested to this researcher's interpretation of the results, and the final manuscript was shared with the research team.

## **Challenges**

An anticipated issue with the data analysis plan involved the use of only a single coder and the inability to arrive at true inter-coder agreement (Creswell, 2013). Given the epistemological positioning of directed content analysis, post-positivism, the use of only a single coder reduces the likelihood of achieving objectivity in data analysis. However, Elo and colleagues (2012) note that the use of a single coder is consistent with the method of directed content analysis, provided that a larger research team ensures coding and analysis are consistent. By including a larger research team at each stage of the process—including a peer reviewer, an

auditor, and other members—the present study was strengthened through having multiple researchers examine interviews to ensure dependability and confirmability of the original categorization matrix and emergent codes. Additionally, the coding consistency check provided a structured opportunity for the peer reviewer and primary researcher to assess the analysis for consistent application of category definitions and the groundedness of emergent categories in the data. Coding checks were important in achieving trustworthiness, as understandings of categories changed through the process of directed content analysis and new categories emerged in the middle of analysis that were not present at the outset (Zhang & Wildemuth, 2009). Finally, the use of methodological journaling provided a structured opportunity to document the creation of new categories, the elimination of old categories, and the shifts in category definitions over time. These entries were shared with the peer reviewer and auditor and helped to ensure that definitions in the final codebook, included in Appendix E, were applied consistently.



## **Chapter 4: Results**

### **Overview of Results Section**

The following section will describe the results of the study in order of the aims and research questions in the Introduction section of this manuscript. Research aims and research questions have been combined as headings for clarity. Figures will be used to provide a visual representation of the results when appropriate.

### **Aim 1: Assess the utility of Hasenfeld & Brock's Political Economy Model of Implementation**

**Deductive analysis results.** Overall, the results of the study indicate that the domains and subdomains from Hasenfeld and Brock's (1991) Political Economy Model of Implementation—hereafter referred to as Hasenfeld—were well-grounded in the experiences reported by DDPAAs, the individuals charged with implementing self-directed supports. The implementation domains of policy instruments, critical actors, driving forces, service delivery system, and policy output were among the most common codes within the data set. Specifically, the frequencies of codes from the domains derived from Hasenfeld's model are: Service Delivery System (622), Driving Forces (581), Policy Output (562), Critical Actors (480), and Policy Instruments (374). A significant finding was the lack of quotations related to the Policymaking (20) domain and its subdomains of Policy Problems (17) and Policy Solutions (15) in comparison with the other domains from the implementation model.

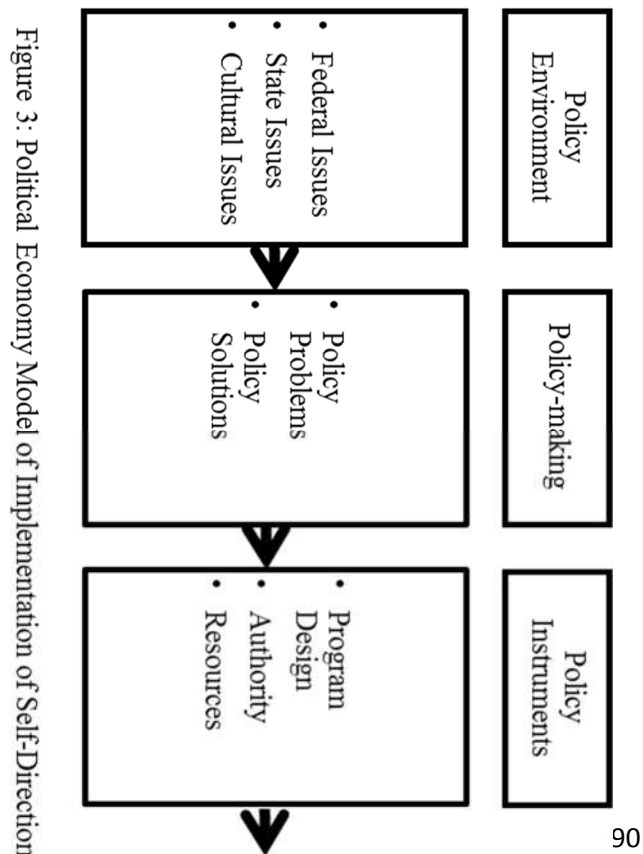
For the subdomains in Hasenfeld's original model, almost all were highly grounded in the data set. Aside from the low frequencies for policymaking and its subdomains, all subdomains were grounded in at least fifty quotations in the dataset. The most frequently used subdomains were Technological Specifications (456), Control Mechanisms (407), Technical Core (374),

Implementing Department (363), Program Design (294), Interorganizational Network (239), and Power Relations (178).

Between the first and second round of coding, additional codes were derived from Hasenfeld's model that were not in the original coding matrix. The codes Rationality and Coherence (344) and Irrationality and Incoherence (125) were included to provide a better understanding of the technological specifications in the original model. Hasenfeld argues that technological specifications—how the program components should be assembled—can be rational or irrational, leading to ease or difficulty in the implementation process. Additionally, the codes Target Population/Needs to be Addressed (108) and Available Supports/Services (123) were added to provide more specificity to the program design. These new codes were also well grounded in the experiences of administrators.

**Inductive analysis results.** New domains of implementation were added to the Hasenfeld model that provided a place in the final model for administrators to think and act. These interpretive domains were well-grounded in the data set—Administrator Conceptualization (620) and Policy Refinement (447). Administrator Conceptualization comprises both the preferences of administrators as well as their knowledge and opinions about implementing self-direction. Policy Refinement refers to the process of changing program components during the implementation process. Although impacted by all of the implementation domains, these domains are situated subsequent to the Policy Output as DDPA's reported examining the outputs of their programs, detailing how they thought through positive or negative outcomes, and taking concrete steps to ameliorate perceived problems. These interpretively-derived categories are conceptualized as a specific and important component of the feedback loops in Hasenfeld's model.

In addition to creating two new implementation domains, another significant revision between rounds one and two of coding was reconceptualizing the political environment subdomain in Hasenfeld's model. The political environment is thought by Hasenfeld to impact the policymaking process by creating a turbulent or calm environment—one in which policymaking can create rational coherent policies or incoherent policies. However, the responses of administrators indicated that this environmental context also impacts other domains—including driving forces, service delivery system, and policy output. The political environment was reformulated as the Policy Environment (352) with subdomains from Hasenfeld and Brock that indicated Turbulence (60) or Calm (60) in the policy environment. The Policy Environment domain was also instrumental in providing a conceptual space for other contextual forces that impacted implementation of self-direction, including state, federal, and cultural issues that did not fit into the original Hasenfeld model. The final coding matrix is pictured below:



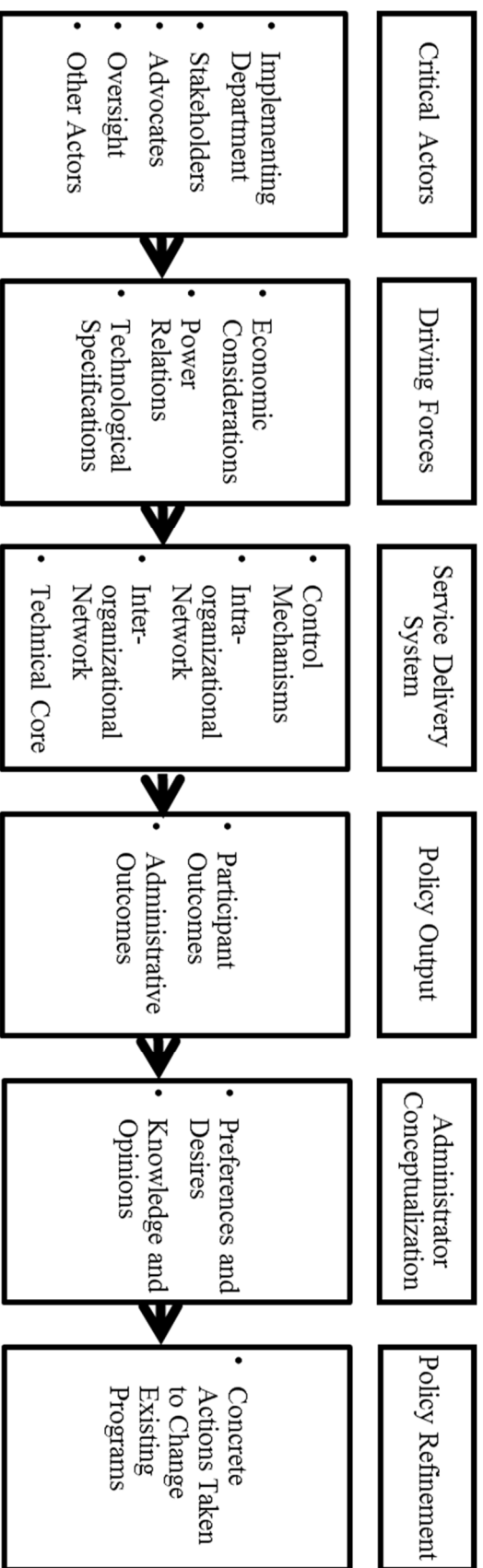


Figure3: Political Economy Model of Implementation of Self-Direction

## Aim 2: Important Features of the Service Delivery System

The first question in Aim 2 asks what the important features of the service delivery system were in the responses of administrators. In the final conceptual model, the service delivery system was composed of four domains—technical core, control mechanisms, interorganizational network, and intraorganizational network. The control network was further subdivided into non-budgetary rules and budgetary rules. The interorganizational network was subdivided into components provided inside or outside of the home.

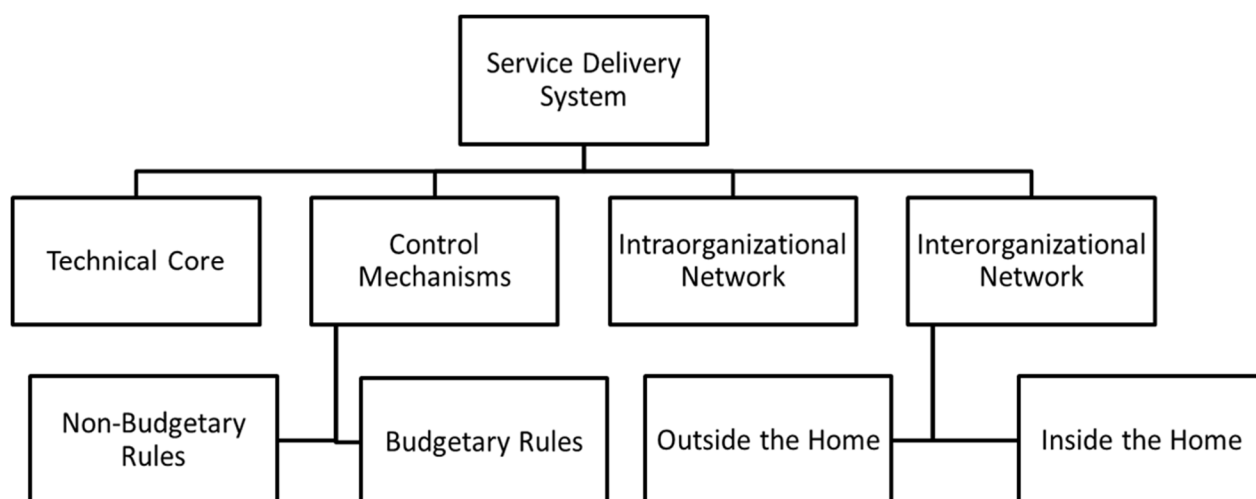


Figure 4: The Service Delivery System

**Technical core.** Interviews with DDPAs began with a simple question: “how do you define self-direction?” DDPAs largely responded to this question in terms of the technical core, the domain of implementation that directly impacts participant outcomes. Within the final model, the technical core incorporated opportunities for self-determination, employer authority, budget authority, individual budget, traditional supports, common law employer, person-centered planning, and agency with choice (in descending order of frequency).

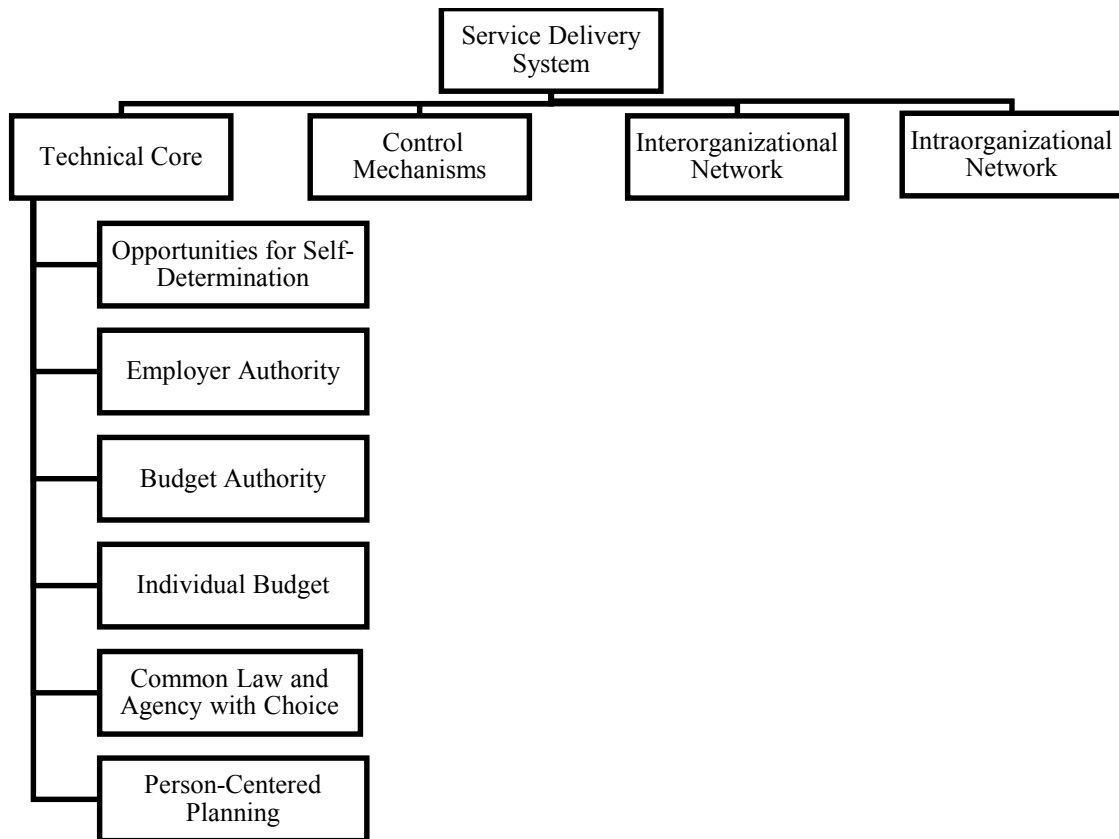


Figure 5: The Technical Core

***Opportunities for self-determination.*** Opportunities for self-determination were expressed through both employer and budget authority, described subsequently, but administrators detailed particular aspects of self-determination they believed to be important. Flexibility for participants was mentioned consistently by administrators as an important aspect of self-determination. To administrators, flexibility described the ability to mold services to “meet changing needs.” Compared with the system of traditional supports, participants were viewed as being able to individualize not just the service types that are included in their plan of service but what should occur today, two weeks from today, or during a crisis. Administrators expressed understanding that “life changes from day to day [so] service need to be flexible, too.” Flexibility also encompasses how service needs may be fulfilled by providers. An administrator

in the Northeast contrasted hiring a worker from an agency to assist with cooking tasks via traditional supports against taking “a community class that is integrated and learning about cooking or healthy eating or better health through a generic community class that the regular population is accessing as well.” This flexibility was also indicative to administrators of another important aspect of self-determination—the individualization of supports—wherein broad classes of service types are personalized into the things individuals need or would like to do on a given day to meet their support needs. Moreover, self-determination was often described in terms of “decision-making” or “choice” between different providers, different support workers, and different ways of meeting the same support needs

Flexibility was often mentioned by administrators alongside the responsibility that participants—either individuals with IDD or their family members acting as an employer of record or representative—must demonstrate while engaging in self-determination. While traditional supports were reported by administrators to involve some responsibility, self-direction involved “extra” responsibility that “requires the time and energy” of participants. Ultimately, “a lot is in the hands of our participants,” as administrators acknowledge they are partially ceding their planning and management authority to participants in self-direction. Administrators emphasized that participants must have the capacity to comprehend their responsibilities and the workload that comes with engaging in self-determination. Without responsibility, the “control” that participants were granted—another important term for administrators—may lead to negative outcomes.

***Employer authority.*** For administrators, the choices entailed by self-determination largely occurred within employment relationships. Based on the frequency counts, self-determination was largely conceptualized within the context of employer authority, or

“managing, supervising, recruiting, hiring, retaining and firing their own professional staff.” Significantly, DDPAs emphasized controlling who was coming into the individual or family member’s home, more so than a general contractual employment relationship as a key component of employer authority. Employer authority was also associated with the capacity of individuals with disabilities, or a representative, to fulfill the obligations of being an employer of record. DDPAs described this capacity as both understanding the concepts and regulations around employing support workers and taking responsibility for making sure their support needs were being met.

In the co-occurrence frequencies, employer authority (27) was used twice as often as budget authority (12) to define self-directed supports. The predominance of employer authority even persisted in states where budget authority was offered. A state in the Northeast explained that while “we include people, when we report numbers, that have an individual budget and use...an agency to have some greater control over their budget...we really define self-directed service [as] people who actually hire their own employees...that they’re the employer of record.” Without employer authority, the ability for individuals to express self-determination is not eliminated, as many administrators reported that provider agencies honor requests by participants for other staff members if service was unsatisfactory. However, in the descriptions of program administrators, employer authority is most often the place where self-determination is expressed.

***Budget authority.*** Although it was mentioned less often by administrators than employer authority as a necessary part of self-directed supports, budget authority was often a part of how DDPAs conceptualized the service delivery system. Budget authority was termed by one administrator as “controlling the financial system” of the participants’ life, a response echoed in the reports of other administrators. Many of the descriptors attached to budget authority were



similar to employer authority, including “deciding what services they will use, who will provide those services, how those services will be provided” but with the addition of “how they will use the budget that is allocated to them.” Some administrators in states that did not currently offer budget authority reported that they had considered adding it to their service offerings, contrasting their state’s programs with “true self-determination” that included both authorities.

DDPAs often linked budget authority with the ability to meet unique support needs for participants, as individuals might make choices to economize in some domains and redirect funds for special purchases such as assistive technology, music therapy, equestrian therapy, or therapeutic camps. In purchasing these niche goods, self-direction achieved for administrators the individualization and personalization of supports that was common to descriptions of self-determination. Moreover, many administrators spoke approvingly of the capacity for individuals and families to manage their own budgets, with many DDPAs reporting participants as responsible stewards of public funds. The success that administrators report was illustrated well in this example from an administrator in the Southeast:

“We get scenarios where they will mention how they were accessing it from an agency that was charging like say, upwards of \$10,000 a year for let's say, nutritional supplements, for example. They found that they can go out and buy it at Walmart for, let's say over the course of the year, \$2,000. They were raving about that. They were saying, ‘Hey let's save money.’ We sit back sometimes saying, ‘Wow. They're thinking of the state dollar, too. That's great.’”

***Individual budget.*** Administrators related exercising budget authority to the individual budget, or a specific allocation for each individual participant. While the individual budget was a frequent code in the data set, the descriptions of the individual budget largely related to

engaging in budgetary authority—moving around funds—or the statutory limits on budget size—such as tiers or algorithms. Some administrators (8) mentioned individual budgeting as a necessary part of self-direction, but most addressed the creation and use of that budget instead.

***Common law and agency with choice.*** In the literature, the two technical mechanisms through which self-direction is implemented are common law employer—referred to as employer of record (EOR) by administrators—and agency with choice (AWC). Administrators’ descriptions of EOR included the use of a FMS provider, taking on employment responsibilities either by the participant or a family member, and engaging with a support broker (for some administrators). AWC was described as a co-employer model with a provider agency wherein the person can exercise control over which agency DSW is providing supports in the home.

In the responses of many administrators, EOR was often viewed as “pure self-direction” or an integral part of the definition of self-direction. When administrators were asked about self-direction, they often asked clarification questions about whether the researcher’s definition encompassed just EOR or also included AWC, which was described as a more limited version of self-direction. The distinctions between EOR and AWC are conceptualized in different ways across administrators. For some, there was a clear differentiation between AWC and EOR because of the greater involvement of provider agencies in AWC that is not present in EOR—including the registration of family DSWs with providers. This differentiation, expressed by an administrator whose state introduced EOR less than two years ago, led to frustration with the slow adoption of EOR in their service area, as few participants were experiencing what the administrator believed to be true self-direction or self-determination.

For others, EOR and AWC were described as points along a continuum of options in which participants can express self-determination. According to one administrator in the

Northeast, “people can dip their toe in” by using AWC to see if exercising self-determination over support workers “works out well.” This midpoint between traditional services and self-direction was valued by this administrator, as EOR was seen as “daunting” with the novel and complex tasks of employer and budget authority. EOR was described by multiple administrators as a “challenge” for participants and “a lot for a family member to take on.” Another administrator reported that “cognitive limitations” in the IDD population also necessitated family members taking on employer responsibilities within EOR, which could be a barrier for some participants. AWC was also characterized as helping to minimize the paperwork that participants must complete, as the administrative tasks and paperwork are largely handled by the provider agency that co-employs the support worker.

***Person-centered planning.*** Person-centered planning was the least frequent code in the technical core. It was mentioned by few administrators (3) as one of the necessary components of self-direction. In the more detailed descriptions of self-direction that followed in the interviews, it was only mentioned by ten state administrators. For those administrators who discussed person-centered planning, it was described as contributing to the assessment process, the creation of the individual service plan and budget, as well as compliance with CMS rules. One administrator expressed that self-direction takes away from the “dreaming” aspect of person-centered planning by focusing solely on how funds will be spent, but this level of reflection on person-centered planning was not present in other interviews.

**Control mechanisms.** Control mechanisms, according to Hasenfeld, describe rules about how program components should be assembled. Engaging budgetary or employer authority, according to administrators, happened within a rule-based context determined by the implementing department—supporting the utility of Hasenfeld’s category of control

mechanisms. Within the responses of administrators, control mechanisms were further subdivided between budgetary and non-budgetary regulations.

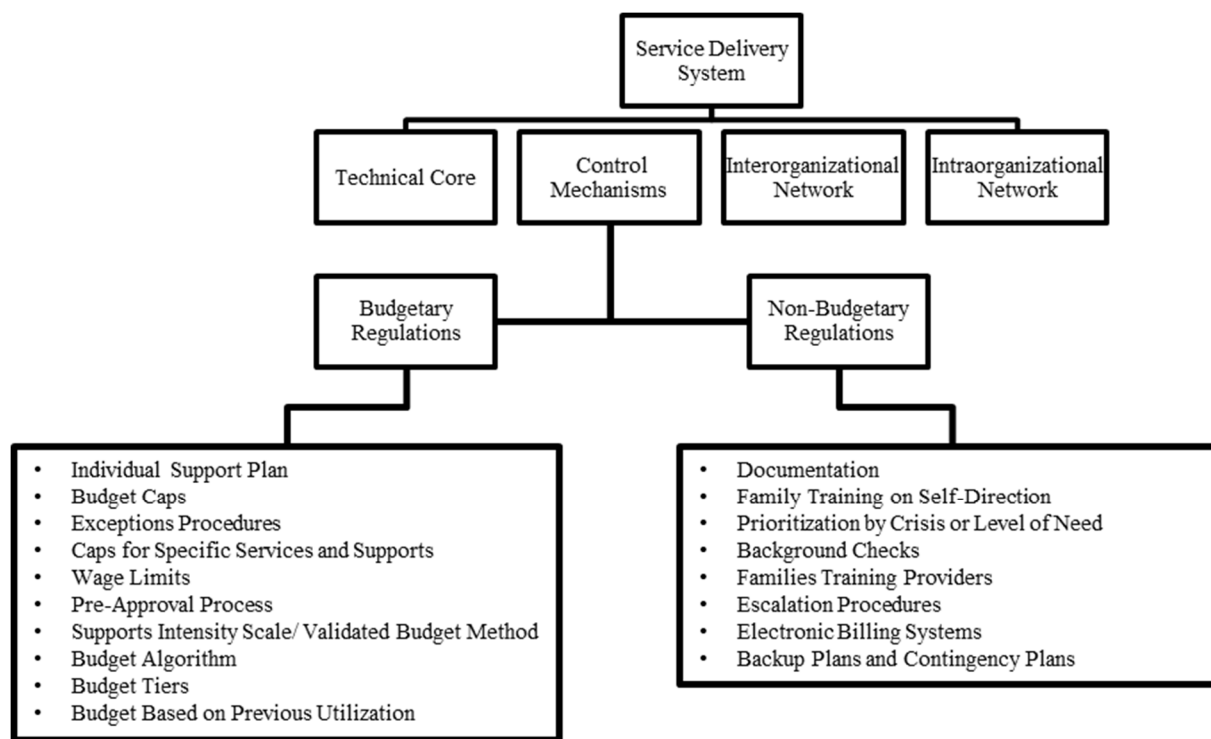


Figure 6: Control Mechanisms

***Budgetary regulations.***

*Individual support plan (ISP).* Administrators reported that when an individual is screened to receive supports in self-direction, an individual support plan is created with the assistance of a case manager that describes the services to be provided based on the assessed needs of the individual. Administrators described the ISP as forming the basis of the participant’s individual budget, often based on the amount of “hours” of service a person requires. Most administrators explained that they used the ISP to calculate the amount of the individual budget. As an administrator from the Southeast described, “if you have X number of hours on your care plan, it’s converted to units and dollars” based on the wage rates set by the state. For example, if a participant needed support from a personal care attendant, the ISP would

describe how many hours that person is assessed as needing, multiplied by a value set by the state for the hourly rate of pay for that support, and that would establish that portion of the participant's budget. Administrators also reported that ISPs will often specify who is to be providing supports as well as backup providers in case of an emergency.

Once the ISP is established and the participant is engaged in self-direction, administrators consistently emphasized that purchases must be made in accordance with the ISP. For many service types—in particular states that only offered employer authority—purchases must specifically align with the service designations provided in the ISP. For example, a person must spend money from their respite budget on services for respite. In states that offered budgetary authority, and in particular individually directed goods and services, unique purchases of assistive technology, physical training, dietary supplements, and other goods must be associated with a specific need present on the ISP, according to administrators. In relating every purchase and employment relationship back to the ISP, administrators emphasized that the process provides a sense of “accountability” that was valuable to administrators. Any deviation from the ISP requires going through a specific exceptions process or the creation of a new ISP.

The process of creating the individual support plan also varied from state to state. Administrators in some states reported using booklets or guides to assist participants and their natural supports with better understanding their service needs. One administrator cited an example question from these booklets as “How [are your support needs] different for weekdays versus weekends?” Other administrators reported relying on case managers to help individuals understand their support needs and how Medicaid fit into meeting those needs. Very few administrators reported that the ISP creation process was the result of person-centered planning.

*Budget caps.* In an effort to contain costs, some administrators reported setting caps on how large a participant's service budget may be. Administrators described that for all Medicaid waiver programs there is a cap based on a comparison between the services provided in the waiver and those provided in an intermediate care facility. This is a cost neutrality provision in federal law. Within these rules, some administrators reported not using budgetary caps. In those states, administrators reported calculating budgets simply based on the services included on the participant's ISP and the pay rates for those services determined by the states. One administrator attributed the lack of a budget cap to the managed care structure, but that was not echoed in the responses from other managed care states.

In the descriptions of administrators, a majority of states imposed some type of budgetary cap on at least one self-directed program in the state. The simplest caps were fixed rates for everyone, and the caps varied widely across states. One state sets a participant's monthly budget at two times the Supplemental Security Income (SSI) payment rate for children and three times the SSI payment rate for adults. A few other states also differentiated budget caps for children and adults, varying in range from \$13,844 to \$25,000 for children and \$20,761 to \$40,000 for adults. Other fixed caps did not vary by age and ranged from \$30,000, \$50,000, and \$135,000 for all participants. Some budgetary caps varied based on specific characteristics, usually level of need. These budgetary rules were termed budget tiers and are described in a subsequent section. In some states, budget caps were present in some self-direction programs and not present in others. While a few administrators described the difference as a result of needing more "comprehensive" supports on one waiver versus another, that distinction did not apply to the experiences of most administrators in states with varying budgetary caps.

More than one administrator emphasized that although budget caps exist, that does not mean that each participant will receive that amount. “They have to justify the services that they receive,” said one administrator in the Midwest. Another administrator in the Southeast described the difficulty that comes with participants learning about the budget caps, as they will “shoot the moon” hoping to get the entire budget. If these participants were successful, the state would be “replacing natural supports” that could have provided the support for free.

*Exceptions procedures.* Whether a participant exceeded the budgetary cap for the program or simply exceeded their individual budget allotment, administrators detailed exceptions procedures as the regulations that govern whether and how participants may receive additional funding. There were many reasons why individuals might exceed their budgetary allotment, according to administrators. Individual budgets are usually calculated with the expectation that family members or other natural supports will provide assistance when DSWs are not there. When family members experience medical issues, are affected by natural disasters or weather events, or unfortunately pass away, administrators reported that exceptions procedures are activated to provide additional funds until a new equilibrium point can be found. Other times, exceptions are triggered by the changing needs of the individual with IDD, including health and safety issues, the desire for employment, or an increased need for supervision.

Across administrators, exceptions procedures generally begin with the participant and family interacting with the case manager who assesses their emerging needs. Case managers forward the request to regional authorities, or in rare cases, the state-level implementing department. Administrators reported that there are often specific committees convened to evaluate changes to resource allocation based on the documentation provided by the participant and the case manager. Across most administrators’ responses, the majority of exceptions are

dealt with at the local or regional level and result in a temporary agreement for new funds in acute crises or new assessments for more long-term changes to a person's individual support plan.

When a participant continually request exceptions, administrators reported varying levels of consequences that can arise. For one administrator in the Northeast, the first intervention involves technical support through the case manager or moving to agency with choice for a short time. If a participant continues to overspend their budget, particularly by authorizing overtime to an exceeding degree, the administrators reported taking steps to remove the common law employer status of that individual and moving them to traditional supports. Without these procedures in place, administrators reported the participant would be unable to pay for their supports through the end of the fiscal year or the state would have to provide a "bailout" for that participant's budget.

*Caps for specific services and supports.* In addition to the caps placed on the aggregate budget amount, states also impose caps on the amount individuals may spend on specific services and supports within the program. An administrator in the Midwest termed these "subcaps" and they apply to particular services, such as personal support or support brokerage, as well as goods and one-time purchases like environmental modifications and technology. Participants and advocates were often described as opposing subcaps within a waiver as they limit the degree to which individuals may express control over their supports and in some cases limit participants from finding a provider for a support need.

Administrators cited many reasons for including subcaps in self-directed programs. One administrator from the Northeast related an example of a family whose budget was \$25,000 and spent \$15,000 on recreation. In their words, "that's just not Medicaid." Program integrity was



also important for an administrator in the Southeast who reported negative participant feedback around the restriction against using an entire budget for “congregate services in a group setting,” spending which would go against the waiver’s objective of community integration.

Administrators also reported that caps for specific services helped to ensure the health and safety of participants by, for example, guarding against excessive time spent with respite caregivers rather than fully trained direct support workers. Caps on specific services were also related to cultural values within the state, according to administrators. For an administrator in the Southwest, they were reconsidering a cap on the amount of reimbursement for respite, asking, “the family is making a choice to have that consumer still living in their home, so what expectations do you have...does somebody really need \$300 [per month]?” Caps on specific services were also described as part of the general trend in self-direction towards more restrictions over time.

*Wage limits.* Similar to subcaps, administrators described wage limits as restricting the amount that participants can pay providers for support work. Wage limits vary in restrictiveness between states. A few states limit wages to one specific rate designated by the state, and administrators reported that these states only offer employer authority. In other cases, different services vary in flexibility on wage ranges with some having little to no variability and others having a higher degree of variability. An administrator in the Midwest gave the example of physical therapy, which had one wage rate that is mandatory for all participants, and personal support, for which wages were negotiable. Exceptions to wage ranges were reported by one administrator to be considered when justification was provided by the participant, such as continuing a long-standing service relationship.

Wage rates were often mentioned alongside the individual budget. Administrators described that if a participant decides to pay their support workers less or more, that impacts how many hours they may be able to afford for that service and how much money they may have to purchase other services. The budgets themselves are often calculated using the wage ranges and multiplying them by the number of hours approved for a given service with the product being their monthly budget for that service. An administrator from the Midwest provided this example:

“Basically, the family and the program manager decide we need coverage from 3-6 every day, or we need a second pair of hands in the morning to help them get ready for school, that type of thing. They come up with how many hours in a month they're going to need. Then you just take that and you multiply that times that hourly amount, and that gives them that monthly allotment that they have.”

Some administrators reported that wage ranges are the product of negotiation with provider agencies and unions. They are subject to increases over time in order to adjust for inflation and also based on participant feedback in order to ensure a robust provider pool.

*Pre-approval process.* In exercising budgetary authority, administrators described that participants are also subject to regulations around pre-approvals, or seeking the permission of the regional authority or the state department to purchase a good or service. While not emblematic of all pre-approval processes, one administrator from the Midwest described the pre-approval process in this way:

“The pre-approval process is not difficult. They need to provide us with a recommendation from a professional, which that could be their doctor, or their therapist, some professional who has a license. They need to have an invoice for the service that

they want, and then they need to be able to show how that service is going to improve the individual's functioning related to the disability, or increase their safety in the home, or decrease dependence on Center of Care funded services. If they can show us those things, and then why the individual would benefit from that service, we'd be on our way to approving it, probably.”

Although environmental modifications were mentioned by a few administrators, the majority of pre-approvals mentioned in the interviews were triggered by the purchase of “goods and services,” a kind of catch-all category in self-directed programs that allows participants to purchase items that will contribute to their assessed medical needs. To ensure that participants will actually use the good, one administrator reported encouraging “free trials” of technology and equipment before a purchase would be approved. Administrators consistently pointed to two sources of authority when making decisions about pre-approvals—regulations and the individual’s service plan. Participants like the one in the example were described as needing to demonstrate clinical need for a specific good. Regulations, according to administrators, often do not provide clear answers and “what we try to do is compare that request with basically the definition of the regulation and try to say, is there any way we can fit this in?” This administrator elaborated that matching regulations can be a challenge for unusual requests, relating somewhat humorously:

“Somebody did ask to use goods and service dollars for cremation. We had to look at the regulation language and it says, ‘Goods and services are used to provide a direct medical benefit to the person.’ We're sitting here thinking, ‘Well if the person's dead, I don't think that they can benefit medically, from that. Looks like we'll have to turn it down.’”

Because administrators in states that allow goods and services to be purchased often described them as a benefit in meeting the unique support needs of participants, they reported dedicating staffing resources and often their own personal time to evaluating requests. However, not all pre-approval requests are funded, and many administrators reported formalizing the review process by creating a list of disapproved goods and services. These disapproved services includes air conditioners, cosmetic or regular maintenance on housing or vehicles, and educational supplies. An administrator from the Southeast described a list that is maintained on the federal level that their state uses to classify goods and services as either covered or “experimental” and therefore not covered by self-direction; however, this federal list was not mentioned by any other administrator.

Administrators described ongoing conversations within their departments about what goods and services should be covered, and discussed the challenge in drawing the line between a device like a iPad that can be used to assist with communication but also can be used by the entire family. An administrator in the West reported that pre-approvals “help us stay on our game [because] there’s a lot of very unique requests that come in...on a weekly basis” and they have to ensure “that we’re keeping up with the uniqueness of the requests and that we’re being consistent throughout the state.” The lack of a “black and white, yes and no, for every single thing...makes it tough” for administrators and increases the amount of time spent coordinating with regional administrators who interact more directly with participants. Finally, similar to other budgetary rules, there was a general trend reported by administrators of transitioning from a relatively liberal program with few restrictions on pre-approvals to a program with many regulations as a result of participants pushing the boundaries over time and hoping that by “throwing everything at the wall [they’ll] get a few things.”

*Supports intensity scale or other validated budget method.* Although budget calculation methodologies vary between the states, many administrators reported using the standardized assessments like the Supports Intensity Scale (SIS), or in fewer cases, the Inventory for Client and Agency Planning (ICAP) in some capacity. In some states, administrators reported using only a standardized assessment and calculating the budget directly from its results. In other states, a standardized assessment is used in conjunction with other instruments devised by the state that measure concepts such as environmental supports and health risks. Only one administrator reported using the SIS in conjunction with person-centered planning. Multiple administrators described “moving towards” using the SIS on a statewide basis, with ongoing pilot projects. The goals administrators described in transitioning resource allocation and assessment towards the SIS were to ensure “budgets are fair, based on need...and help us make sure we’re using our money in the right places.” Another administrator added that the SIS may be helpful in identifying individuals who would be better candidates for self-direction. In a negative case, one administrator reported that their state uses their own “statistically validated” budget methodology that factors, much like the SIS, directly in to the budget algorithms used to calculate individual budgets.

*Budget based on average utilization or algorithm.* Many administrators reported that budgets for participants are based on a mathematical calculation incorporating the average cost within the state, sometimes termed an algorithm or regression methodology. Once an assessment is performed, an individual is authorized for a certain level of need for a specific service—e.g. respite or transportation. For each service, administrators described that the results of the participant’s assessment are fed through the state’s algorithm which includes weighted variables

based on the average utilization of other participants. An administrator from the Midwest detailed the algorithm methodology for their state's implementation:

“Our Medicaid director at the time, said that he was a little hesitant about going statewide with [self-direction] because of the potential costs. We wanted to have some kind of a cost neutrality formula put in. What we did is we said, "Here's how we're going to make sure that we're cost neutral." We'll take the average statewide cost for a unit of that service and then we'll actually look at the usage of that service compared to what's authorized in a plan of care. We know that if you authorize 100 hours of [personal care] in any given month, not all 100 hours is used. We take the average use per month for the service and we apply a utilization factor to the statewide cost to get it down to the budget amount. If we have 100 units of [personal care] as the average of what we'll be using. If the average is 10 dollars per hour but we know that only 80% of the services that are authorized in a plan actually get used, we would reduce the average statewide cost by 20%. We would give the member 80% of the statewide average cost. We do that with everything, with most services. There's some that we give 100%. Respite was one where a lot of people authorized respite but they weren't using it so it was dropping it down to the 50% level or less. It wasn't feasible to have a budget that would meet the needs based on the utilization factor that's applied. Yeah. We just gave 100%, so we gave 16 bucks an hour. That's what the average statewide cost is and we gave that to the member to manage.”

For those administrators that reported using algorithms, they were described as helping contain the overall cost of the program as well as measuring future costs as participants lives change. While the preceding example was from an administrator using an algorithm proactively

to avoid overspending, another administrator described instituting an algorithm after going “100 million dollars” over budget. The transition for this administrator was described as “contentious,” with lawsuits from participants and families as well as negative feedback from advocacy organizations. In spite of these challenges, the administrator reported satisfaction with the algorithm, in particular the goodness of fit which was nearing the state’s target of 80 percent.

*Budget tiers.* Another budgetary rule that administrators described using to contain costs is the use of budget tiers. Once an assessment is completed, participants are placed into categories based on their level of need which corresponds with a specific dollar amount. States vary in the number of tiers within the program—usually between three and five—though one state bases tiers on the age of the participant. One administrator reported having transitioned from tiered budgets to using an algorithm to calculate dollar amounts.

*Budget based on previous utilization.* A few administrators reported that budget calculations are usually made based on previous utilization within the system. If a participant’s support needs do not vary from year to year, the budget amount is carried over to the next year. While historical data is important in budget calculation, one administrator reported that the historical data does not transfer along with participants when they transfer between the multiple waivers within the state. Therefore, if a person is better suited to a new waiver program, a new assessment has to be completed, rather than continuing to receive the same dollar amount but under the new program.

***Non-budgetary regulations.***

*Documentation.* Almost all administrators expressed that the level of documentation and paperwork required for individuals participating in self-direction is a source of stress and burden. The “volume of paperwork that comes initially [is] extremely time consuming and [takes] away

from other things that people would like to spend their time on.” The responsibilities of an employer of a support worker were described as including signing and approving timesheets, drafting and retaining employment contracts, maintaining progress notes, and submitting state-mandated forms to a case manager on a regular basis. Similarly, exercising budget authority was described as requiring that someone maintain receipts for transportation and approval documents from the state department. While these were reported by administrators as necessary for the proper processing of claims data through the FMS, many expressed dismay that participants often choose to minimize their involvement with documentation by choosing traditional supports or agency with choice rather than employer of record model of self-direction.

*Screening of participants.* According to administrators, before participants may begin engaging in self-direction, they must be screened by the state for appropriateness. Administrators reported significant variation in the tools used to conduct assessments. Many states created their own unique assessment tools which evaluate different aspects of a participant’s life. At minimum, administrators stated that assessment tools ensure that the person meets the qualifications for the program, is diagnosed with a specific intellectual or developmental disability, meets the level of need based on that diagnosis (generally the ICF/ID level mandated by Medicaid 1915c waivers), meets the monetary requirements for assistance, and resides in a location where self-direction can be used. In addition to these programmatic requirements, administrators reported that case managers screen for more complex factors such as: “Is [self-direction] a good fit? Does the family have the ability to self-direct at least a portion of [their budget]?” In this way, the screening interview is the first opportunity for the administration to assess competency to engage in self-direction, either personally by the individual with IDD or with the assistance of natural supports. Screening tools were developed



over time and were influenced by the funding priorities of the state, particularly in those where administrators reported using waiting lists. Some states use a standardized assessment such as the SIS or ICAP to assess a person's strengths, challenges, potential risk factors, and environmental supports. Other states reported that they have multiple assessment tools, depending on the specific population (e.g. child, adult).

According to administrators, screenings are usually performed by a case manager—though the specific title varies widely from state to state. Usually, these case managers are employees of area agencies, which may be publicly owned, privately contracted, or managed care entities that are assigned to a given area of the state. Once the case manager completes the assessment, administrators described that it is sent to the area agency or the state department for approval. These higher-level administrators factored in things like funding priorities—which specify certain levels of need as able to receive funding—or other budgetary rules like budget caps, tiers, or algorithms in order to arrive at a final budget. Assuming that qualifications are met and there are available slots in the program, the participant may begin self-direction.

*Family training on self-direction.* During the screening interview, according to administrators, case managers also provide an orientation to self-direction and the responsibilities involved for participants in the program. As one administrator from the Southeast described:

“The case managers ... will basically show them the ropes that help coordinate what's available to the person. What kind of pay rate ranges can they provide. What kind of duties can someone provide under a given service. What happens with multiple employees involved. Then of course the financial management functions, they will help out with trying to get those forms filled out. To designate that financial agent as a third

party payer. Someone that can designate the payment of taxes, for that person. Handling the paychecks and quarterly taxes. Things like that.”

In addition to orienting them to the components of the program (e.g. FMS, wage rates), case managers also educate participants on the documentation and the relevant regulations for the program. Administrators described the utility of creating workbooks and guidebooks that help to orient participants on “how to make good choices and decisions about who’s going to be supporting you and how to ask questions” about your supports. These manuals are often created with the assistance of participants and family members already in the program, ensuring that they are more responsive to the needs of new participants, according to administrators. A few administrators also mentioned that formal trainings by the implementing department are often provided as part of the outreach process, sometimes with the assistance of families or self-advocates. For participants who planned to hire family members as direct support workers, administrators varied significantly on the level of training required. Some states do not require training aside from what the participant provides on their specific support needs. Other states require parity between family DSWs and agency DSWs in the amount of training, particularly for services that fall outside of personal care such as support brokerage or supported employment.

Administrators stressed the importance of training on the front-end, in order to prevent instances where participants engage in inappropriate spending because they do not understand the rules of the program. When misspending occurs, case managers are tasked with providing technical assistance to families—a process that provides more specific training on areas that need improvement. Administrators reported tracking individuals who continually misspend money or exceed allotments, and conceptualized those issues largely as problems of education on

regulations and spending. The impetus for technical assistance was also mentioned in tandem with changes made by administrators to the program from the top-down. As administrators described a trend from more open programs to ones with greater amounts of restrictions, the transition for families was reported as challenging. Technical assistance and training was seen as helpful in making sure participants understand the new regulations and are better able to integrate them into their spending plans.

*Prioritization by crisis or level of need.* Although administrators reported the desire to serve all individuals in their states who have service needs, budgetary issues on the state level often necessitate limiting access to the program and creating waiting lists. During the screening process for participants, case managers assess the level of need and in these minority of states, assign them to a specific category. The specifications of levels of need vary by state. In one state, the administrator reported that prioritization is based on the type of service needed, with lower priorities not receiving any supports, medium to high priorities getting family support or day programming, and very high priorities receiving intensive supports. Within the waiting lists, level of need also impacts how quickly a person will move off the list and receive services. One administrator reported that some participants wait for over ten years to receive supports, and another reported that participants register for the waiting list in anticipation of needing supports in the future. Another administrator reported having tiers on the waiting list, for those that have urgent needs, emergent needs, and future planning needs. If a participant has a life circumstance change and enters into crisis, they can transition from the waiting list to receiving services. One outlier in this pattern was a state that prioritizes the waiting list by funding priorities set by the legislature that were not elaborated upon in the interview.

For individuals on the waiting list who have significant needs, very few states offer any state-funded services—though a few offer short-term respite. For those on the waiting list with lesser needs, some administrators reported that state programs not run through the federal government are helpful in alleviating some of the need while they wait for supports.

*Background checks.* The specific employment regulation mentioned most often by administrators was background checks for direct support workers. This regulation was particularly important to administrators, as individuals are able to hire individuals who are not affiliated with or trained by an established agency. Administrators reported variation in what entity is responsible for completing the background checks, with the responsibility usually falling to the FMS or the participant. In a few cases, the implementing department conducts background checks. One administrator focused on the tension between the state's mandate to ensure health and safety and the importance of self-determination in the employer relationship as part of the thought process for setting background check standards.

*Families training providers.* When participants hire providers to provide direct support work, administrators reported that training them on their specific support needs is the responsibility of the participant that falls under employer. Some administrators reported having no specific training requirements for non-agency DSWs and delegating that responsibility solely to the participant. In other cases, the participant provides training that is supplementary to the training required by the state. These additional requirements, when mentioned by administrators, generally covered safety and emergency issues such as CPR, first aid, and allergies. Another administrator underscored that DSWs who are hired through the agency with choice option are also subject to the training requirements of the provider agency that serves as co-employer.

*Escalation procedures.* Administrators also mentioned escalation procedures as important control mechanisms within the service delivery system. These procedures may be triggered by the periodic visits by case managers who screen for unusual occurrences, injuries, high risks, neglect, and abuse—according to administrators’ reports. More often in the responses of administrators, the participants themselves initiate escalation procedures when unusual “incidents” occur in the process of delivering self-directed supports. Administrators emphasized that these incidents are responded to by case managers while also being forwarded to regional and sometimes state authorities. Many administrators reported having close relationships with child protective services and adult protective services in order to provide the appropriate support for individuals who reported abuse. An administrator from the Northeast related that these procedures are part of the mandatory training that all participants must complete before entering the program.

*Electronic billing systems.* In a minority of interviews, administrators reported using electronic billing systems in order to track the spending of each participant in real time across the state. Electronic billing system connected each component of the self-direction program, including the participant, case manager, FMS provider, state or local administrators, and provider agencies by providing information on budgetary spending. There are multiple benefits described by administrators for using electronic billing systems. Administrators reported that it reduces or eliminates paperwork for both participants and administrators. Additionally, it provides case managers with accurate tools for monitoring and quality assurance. As described by one administrator in the Midwest:

“It really coordinates and documents everything.... It identifies, here's the services that are authorized, the amount, the budget amount, the cap amount. It really gives all the

information. We also have our FMS that enters all of their transaction information into it. A case manager can click on a view transaction button and it will bring up all of the expenditures, the employees, how many hours they worked, what they were paid, any goods and services that were purchased, anything that was placed into savings. It's real time. A case manager can go in and click on a button and say, 'You only used 20 hours last month when you were authorized for 100. What's going on?' Or, they can look at it historically because all the historical information is held. We can go back for members that have been on [our program] since 2007. All the transactions are held there. We can go back and look at usage. As you're starting to authorize services for the next year you can say, 'We had you authorized for 100 hours of service last year but you were consistently only using 50. Maybe we drop that down to 50 this year?' Anybody that has access to the system, like I can go in and do a look behind. When we do purchase approvals, so that's that prior authorization process. [Our] reviewers that are doing that go in and look at ... somebody says, 'I want to do equestrian therapy.' They can go in and say, 'What's authorized? What are you using? How many hours of service? Let's take a look at your budget.' We can get pretty close to saying, 'This makes sense because you're getting all your service needs met and you're staying within the budget.' Or we can say, 'You're not getting your service needs met so we're not going to be approving additional services because you're not using the stuff you have right now. From a Medicaid standpoint it doesn't make sense for us to approve that at this time.'"

Other administrators reported working towards implementing electronic billing systems in the future for similar reasons.

*Backup plans and contingency plans.* Although it was not mentioned by as many administrators, the use of backup plans in case the normal support worker cannot work on a given day as part of the support plan was described as important for some administrators. In some states, multiple backups are required to be written into the individual support plan. Administrators contrasted self-direction with traditional supports, in which backup is provided by the provider agency—an “absolute assurance that they have coverage every single day,” that administrators reported as valuable for some participants who choose not to engage in self-direction. Another administrator reported that the varying quality of supports provided by backup workers in traditional supports were motivating factors behind some participants entering into self-direction where they would be able to choose backup employees themselves. For many administrators, the participant was viewed as responsible for designating a backup and engaging that backup if needed. Administrators expressed fear that participants will remain in the community without receiving services in an emergency and not inform the provider agency or their case manager if backup services are needed.

**Interorganizational network.** The interorganizational network refers to the network of agents and organizations that are external to the implementing department who are relied upon to provide services to participants in self-direction. The design of self-direction breaks down the traditional model of support into many component parts enacted by private, non-profit, or family actors. Within this subdomain of implementation, there was a distinction in the reports of administrators between those components that are provided within the family or individual’s living environment—including direct support workers and support brokers— and components that were external to that environment—such as FMS providers and residential programs.

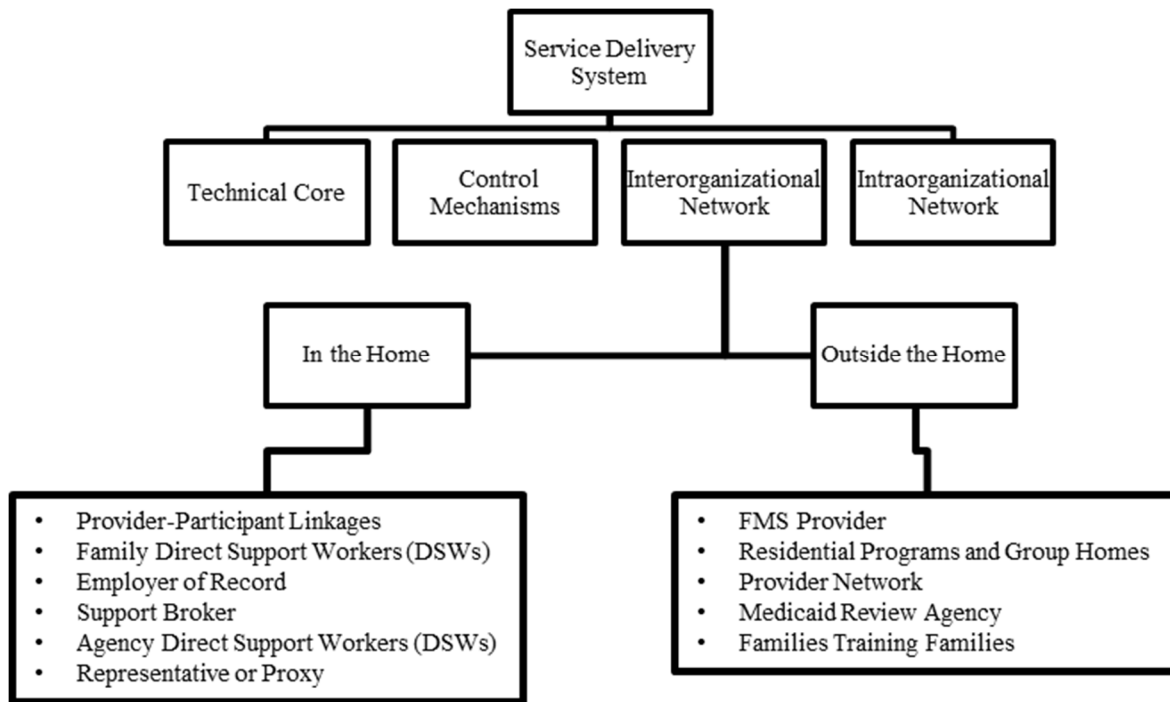


Figure 7: The Interorganizational Network

***Components within the home.***

*Provider-family/participant linkages.* For administrators, the most frequent code within this subdomain was the linkages or relationships between providers of direct support and the families and participants they served. Administrators reported a high amount of participant and family satisfaction with the support relationships they engaged in with support workers. For administrators, this satisfaction had many antecedent causes. Administrators described participants who derived satisfaction from the hiring process itself, being able to control who comes into their intimate environment and finding a support worker who truly knows them. Because participants have control over this process, participants are able to choose support workers who “are more familiar with them”—often family members or friends. The process of hiring a family member or friend as a support worker was described as “allowing a person to bring...folks that they’re familiar with and who are familiar with them...into their circle of



support.” Even when agency support workers are hired, the ability to build “a longstanding relationship with a traditional provider” is seen as a significant benefit because of the extensive knowledge the support worker has about the participant’s unique preferences and needs. Moreover, administrators reported that participants derive satisfaction from providing payment for support work that family members or friends would otherwise have provided for free, and participants are “more apt to ask for help when they needed the help than they did before when [the family member] wasn’t a paid provider.”

When participants exert control over the employment process, administrators reported that they are also able to bring greater consistency into the support relationship. Consistency is fostered, according to administrators, through the exercising of budgetary and employer authority. Participants, often with the assistance of support brokers and case managers, engage in a search process for support workers, interview potential employees, define the scope of the support relationship via contracting, provide individualized training on the participant’s needs, schedule support workers based on mutually agreed-upon times, and track and document the delivery of supports. When administrators described support relationships in self-direction, they often used terms of “flexibility” and “choice” as key descriptors. As one administrator in the Northeast described:

”self-determined or [people] in the self-direction waiver we have people that stick with people and stay with people...We have people that they’re working with them, if they’ve been in the waiver for five years, they’ve had the same PA staff for five years. It’s consistent.... People have consistent care, which is very important and people really, really get to choose how they want that care and when they need that care. To us, going

in and just giving them some predetermined hours based on what protocol we have, we actually, it really, really suits the family and their needs.”

Many administrators contrasted the support relationships in self-direction with unsatisfactory relationships within traditional supports. Administrators reported that participants value being “less at the whims of an external agency” and “that there’s not qualified providers in the area that can meet that level of need better than what the parents and families can provide.” For administrators, participants who “were fairly difficult in the traditional environment” or “who’ve had real trouble getting along with their staff in the past, we’ve seen that flip around now that they’ve really...been in control of the recruitment and hiring process.” When administrators solicited formal feedback from participants, they reported that participants and families who are satisfied with self-direction state that “traditional supports [were] just not cutting it for us [due to] low quality, high turn-over rate, whatever it may be.” Many administrators reported that relationships between participants and traditional providers are strained due to the rurality of the state and the difficulty of servicing such a large area. Finally, for new participants, administrators reported that “younger families” are not interested in traditional supports because of “more bureaucracy, you don’t control staffing, you don’t control scheduling, you have to compromise more things in life.” Administrators displayed high sensitivity to the negative support relationships reported by participants, and often understood self-direction as a way to address these shortcomings:

“That consistency, I think what we've heard anecdotally is that the consistency around the caregiver is really important to a participant. When you have an agency caregiver, depending upon who calls in sick or how many people they're serving, you may or may not get the same person from day to day, which impacts your quality of care for people

who are self-directing because they're the ones making those decisions around hiring and establishing expectations and back up plans. Who will be their caregivers as a part of their backup plans is contributing to the success of [the self-directed] option.”

Although administrators described many improvements in support relationships in self-direction, a few discussed challenges and difficulties for these relationships within self-direction. Without a “pool” of support workers provided by traditional provider agencies, “there need to be natural supports in the community that will take on the role of provider and provide those supports...but what we hear is that there is a staffing crisis...those staff that are retainable and knowledgeable and have that compassion are underpaid.” The lack of available people to provide support work could make it difficult for participants to find “consistent providers,” and can eventually lead to participants returning to traditional supports—an outcome that administrators did not prefer when it did not align with participant preferences. In other cases, administrators reported that traditional supports provide a “level of security” that is valuable to participants, particularly regarding backup plans if a support worker “is out that day.” From an administrative standpoint, there was also more difficulty reported in ensuring participants are not being abused, as one administrator from the Southeast reported that participants are less likely to report abuse by a family support worker because of their familial relationships.

*Family direct support workers.* As highlighted in the previous section, the ability of participants to hire family and friends as direct support workers is an important component of self-direction to administrators. They reported that family DSWs are usually recruited through word of mouth and are required to complete an employee agreement that set the parameters for the paid support relationship. States impose different restrictions on which family members can become family DSWs—with some simply excluding spouses and parents of minors while others

expanding that list to individuals living in the same home, legal guardians, or other specific relatives. Few administrators reported no restrictions on which family members may become family DSWs. These restrictions were often justified by administrators as not replacing natural supports with paid supports, the confusion or difficulty of managing familial and employer roles for participants, as well as potential conflicts of interest within the participant's circle of support. While no state restricts family members outright from becoming family DSWs, more restrictive states require participants to demonstrate that they have exhausted all other options.

According to administrators, the benefits of employing family DSWs derived from employing people "who know [the participant] the best and could provide the best supports and services" to them. Similar to the previous section, themes of "knowledge" and "consistency" were important for administrators who spoke of the benefits of hiring family DSWs. For individuals living in remote areas, they are able to recruit workers from familial or neighborhood connections, whereas in traditional supports, they are limited to agency DSWs that might not be willing or able to service rural populations. Administrators spoke positively of the impact family DSWs have on mobilizing or expanding the participant's "circle of support." While family DSWs were characterized positively by some administrators, other administrators reported that having the option is important but many participants continue to use agency DSWs for support work.

There were also some challenges with employing family DSWs noted in the interviews. Administrators described helping participants differentiate roles within the participant's circle of support. An employer of record could not also be a paid support worker, for example. Similarly, a representative or proxy could not be an employee. Administrators feared that potential conflicts of interest may leave participants vulnerable to exploitation when employing family

DSWs, as participants may be less likely to report problems with care when a family member might lose their income. The lack of “accountability” and difficulty with monitoring in-home interactions between participants and family DSWs were often described as challenges. Another administrator was concerned that families may keep individuals with disabilities in their home solely so they can receive payment through self-direction, rather than because they wish to provide superior care than a traditional provider or residential treatment center.

*Employer of record.* For many administrators, the employer of record is one of the necessary components of self-direction. While some individuals with IDD may perform the function of the employer of record, administrators reported that it is common for another family member to perform this function. The employer of record was described as a unique component in that it performs a vital service but is financially uncompensated. Administrators reported responsibilities of the employer of record as including interviewing and hiring employees, ensuring training, supervising the provision of services, reporting abuse or neglect, keeping documentation, submitting timesheets to the FMS for payment, or in rare cases, providing that payment directly to support workers without the use of an FMS. An employer of record must be a different person than the employee, a conflict of interest that was noted as important to administrators.

While many administrators expressed satisfaction with the competency of employers of record in fulfilling their role, there were significant challenges noted in the interviews of administrators. Administrators reported that employers of record often do not fully grasp their roles and responsibilities. The documentation and paperwork, noted previously, could be overwhelming for employers. Case managers who interface with employers of record were described as reporting some negative interactions, in which employers believed case managers

were responsible for tasks that were designated for the employer of record. Administrators described endeavoring to streamline processes for them and bring additional training support for employers. One administrator in the Southeast described frustration that “despite all my efforts to train all the case manager support brokers over the years, to tell consumers to set up disciplinary actions and reasons for termination in job descriptions, nobody does this.” Without these boundaries on the employment contract, participants were reported to be at risk of losing a significant portion of their budget if a successful unemployment claim is lodged against them.

*Support brokers.* Support brokers are another important component of the interorganizational network. Unlike case managers, support brokers are employees of the participant and are nominally independent of any other party. “They don't work for agencies, they work independently, they're endorsed through the state.” They assist the participant with managing employer and budgetary authority, providing support throughout the process, interfacing with other components in the network, and helping participants “navigate the world with taxes and employers and advertising and anything else.” According to administrators, support brokers also serve a monitoring function in the interorganizational network, performing in-home visits on a regular basis and conducting follow-up visits when prompted by the FMS. Not all administrators reported offering support brokerage and this data set did not include detailed questions on support brokerage, so knowledge on the use of support brokerage across states is consequently limited.

Support brokers who are trained, “seasoned,” and “passionate” were described by administrators as vital assets in the implementation of self-direction. Having a support broker is “something that can make or break the service because a lot of people don't know how to go about advertising or hiring or don't feel comfortable with firing whatever and so that Services

Facilitator is there as a support to them.” However, many administrators reported challenges with support brokerage as a component of self-direction. Administrators reported that both they and participants had some confusion about where the responsibilities of the case manager, support broker, and FMS provider overlap; moreover, sometimes each component will provide contradictory answers to participant questions during service. Multiple administrators reported that as a result of their efforts to increase enrollment in self-direction, many support brokers became overworked and increasing the supply of support brokers required bringing in novice brokers that lacked the institutional knowledge brokers are designated to provide. One state administrator reported an opportunity for families to become support brokers, though they first had to attend a series of trainings. Independent of capacity, support brokerage could be a time-intensive job, and when issues arise, support brokers have to “scramble” to fix errors to payments that participants and workers rely on to survive.

*Agency direct support workers.* Within self-direction, agency DSWs remain an important part of the interorganizational network for administrators. Agency DSWs were described as one option among many for participants to employ, alongside family members, friends, neighbors, and DSWs unaffiliated with an agency. For participants who had a longstanding relationship with an agency DSW, being able to continue that relationship was important for an administrator in the Northwest, who described designing regulations for that relationship to continue. Agency DSWs were often mentioned in the interviews in tandem with the agency with choice model of self-direction. When provider agencies send agency DSWs that are satisfactory, participants often choose to remain in agency with choice rather than employ their own DSWs by becoming an employer of record. The quality of agency DSWs was a significant issue for administrators, as many interviews discussed the impetus behind self-direction arising from advocate and

administrator frustration with poorly performing agency DSWs and unresponsive provider agencies.

*Representative or proxy.* Within the interorganizational network, the representative is a person who “acts on behalf of” the participant within support relationships. Administrators reported that although individuals with IDD sometimes perform employer and budgetary functions themselves, the use of a representative is common. This function was seen as a necessary component for self-direction with individuals who have IDD because of the “level of responsibility” that is required.

***Components outside the home.***

*FMS provider.* There was significant variation between state administrators in how FMS providers are incorporated as part of the service delivery system. While most agreed on the general functions an FMS provides—registering and paying support workers, running background checks, deducting employment taxes, and tracking spending—there are unique implementation decisions within each state that impact how the FMS component functions. The majority of administrators reported that FMS services are mandatory, though a few states offer the option for individuals to take on all fiscal responsibilities themselves—described as an unpopular option among participants due to the workload involved. In some states, there is only one private company that provides FMS services that all participants are required to use, while others contract with multiple companies who offer FMS services. The addition of more FMS providers was described as a way to provide more choice for participants—“the more [fiscal intermediaries] we have, the more choice people who choose self-direction will have.” While some administrators reported that FMS providers are agencies that provide only this one service, multiple administrators reported that FMS is only one of many services provided to participants



by a given agency. In some states, traditional providers have expanded into providing FMS for self-direction participants. As self-direction grows in popularity within a state, administrators reported that traditional providers, who already have the capacity to fulfill FMS functions—screening and paying employees, deducting taxes—view FMS as another potential revenue stream. In other cases “area agencies” or regional administrators fulfill FMS functions. Area agencies are conceptualized in this study as part of the intraorganizational network, as they provided monitoring and assessment functions on behalf of the implementing department, but in some states they also provide FMS services. This arrangement can be difficult, according to administrators, when participants move between service areas or when local administrators are resistant to self-direction.

Although there is significant variation in the implementation of FMS between the states, administrators consistently reported that a strong relationship with FMS providers is a vital component of implementation. The FMS provides an invaluable monitoring function for the state, translating the complex and dynamic network of state and federal regulations into a coherent experience for front-line support workers, participants, and administrators. FMS providers ensure that participants have enough money to pay for future supports throughout the year, assure that documentation matches with services approved on the individual support plan, and provide timely payment to support workers. Because of their centrality in the interorganizational network, linking each component and person through the flow of money, administrators expressed that a solid relationship with an FMS provider is “key” to implementation. One administrator was effusive in their praise for the state’s one FMS provider:

“A lot of it has to do with, and I promise you they are not giving me any money to say this...to having a really, really good financial brokerage firm. They are awesome. I mean

their customer services. Their customer service is stellar. They're stellar. Our meetings now are and our conference calls are twenty minutes.... Every now and again, we have a little issue or concern to arise. I promise you it has a lot to do with that partnership we have with [name removed], who makes it extremely easy ... A good support brokerage that's awesome in our financial administration piece is what makes that I think our program go smoothly."

While this administrator's description of the state's relationship with their FMS provider was somewhat extreme, similar sentiments were expressed by many of the administrators in the study. However, there were some administrators who reported difficulty with their FMS provider. One administrator reported a "pretty good" relationship with "some glitches" and delays in payment and screening. Another administrator reported more significant problems with their FMS provider, describing how glitches can multiply across a system:

"I think that part of the fiscal intermediary is the hard system for people to navigate. To have a customer service center that doesn't answer the phone. There are things that... it's when you miss a payment, it's enormous because people like to hand them out. There are things like that that we spend a lot of time trying to firm up. That is a challenge when it doesn't go right. Let's say it's a time sheet. If the time sheet doesn't get approved because they forgot something, whatever they forgot to sign it, they forgot to put the right date, end date or whatever. There's a notice that goes to the service broker. If the service broker isn't there and it's not fixed, the payment can't go out. Then you find out on Monday that the check they thought they were going to have in the mail on Saturday isn't there. There's a lot of scrambling, a lot of work that support brokers have to do with the individual to get the payment the week later. Most of these people are not financially,

they depend on this money. That is a challenge that we've been working on for three years to try to get those kind of issues resolved.”

This administrator reported that problems with this FMS provider were so significant that “word spread” and “now that we have agency with choice in my region, I’m seeing people leave [FMS provider] to go to agency with choice [because it’s] the same self-direction but they don’t have to be involved with all the headache of the financial management system.” Difficulties with FMS providers also burden administrators who have to assist participants in meeting the FMS provider’s documentation demands, work with FMS providers to discuss issues, and engage in outreach to a population of participants that might be less receptive to self-direction now. A few administrators reported considering moving FMS services into the administration itself in order to save money and reduce workload.

Other negative cases related to FMS occurred in states that do not have a third-party FMS provider. In these few states, the functions of the FMS are performed by the implementing department. The implementing department also provides FMS functions in a few states that do not use FMS providers for state plans but do use them for Medicaid waivers.

*Residential programs and group homes.* Although self-direction is generally conceptualized by administrators as moving services away from congregate settings and into individual or family homes, residential programs and group homes remain an influential part of the interorganizational network. In some states, living in a congregate setting can disqualify you from participating in self-direction. This feature is described as congruent with their administrator’s focus on in-home supports but is noted by one administrator as a constraint on the reach of self-directed programs. An administrator in a state that at one time included residential supports in self-direction noted the high costs as a challenge to the sustainability of

the self-directed program. Furthermore, administrators highlighted that including residential services on self-direction may elicit more scrutiny from CMS under the new community setting rules.

For those states that allow self-direction for individuals living in group homes, there is a further distinction between those states that allow participants to self-direct their residential supports and whether those supports are provided through the traditional provider-participant relationship. Only one administrator reported that it is possible, though unusual, for residential supports to be self-directed. An administrator from the Northeast explained that if residential services were self-directed, it would result in incoherence within the setting. Since some residents might be self-directed and others might not be, providers would have difficulty, for instance, scheduling the staff as each resident might select a different staff member for the same time. Despite these limitations, administrators reported that self-direction and self-determination are being infused into residential supports. The infusion comes in the form of providing more choices to individuals in group homes—“having their own keys, their bedroom can lock, making sure it’s a home-like environment.” A few administrators reported working on new programs for self-directed residential support. In one example, self-advocates have asked if individuals with disabilities can live outside a group home with “maybe one or two other roommates” in an apartment or house and still receive self-directed supports. Another administrator described a pilot program for self-directed residential staff that is demonstrating successful outcomes: “In this pilot that we’ve got in residential, the individuals are picking where they want to live, they’re picking their roommates and their staff, and that sense of ownership that they get from that reduces behaviors, reduces eloping, because it’s their house, why would they want to run away from it? It bring in staff they brought in. They hired that staff. They picked that staff, so

the conflict there is gone which makes it easier for the staff to work with individuals. We've been able to eliminate an entire shift, if not more, from these residential homes, so in essence it's saving money. The more you can bring in self-directed studies, I think you'll see a reduction in cost all around.”

*Provider network.* Administrators described the importance of having a robust provider network from which participants can choose. Within traditional supports, the provider network was described as a significant problem for participants in rural areas, far away from metropolitan areas where providers are usually located. This provider network expanded to include non-agency affiliated individuals within self-direction, an expansion in the supply of labor supported by administrators. Family DSWs, however, cannot provide all of the supports that participants need. There remain medical functions, such as skilled nursing, or administrative tasks, such as support brokerage, that require significant training. For these positions, self-direction does not expand the supply of labor in the provider network. A notable exception to these general themes is one state who relies upon a network of independent, non-agency affiliated providers that is reported to have remained relatively stable over the past few decades.

*Medicaid review agency.* A few administrators reported using a Medicaid review agency as part of their interorganizational network. The functions of the Medicaid review agency relate largely to monitoring, termed by one administrator as a “third-party assessor.” Specific tasks include reviewing plans of care before they can be implemented as well as on a regular basis for quality assurance, ensuring budgets comply with regulations and standards, checking provider qualifications, surveying participants on their satisfaction with the program, serving on committees and working groups, and in one state, providing training and technical assistance to

participants. Administrators did not describe how they felt about their review agencies, though they spoke positively of their role in monitoring and compliance.

*Families training families.* A few administrators reported that a network of peer-to-peer or family-to-family trainings is an important component of the interorganizational network. One administrator reported success in creating a network of peer support groups that provide assistance on how to best use the program. Another administrator reported that although this feature was at one time important, it is not “utilized very often” because training is generally provided by the case manager. Two administrators reported trying to build infrastructure for peer support groups and trainings, but few details were provided.

**Intraorganizational network.** The intraorganizational network refers to the components in self-direction that are part of the state, as in regional officials and managed care organizations, or act directly on the state’s behalf, as in case managers. The intraorganizational network also includes the relationships between these components as well as their interactions with family members and participants in self-direction.

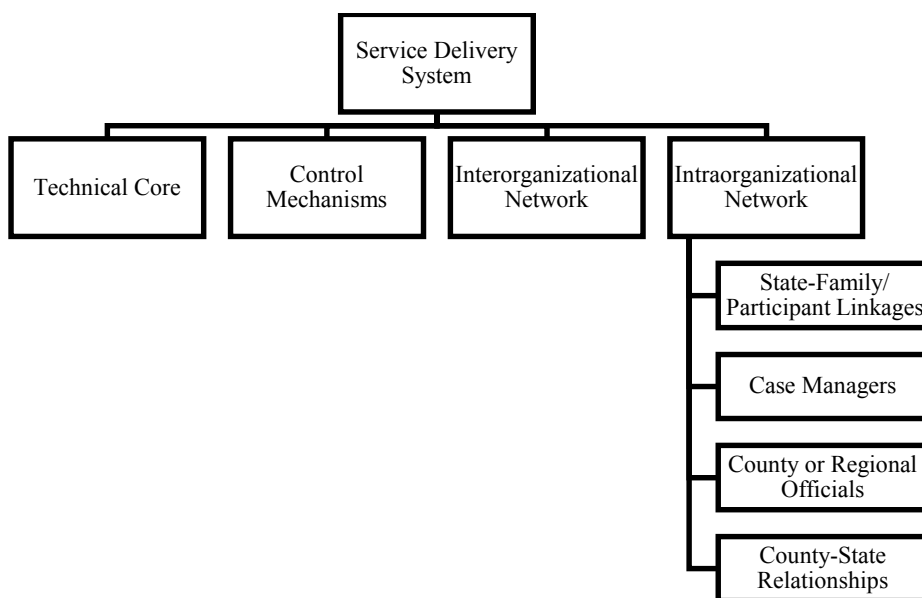


Figure 8: The Intraorganizational Network

***State-family/participant linkages.*** The relationships between the participants or families and state actors were the most frequent codes within the data set. While members of the intraorganizational network and participants are linked through many of the tasks in self-direction—in-home monitoring through case management, seeking pre-approvals for large purchases, and so on—this category describes the quality of those relationships and interactions. Strong linkages between participants and the state are facilitated by components within the intraorganizational network that are well designed and perform their functions adeptly. Case managers are often highlighted as strong sources of connection between the participant and the state. When case managers are well trained in self-direction and administrators, provide participants “the right information,” and are able to communicate in the participant’s language, communication was described as effective, and as a result, the relationships are stronger. The work of the case manager and the state is facilitated by the use of technology. Multiple administrators reported the simplification of budget approvals, person-centered planning booklets, and participant handbooks as strengthening the program over time and easing the burden and stress on case managers, participants, and administrators. These components allow knowledge to be communicated and populated throughout the system, facilitating stronger relationships.

Descriptions of effective communication and strong links are counterbalanced with those of ineffective or difficult communication and comparatively weaker links. Multiple administrators reported the case management function as a crucial piece where communication can break down. If case managers are not properly trained or are new to their jobs, they may not be able to train family members on how to effectively engage in self-direction. For some case management agencies, administrators reported difficulty getting case managers to engage in the

specialized training needed to engage in self-direction, reducing the number of individuals entering the program. State-family linkages are also facilitated through administrators themselves, as part of training or responding to advocacy. State administrators who are passionate about self-direction, according to administrators, may alienate those who choose not to participate or those who may no longer be able to participate due to life circumstances. Communication can also be strained when participants are dissatisfied with a particular issue, such as a denied pre-approval or problem with a service provider, and administrators are unable or unwilling to accommodate their preferences.

***Case managers.*** In the experiences of administrators, case managers are a mandatory component of self-direction and perform numerous functions within the intraorganizational network. Although case managers were most often reported by administrators to not be direct employees of the implementing department, they are described by administrators as “a part of the department” or “agent[s] of the department.” In other states, case managers were described as part of regional authorities—state offices, non-profit agencies, or managed care organizations—that engage in monitoring and coordination of self-direction. For this reason, they were classified under the intraorganizational network rather than the interorganizational network. Administrators described case managers as “our number one resources,” the individuals who have a “direct relationship” with family members, and their continued interactions with family members “help ensuring the program is doing exactly what it’s supposed to do.”

Participants first encounter case managers during the intake and assessment process where administrators reported that participants are screened by case managers, they review the components of self-direction, and in some cases, complete a person-centered plan. If there is capacity in the program for the participant, the result of this process is the individual support



plan. Once a participant is accepted into the program, the case manager is also responsible for training participants on their responsibilities, as one administrator described:

“Then from that point, you have the case managers ... that will basically show them the ropes that help coordinate what's available to the person. What kind of pay rate ranges can they provide. What kind of duties can someone provide under a given service. What happens with multiple employees involved. Then of course the financial management functions, they will help out with trying to get those forms filled out. To designate that financial agent as a third party payer. Someone that can designate the payment of taxes, for that person. Handling the paychecks and quarterly taxes. Things like that.”

After participants begin to engage in self-direction, case managers engage in monitoring on behalf of the implementing department. Administrators reported that case managers must conduct regular remote and in-person consultations with family members. These meetings were referred to by many administrators as the first and most important source of monitoring within the program. Case managers speak to participants about their satisfaction with services and support workers, discuss potential changes to the ISP based on utilization during the year or changes in natural supports, review documentation for employer and budget authority, and screen for overall health, abuse, neglect, fraud, or other “red flags.” If misspending is identified by the implementing department, case managers are used to provide technical assistance to participants to ensure regulatory compliance. Once annually, according to administrators, this visit will include reviewing the entire ISP and engaging in a new planning process for the coming year.

During the service year, participants may wish to make large purchases or move money between budgetary categories. Administrators reported that these tasks are largely accomplished

in coordination with the case manager. For smaller changes, such as moving money from “adult day training center to supported employment” the case manager “moves the money around,” according to administrators. For larger changes, such as “moving money from adult day training center to dental” the case manager works with the participant to formulate a request and it is forwarded to the regional or state official who will approve it. For purchases or technology, case managers will work with the participant to make sure the technology is working appropriately during a trial period and assist with requesting a full purchase order from regional or state authorities. Participants who require substantial changes to spending have to work with the case manager to create a new ISP in order to authorize new categories of spending.

Case management is a required service in self-direction, but the degree to which individuals can exercise self-determination over case managers varies. One administrator reported that individuals can dismiss case managers. Although this was not found in the reports of other administrators, one other administrator reported potential reforms to case management that would allow the participant to choose their own case manager, define the case management relationship in a contract similar to other employees in self-direction, and opt out of case management entirely. These reforms are not likely “in the near future,” but the administrator stated that they would like to get a place where participants can say, “I want you to work with me, and this is what we’re going to work on together. In a significantly more limited way, participants in another state’s program can exercise self-determination by purchasing more case management than what is required by the implementing department because case management is a service on the self-directed waiver. These states are the exception, however, as case management is usually “outside” the waiver and is a required support for all participants.

Administrators also identified many challenges in implementing the case management component. Foremost among these is the opposition many case managers have to promoting the adoption of self-direction. Multiple administrators reported that case management agencies can be a barrier to access for individuals in traditional supports who want to engage in self-direction. As one administrator related, “if a consumer brings it to a case manager saying ‘hey I’d like to try participant directed,’ they’ll indicate we don’t do that here.” Another administrator concurred, finding that “there are certain [case management] organizations that have zero percent of their individuals served in participant direction...we know that's just technically saying it's can't be a coincidence.” This is particularly challenging for administrators, as case managers are often specifically tasked with promoting self-direction during the annual service meeting. One administrator cited lack of training as a possible issue, stating:

“Education's a big problem because I think that's one of the reasons we don't see much growth. Our case managers, in general, are supposed to talk to families annually about self-directed services and whether they're interested in self-directed services, but I feel like our general, most of our case managers generally don't know a lot, enough about self-directed services to describe it well to those families, so they don't know ... Maybe they don't know what self-directed services really looks like. I think that's probably our biggest problem with growth”

Training is a particularly important issue for case managers, as self-direction was described as a complex program that requires “special training...and not all [case managers] want to take on that additional responsibility. One administrator described targeting specific case managers for self-directed services and providing more training, helping make sure that when participants ask about the program, case managers are able to assist them. While

administrators did not state that there were specific case managers for self-direction and others for traditional supports, the additional education needed to provide appropriate supports and training to participants was an important part of the implementation process. The problem of inadequately trained case managers is compounded by multiple administrator reports of high caseloads that can overwhelm case managers.

***County or regional officials.*** Case managers were described by administrators as the front-line workers in the intraorganizational network, and they are often the direct representatives of county or regional officials—also termed “area agencies.” These agencies have similar functions to case managers, according to administrators. Once case managers complete the assessment, it is reviewed and approved by the area agency. Accordingly, when participants wish to move funds within their budget or purchase a good or service that requires pre-approval, regional officials will provide the first look at any requests. Not all purchases or approvals need to go through the regional agency, and state departments set regulations which regional agencies must follow in their approvals. One administrator referred to this monitoring function as part of “decentralization” of authority, in which area agencies are given funding and operate it on behalf of the implementing department and under their supervision.

While the monitoring role is clear in the responses of administrators, the structure of each state’s regional system was often difficult to discern. Area agencies often fulfilled multiple functions, including case management but also FMS, support brokerage, and approving spending. These roles are particularly complex in a managed care framework, wherein area agencies are also managed care organizations, though additional area agencies that perform case management and spending approvals also exist. Although the relationship between the area

agency and the case manager is clear, its relationship with other components is often more complicated in the reports of administrators.

Multiple interviews also described the use of regional administrators for the explicit purpose of promoting self-direction and the philosophy of self-determination. In some states these were the same administrators who oversee regular regional operations. They were tasked with “providing the support that the field needed...as well as telling the story” of self-determination and “providing awareness even for folks who don’t even know what [self-direction] is.” Administrators described the importance of these positions during the early parts of their programs. In another state, the positions were still broken down by region but were more associated with the state-level department. They were designated as “trainers and system change agents” without direct supervisory responsibility so they could focus more on “helping everyone to understand what this meant to the organization and how it was different from the way we did business previously.” These actors on the regional level were “critical” to the eventual success of self-direction.

***County-state relationships.*** The relationship between county and state administrations is mentioned in some of the reports of administrators. As discussed previously, the state designates regional administrators to implement and promote self-direction, and their problem-solving and collaboration was described as instrumental for successful implementation. Another administrator elaborated on the importance of being “bottom-up” in order to arrive at “solutions and strategies for better service delivery.” Using their state authority, that same administrator reported a top-down approach to change in which area agencies were incentivized financially to increase adoption of self-direction—suggesting the need for both strategies.

The desire for consistency across the state were reported in some cases to lead to frustration for administrators in their interactions with regional officials. Area agencies were often described as “challenging,” “reluctant,” and “fearful” of self-direction. Administrators cited the novelty of self-direction in comparison to the more “patriarchal” approach of traditional supports, and in this way, expressed understanding towards recalcitrant area agencies. For these administrators, training often done personally by them is a key component of arriving at the desired change—more self-directed participants and better understanding of self-direction.

## **Aim 2: How Do These Features Reinforce or Challenge Best Practices?**

For many components of the service delivery system, the results of this study are likely to support the existing literature on best practices. The primacy of opportunities for self-determination may reinforce best practice in the literature by demonstrating the penetration and adoption of the self-determination movement and self-determination theory. Additionally, the use of algorithms and standardized assessment tools maintain the person-centeredness of self-direction while introducing some measure of cost control and consistency across participants. Other components of the planning process are similarly congruent with the literature on best practices, including the use of backup and contingency plans and escalation procedures for cases of abuse or neglect. Within the interorganizational network, the literature describes improved support relationships when participants hire family members or friends, a finding that is supported in the results. Administrators reported that improvements in these relationships allow participants to remain in their own homes or the homes of family members, which is mirrored in the best practices literature. The specific roles that family members adopt within self-direction, as described by administrators, are important to differentiate. This is also supported in the best

practices literature, with specific roles for employer of record, representative, and direct support worker.

While many results in the study are indicative of best practices, there were some features of the service delivery system that challenged best practices. Most importantly, the dominance of employer authority in the descriptions of self-direction and self-determination offered by administrators presents a challenge to the literature in which budgetary authority is considered of equal or greater importance to employer authority. Similarly, the lack of person-centered planning as a constitutive component of self-direction explicitly contradicts the very model of self-direction. While the roles of support broker and case manager are well differentiated in the literature, the descriptions by administrators portrayed these roles as somewhat interchangeable. Similarly, area agencies often fulfill multiple roles for participants—training providers, engaging in FMS, employing case managers—which may lead to conflicts of interest.

Within the service delivery systems described by administrators, there are results that have mixed support in the best practices literature. The characterization of employer of record as “true self-direction” may reflect a difference of opinion on what self-direction actually means. The training of support workers, varyingly described by administrators as solely the responsibility of the participant versus the responsibility of the state, is also a mixed result in terms of best practices literature. Cost control mechanisms implemented by administrators, including using discrete budget tiers or caps eliminate the person-centeredness of self-direction, may be viewed as less than ideal but understandable in some circumstances within the literature. Finally, there are some results where there is little literature and no definitive statement can be made, including competition between FMS providers and the importance of regional administrators in promoting self-direction.

### **Aim 3: Describe the Salient Forces Impacting Implementation of Self-Direction**

**Policy environment.** As described under Aim 1, the final implementation model for self-direction begins in the policy environment. According to Hasenfeld's original model, this environment can be classified as being turbulent or calm based on whether key actors in the environment agreed on important issues related to implementation. For example, an administrator in the Northeast described a calm environment thusly:

“When the option first started, I think that people were pretty open minded to it ... I think that people trusted that we could figure it out and make it work. At the time that the program was being developed, there was a lot of folks working in state government who really were invested in self-determination and self-efficacy, and really wanting that to work for people.”

A turbulent environment, conversely, described a policy context in which various stakeholders do not agree on implementation. For example, an administrator in the Midwest described a turbulent environment as confusion between multiple entities:

“CMS has not yet approved our transition plan ... so there's a whole lot of things up in the air as far as whether our transition plan is sufficient even though we have to move ahead, because we are now more than a year into the transition planning. I would say it's bumpy; more so because of CMS not giving us clear guidance as to whether we are on the right path and whether our transition plan is what they want or expect.”

Hasenfeld hypothesized based on an inductive analysis of the implementation literature that turbulent environments negatively impact implementation by creating less coherent policies, and that calm environment will lead to more coherent and rational policies. These hypotheses were not supported in the data set. While turbulence and calm were present in the policy



environment, their effect on the service delivery system implementing self-direction was complex and unable to be classified as either “coherent” or “incoherent.” Moreover, some elements in the policy environment did not contribute to calm or turbulence, but were simply present. The subsequent section will begin with a description of the subdomains that DDPAs reported as important in the implementation process and detail their effects on the service delivery system.

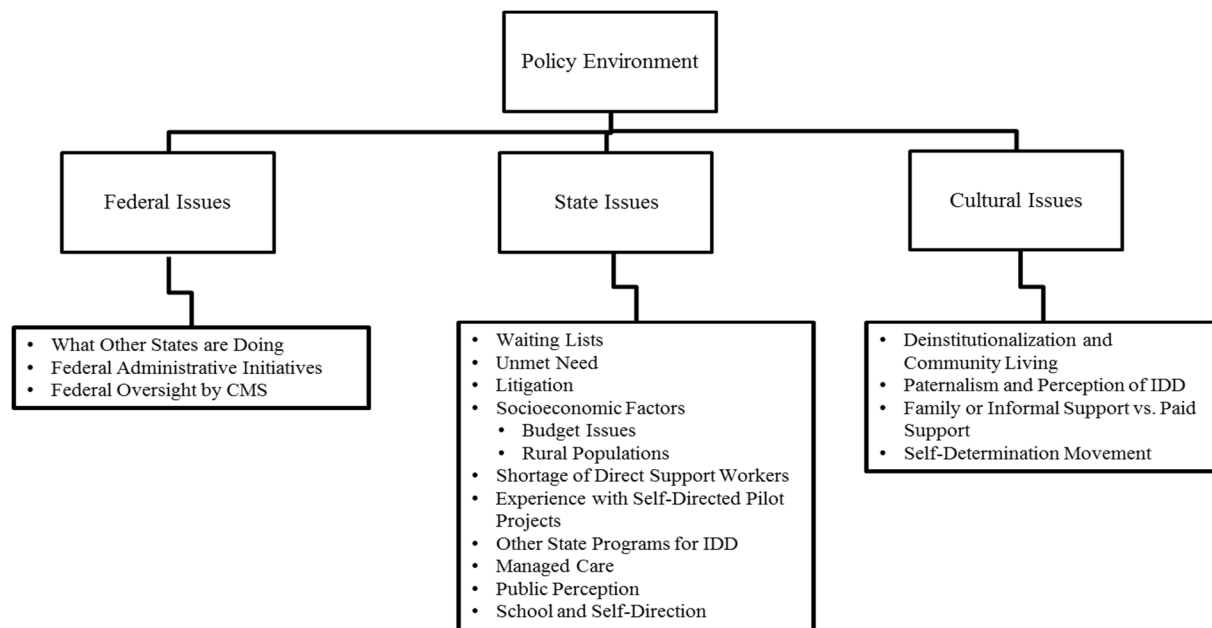


Figure 9: Policy Environment

### ***Federal issues.***

*What other states are doing.* Across the interviews, administrators reported that they are attentive to what is happening in other states. This was the second most prevalent code in the sample. While not a source of calm or turbulence, the events in other states factored into the implementation of self-direction. National trends are observed by state administrators from the perspective of how they impact other states. The implementations decisions made in other states are often used by administrators as benchmarks to evaluate their own state programs. An

administrator in the Southwest reported looking to other states' experiences before introducing a fiscal intermediary into their self-directed programs, and an administrator from the Midwest reported her state is considering moving their fiscal management "in-house" in order to save money based on the experiences of other states. Looking for best practices did not always result in policy change. Another administrator expressed frustration that his state's program was less robust than other programs:

"My perception would be, if I were to look at other states, I would think that this is a very handicapped version or participant directed. Again, while we do have hiring authority, training authority, recruiting and managing employees, setting wages and hours authority, termination authority, it's there. I still feel like it's handicapped, to some degree."

This state-to-state comparison is a source of pride in some states, with an administrator from the Northeast reporting satisfaction that "we are one of the few states where we have a very long list of services that are able to be self-directed. We don't limit, really virtually every service in our waiver...is able to be self-directed." Comparisons between states were also made by administrators regarding other aspects of the policy environment. Administrators compared the higher indigent rates, rural populations with difficult to reach participants, the shortage of direct support workers, and budgetary and financial concerns that are common across states.

*Federal administrative initiatives.* Two important initiatives were found to be impacting implementations of self-direction at the current time—the CMS community rule and the Department of Labor's regulations on home care workers. These were sources of turbulence in the policy environment, though there were some examples of these initiatives contributing to calm in the environment. Additionally, administrators reported that other initiatives impacted the implementation of self-direction including the push for 1915j and 1915k plans.

While the majority of administrators reported that the new CMS community rules were unlikely to impact self-direction in a significant way, they reported the transition as bringing “a little bit of anxiety” and contributing to turbulence in the policy environment. Administrators demonstrated uncertainty about the true effects of these policies once they are fully implemented. One administrator from the Southeast asked, “As we seek the direction of the federal government, are there group homes that will not be in compliance? Are the sheltered workshops already out of compliance? Every state is going through that struggle right now.” Interactions with CMS are reported to contribute to this uncertainty as, “every single time that there's another call, there's more, ‘By the way, we think you should be doing it this way. Can you change your plan to do this? Can you change your plan to do that?’” An administrator from the Northeast concurs, offering that “I don't know that when that rule [was] issued, the challenges involved in serving people with developmental, intellectual disabilities were really considered.”

Contrasting with these negative reactions, most administrators when asked how the new community rules affected their implementation of self-direction flatly stated: “it didn't.” Self-direction was seen as being “provided in an individual's home which is completely community-based,” and therefore in compliance with the new community rules. For those states where an impact was felt, administrators reported “a few tweaks...to person-centered planning, but that was always expected [and] should be done anyway.” Minor tweaks in a Northeastern state involved clarifying specific service types with the fiscal intermediary, which was a source of turbulence, while also making the budgeting process more straightforward for support brokers and participants, which was a source of calm. A state in the West reported needing to create quality assurance measurements to ensure that community integration could be demonstrated to CMS, but that this was their only concern at the time. Many felt that the community rule would

bolster or further strengthen their existing self-direction implementations, as self-direction is the “epitome” of community-based services, according to an administrator in the South.

The Department of Labor regulations, contrastingly, were seen largely as a source of turbulence within the environment. One administrator from the Southeast described:

“the element of care has been broadened so now people providing companion services would no longer be exempt from minimum wage requirements so you know where someone was acting as a companion before could be left making 5 or 6 dollars an hour now they have to be making more which uses more of the individuals budget they are also not exempt from overtime so that uses more of the individual budget. Yet states aren’t getting more money to be able to support this change [MD: right] and what was happening was people had fewer hours to use and staff was people in jeopardy although there was challenge filed to that the Department of Labor ruled on and it’s now waiting for the appeal to finalize so that's in a federal court.”

However, a state in the South described this transition as not stressful, as “we had already kind of set some things in motion, set some things in policy that already met some of those requirements... [by limiting paid care to] 40 hours a week and not [paying for] overtime. That really kind of helped to protect us from some of those overtime and department of labor requirements.”

*Federal oversight by CMS.* Federal oversight by CMS refers not only to the administrative initiatives covered previously but the day-to-day operations of self-directed programs that exist under the supervision of CMS. Self-directed programs must conform to the rules set forth by Medicaid and documentation must be provided regularly in order to support Medicaid billing. A state in the Northwest reported being “dinged” by CMS for inadequate

oversight, and as a result, “paying very strong attention to increasing that” as well as creating an electronic payment system. Another source of turbulence was the issue of “consolidation” of services within Medicaid waivers. States reported that CMS required that states “break out” service types where they had previously been consolidated under a general heading, such as “personal support.” One state administrator reported that responding to CMS with the voices of family advocates was instrumental in retaining the consolidated services, as “that’s not how our lives work.” Another state reported discontinuing an unusual way of service delivery, as “our friends at the federal government are not necessarily crazy about giving money directly to individuals or families.”

#### ***State issues.***

*Waiting lists.* The most frequent environmental variable found within the state issues was waiting lists. This code is highly linked via co-occurrences with the unmet need code. Waiting lists and the unmet need they represent were often forces of turbulence in the policy environment. According to one state in the South, “you have to show you really need the services [because] that’s how people are receiving services, based on a crisis need.” Many states described waiting lists prioritized by level of need. A state in the South described their levels as “urgent, emergent, and futures planning.” A state in the Midwest described their waiting lists as so extensive that individuals “end up going on a waiting list...because people anticipate sometime in the future [needing] waiver services.” Many administrators also described trying to transition current waiver participants to self-sufficiency in order to “serve more individuals off of our waiting list.” Waiting lists were also related to litigation over self-direction, which will be addressed in detail in a subsequent heading.

For those states in which waiting lists had been eliminated, however, the absence of a waiting list was a source of excitement and pride within the interviews. As one administrator in the West put it, “We don’t have a waiting list anymore! That’s what [self-direction] did. It has opened the door to countless families and children. Anyone who comes through the door who is IDD eligible, meets financial Medicaid standards can come in the door for services.” This administrator tied the lack of a waiting list to the creation of a state-wide self-direction program, but administrators reported various causal factors behind the lack of waiting lists including the structure of a managed care environment and the federal funding and the structure of the 1115 waiver. State funding is an important component to waiting list reduction. As an administrator in the South explained, “It’s always driven by money. Everything in what we do, limits are set by money...Our general assembly has been very generous in the last two years especially helping us reduce our waiting list by getting more and more people enrolled in these waivers.”

*Unmet need.* Unmet need and waiting lists were highly interconnected codes in the analysis. One important difference is that unmet need was only a source of turbulence in the policymaking environment; whereas waiting lists were also a source of calm in states where they had been reduced or eliminated. Administrators described unmet need in the policy environment as a source of “struggle,” where there is “a growing list of those who don’t have services compared with those who do.” An administrator from the Northwest described this as a split between the “haves and the have-nots” and that this split contributed to litigation that is still impacting HCBS services in the state. Multiple administrators expressed dissatisfaction with the length of waiting lists and frustration with the inability of additional state dollars and the political will of the governor and legislators to make a significant dent in the waiting list. Many

expressed that providing some funds to individuals with disabilities, even if they did not provide for all of their needs, would be better than the status quo.

*Litigation.* Litigation related to self-direction was mentioned by some administrators, but since it was not asked directly, its effect was likely understated. Litigation was often mentioned alongside waiting lists. Multiple administrators described lawsuits in the 2000s about the length of waiting lists and inability to access services in the community. At the time, these lawsuits would be classified as turbulence, but their effects became more mixed over time. Some administrators reported that the lawsuit sparked political will to deal with the lengthening waiting lists by expanding access to services. Other administrators responded by creating additional waiver programs that better served the population who were on the waiting list for existing services, such as one program created for individuals who needed only non-residential supports. For one state in the Midwest, an ongoing consent decree ensures continued funding for new self-direction participants in spite of budgetary cutbacks in other areas of the state budget. Federal lawsuits are also pending regarding the Department of Labor regulations, and the uncertain outcome of these lawsuits is reported as a source of turbulence in the environment.

*Socioeconomic factors.* States vary both in their demographic makeup, social trends, and economic health. Rurality was often noted as a source of turbulence in the environment, and it will be reviewed subsequently as its own code. Other socioeconomic aspects that contributed to turbulence in the policy environment included the size of states and the inability to ensure consistency across diverse geographical areas. For example, rent subsidies included as part of self-directed waivers were different from a major metropolitan area to the rural parts of the state. Another state offered that its high rate of retirees contributed to large numbers of individuals

waiting for services, particularly for parents of advanced age who care for individuals with disabilities.

*Budget issues.* One of the most important issues in the socioeconomic environment was the health of the state budget. Many state administrators reported “dire” or “interesting...tightly interesting” (euphemistically speaking) budgetary environments. Even in states of comparative fiscal health, self-directed programs are not safe from budgetary cuts. One administrator recalled attending a conference with David Braddock, a well-known researcher on self-direction and policy for individuals with IDD, where he called out their state as lucky because their state’s economy is growing and their budget is balanced. This administrator remembered responding that, “just because the state has money doesn’t mean the developmental disability system has money.” That particular year, they faced a reduction in their overall budget despite the fiscal health of the state. Most administrators, however, reported that their program was well supported in the legislature and that this support was accompanied by enough resources to maintain or slowly increase capacity over time.

*Rural populations.* Having a large rural population who did not have access to traditional services was a reoccurring theme throughout each interview. One administrator in the Midwest reported conducting “a geo-map a few years ago and identified that there was a [supports] provider within 30 miles of [everyone]. But when we actually looked at the ability of those providers to get there, it was hard.” An administrator from the Northwest concurred that “you might have a traditional provider who wasn’t wanting to serve people who might be fifty or a hundred miles away from where their agency was operating.” Administrators reported that the ability of self-direction participants to hire family members, friends, or neighbors as direct support workers was key to the program’s success. Self-direction allows administrators to



support challenging populations, such as people living in very rural areas, including Native American reservations, in their own homes rather than serving them in institutions. Providing quality and assurance and monitoring for a network this decentralized was identified as a challenge by administrators. Many expressed that it was difficult to know whether services were truly being provided, whether there was a risk to individuals, whether state money is being spent effectively, and whether relationships between support providers and support recipients are equitable, especially when compared with traditional supports.

*Shortage of direct support workers.* Many administrators in the sample listed the lack of DSWs available for participants as primary sources of turbulence. While participants are able to hire family, friends, or neighbors to provide personal support work, that mechanism relies on natural supports that are not always present for participants. Additionally, administrators highlight a lack of “knowledgeable” and “consistent” providers to engage in support work for individuals with disabilities. In the case of one state in the Midwest, an administrator reported a “staffing crisis” in which “those staff that are retainable and knowledgeable and have that compassion are underpaid.” A state in the West responded to this issue by piloting a new self-directed program that provided greater flexibility in pay ranges to retain consistent and knowledgeable providers. Not all administrators reported this issue, however, as one in the Southeast reported having “a ton of providers [where] people actually do have a pretty good choice.” Administrators contextualized the lack of quality DSWs in their state within the national shortage of direct support workers.

*Experience with self-directed pilot projects.* The majority of administrators interviewed for this sample were not in their current positions when the programs started; nevertheless, institutional memory and the experiences of coworkers and former administrators were related as

part of the data gathering process. Almost all administrators reported that experience with pilot projects was a source of calm in the environment. For states who had started self-direction beyond the past decade, Robert Wood Johnson (RWJ) grants were spoken of positively as a source of financial and technical support. State administrators described these grants as vital to the success and growth of self-direction in the long-term, as case managers and support brokers “had intensive training” in self-direction and manuals were created to explain services to individuals with disabilities and their families. RWJ grants also “created a focus” on self-direction that helped state administrators who were sympathetic to the self-determination philosophy to create the first pilot projects for self-direction. The funds from the RWJ grants also coalesced the advocacy community behind self-direction, as an administrator from the South explains:

“When the RWJ grant came around... 2004, that's where advocates got involved. That's really going to be the crux of the response here to this question is, advocates came out and basically said, ‘We realize. We recognize what the agencies are getting for providing care to these individuals. Give the power of the money to the people, the individuals themselves, and they will make the money stretch better. When a lot of people choose participant directed or consumer directed options, their number one response is going to be traditional services were just not cutting it for us. They want it available at certain times. Low quality. High turnover rate.’ Whatever it may be. The advocates were basically pushing for it at that point, to try to figure out a way to have all this infused into the waivers. That's where it came about in '04 with that grant. We distributed some startup money to different regional offices that we contracted with and we started it up in 2006, with the Home and Community Based waiver”

In many cases, these programs were seen as “opening the door” to the present self-directed offerings. However, some experiences with pilot projects were sources of turbulence in the policy environment. An administrator in the Midwest described a program with lax oversight, “beyond what I think the average taxpayer would feel comfortable supporting—big screen TVs, things like that.” Transitioning to a Medicaid waiver program involved setting parameters on spending and approved goods and services for participants in the program and a focus on fiscal stewardship and monitoring. Additionally, a few state administrators reported that these pre-Cash and Counseling programs continue to provide benefits today. Administrators reported that transitioning participants from these early self-directed programs to more modern options was an important task.

*Other state programs for IDD.* Administrators mentioned that self-direction operates within a context of other programs designed to support individuals with IDD. In some cases, this interaction was synergistic, in which individuals participating in a child and family services program in the Northeast were more likely to participate in self-directed supports. Other administrators described self-direction as part of a continuum of programmatic supports for individuals with disabilities, wherein individuals could transition from in-home care using self-direction to residential services depending on their needs at a given time. Ultimately, interactions with other programs for individuals with IDD were not described as relating to turbulence or calm in the environment.

*Managed care.* Managed care was not a frequent code in the data set, but its impact on state implementations is likely understated within this research project due to the lack of direct questions about it. Some states who are transitioning to managed care describe the process as contributing to turbulence in the environment—as a change that followed from a governor’s

initiative to be studied and implemented within a calendar year. For those state where managed care, administered via a separate Medicaid waiver authority, was already implemented, the relationship was described as contributing to calm in the environment. A state in the Midwest related that because of the managed care system, “there aren’t waiting lists,” and “everyone that’s eligible is served.”

*Public perception.* A few administrators reported that public perception of their program was an important factor in program implementation. A state in the Midwest described news stories in which support workers complained about not being trained in specific care tasks, and that when there are negative outcomes for participants, who is at fault—the employer of record, the support worker, or the state? Other administrators expressed that greater public awareness of self-direction would be beneficial in terms of outreach to potential participants as well as greater funding for existing programs. National rankings also factored into the general perception of the program, with one administrator from the South highlighting that the way programs are measured—money spent per participant— makes it “look like we’re cheaping [sic] out on people,” when really “we have more people in the family home” so less money is being spent.

*School and self-direction.* The school system in the state was an emergent code in the data set, though its importance is likely understated due to a lack of direct questioning. For those administrators who mentioned schools, the transition from services provided through the schools to those provided through the developmental disabilities administration was often mentioned by administrators. The school system, according to an administrator in the Midwest, “includes” students, and as a result, makes “the self-determination option very appealing to them.” An administrator in the South reported that the flexibility of self-directed goods and services allows

parents to pay for camps during the summertime when children are not provided supports in schools.

“Families are able to go to work during the summer still and not worry about what happens to their individual they have options and respite options available to them now where in the past when children got out of school for summer parents didn't know what they were going to do with their kids. That's positive, and it's great”

***Cultural issues.***

*Deinstitutionalization and community living.* Many of the interviews focused on themes of deinstitutionalization and community living. Administrators expressed pride in the closure of institutions and the proportion of individuals with disabilities who are served in the community versus nursing homes or state-run institutions. An administrator from the Midwest reported that deinstitutionalization sparked advocates and administrators in many counties within the state to create self-directed options using county funds. The success of these programs eventually sparked state-wide self-directed waivers, though the county systems remain in place to some degree. Administrators linked deinstitutionalization with the desire to provide greater community integration for individuals with disabilities as well as the recent CMS initiative to minimize settings that have a tendency to segregate individuals with disabilities. An administrator in the Northeast spoke negatively of the “residential group home mentality” and critically examining if those homes are truly “community integration.” The transition to a more community-focused treatment mindset is not always smooth. An administrator from the Southwest reported that many of their “staff worked at the institution when it was opened, and it's a different mindset and expectation of what people can do.”

*Paternalism/perception of IDD.* Another important issue for administrators was the perception of individuals with intellectual and developmental disabilities in their social context—including family members, providers, and policymakers. As one administrator from the Northeast related, “there is a level of ignorance about what people with intellectual and developmental disabilities can do.” Administrators reported that implementing self-direction involved “more of a system change or a philosophical change with some of our providers who are very paternalistic...you know it’s my way or the [highway].” An administrator from the South offered that participants were often “treated as if they have peaked in their independence...particularly those that have a lot more severe intellectual disabilities.”

When paternalism presents itself in a policymaking setting, administrators reported that having a robust advocacy community is instrumental in correcting the misperceptions of individuals with IDD and promoting a sense of capability to engage in self-determined behavior. Administrators expressed feeling particularly challenged when confronted by paternalism within the family context . An administrator in the Northeast reported that families often feared for their loved one’s safety when they were not in a congregate setting. An administrator in the South reported that the ability to tolerate some degree of risk was important in accepting self-direction, as individuals making their own choices will often make mistakes and the natural consequences that arise can be beneficial. Many reported struggling to educate families about their administration’s perspective on participant self-determination and strengths-focused assessment, and that voluntary trainings according to one administrator in the South, were insufficient to bring families on board with their mission.

*Family/informal support vs. paid support.* Cultural values and state by state variability were noted regarding where a family’s responsibility to provide support ends and the

government's responsibility to provide paid support begins. As one administrator from the Midwest put it, "the family is making a choice to have that consumer still living in their home, so what expectations do you have?" One state in the Southeast reported that stringent restrictions on family members receiving payment from the state for support work was "a social decision and a values decision" that reflected the values of the state. Another state pointed to the ideological values in the state, and that the conservative state faced some difficulty in finding the balance between paid and unpaid family support. A state in the Southeast reported the balance as finding a place where state funds are not replacing natural supports, but that funds are worth paying if that support will keep a person from entering into a nursing home or facility at higher cost to the state. Other administrators reported that paying family members made fraud or abuse of the system more likely, particularly at the beginning of programs when stringent spending guidelines were not in place. As programs developed those guidelines over time, the distinction between unpaid and paid support became more important. One state in the Midwest described the decision-making process for whether or not to cover the purchase of iPads as part of a revision of an existing self-directed program.

"We basically said generic technical devices, so anything that could be used by any family member, we would no longer be paying for. That was met with some resistance from some people when they submit a public comment, but we just felt that the use of our public dollars was ... Certainly a Touch Talk that is programmed for someone is a different item than an iPad. I get the iPad looks a lot ... But it's a generic device that anybody in their family could use, so then it should just be something that the families purchase. Now if there's apps that are specific or something like that, we still allow for some of those purchases"

*Self-determination movement.* A few administrators mentioned the self-determination movement in their responses. For many administrators this movement provided the historical context in which the first self-direction programs were created in their state. Self-advocates in each state were said to have provided the political will to create these programs, ensure access across classes of disability, and retain their viability over time. An administrator from the Southeast specifically mentioned the five principles of the self-determination movement—freedom, authority, autonomy, responsibility, and confirmation—as goals that the current administration strives to achieve. For one state, however, self-direction is reported to have taken the focus away from self-determination and focus solely on economics and spending.

“I think um the other challenge for us because we are involved from the beginning days was it really ah initially started as a self-determination movement not as a self-direction movement and when that term self-direction came about and really began to focus more on the fiscal authority um we really struggled with that I think if the others disagree but I know I certainly did, that um it took away from the person centeredness and the um the division and the dreaming and the planning part of it and really got us into just focusing on how was the money spent and were people doing it in ways that could be justified through the scrutiny of that you know public lens”

**Policymaking.**

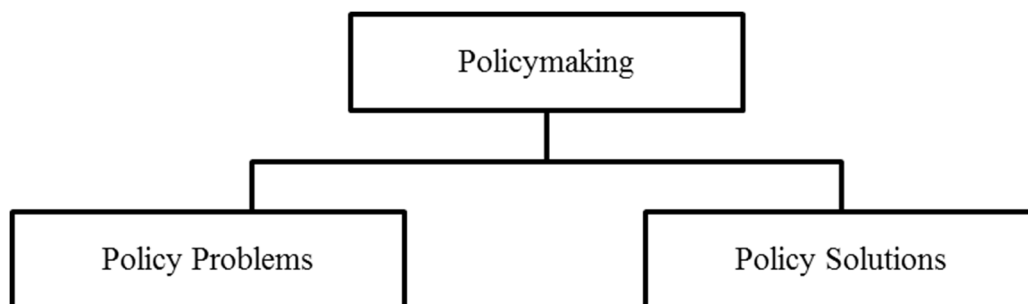


Figure 10: Policymaking



As a domain, policymaking was not often referenced in the data set. Hasenfeld's model proposes that policy problems will be coupled with policy solutions by the legislature. Self-direction presents a challenge to this model. While there were some instances of policy problems and solution coupling, self-directed programs are often created outside of the legislature, from the implementing department in consultation with local, federal, and private agencies. There were some examples, however, of policymaking impacting the implementation of self-direction.

Although self-direction is operated as a joint federal and state program, it must rely on the passage of state law. State laws were viewed by administrators as providing economic and political safeguards for the program. Additionally, as implementation issues arose, implementing departments often worked with the legislature to ameliorate problems. For example, a bill passed in a state in the Northeast created an advisory committee with the task of promoting self-direction and increasing utilization. While the political will to expand self-direction options was often cited by administrators, this did not always result in success. A state in the West provided an example of a failed self-direction initiative which was created based on dissatisfaction of participants with existing providers. This program was designed in the legislature and passed, but ultimately failed to gain federal funding. They reported success with the approval of a pilot project with the same intent—to provide more flexible and robust self-directed supports—but whose design was thought to make it a better fit for CMS funding guidelines. In Hasenfeld's terms, the policy problems were always related to increasing self-determination and access to self-direction for individuals with IDD. However, as one administrator in the Midwest put it, we have “been really good about thinking about those things, [but] where the rubber meets the road it's harder to get it through legislation.” Contrastingly,

one state in the Northeast relates that the policy solution of self-direction was coupled with a previously existing policy problem of community integration. “We see the [community integration] philosophy and participant direction as paying for it.”

### **Policy instruments.**

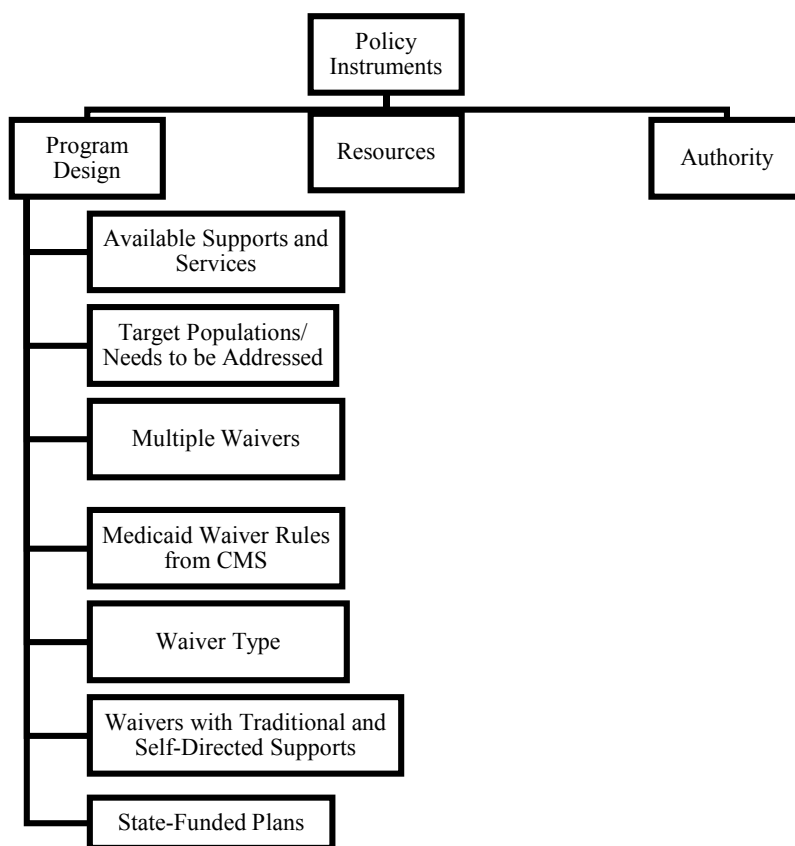


Figure 11: Policy Instruments

### ***Program design.***

Within the policy instruments domain, program design was mentioned numerous times as influencing the implementation of supports. Program design is defined as the specifications of the program—primarily, its available supports and services and target population/needs to be addressed. The available supports and services delimit what participants in self-direction may use their funds to purchase. Target population and needs to be addressed determine who may

qualify for self-direction and what specific needs the program was designed to address the environment. Without this information and the legal basis that the program design provides, administrators would be unable to implement self-direction in a coherent and consistent manner.

*Available supports and services.* There is wide variability between the states as to what individuals with IDD may purchase using funds from self-directed programs. Many administrators reported that parity between existing waivers and traditional programming was important in determining what services would be covered under self-direction. An administrator in the Midwest reported that their state's supports were designed to not supplant supports provided through their state plan option, a separate funding mechanism using general funds from the state. States varied in the degree of specificity in what supports would be covered, with some states bundling multiple supports under one heading, such as "community support." The specific supports in the program design were also accompanied by a specific purpose, which administrators took into account when individuals attempted to move funds from one service type to another in the budget amendment process.

There was frequent disagreement and contentious opinion noted in the "goods and services" category. Administrators spoke highly of the ability of participants to purchase items or services through this category that served unique needs, such as therapeutic camps and medical equipment. Participants and their families were characterized as exercising their budgetary authority through economizing on some service items, such as paying a service employee less or reducing use of respite, in order to pay for goods and services. An administrator from the Northeast reported that because of the goods and services category, self-direction "really opens up the menu of services that they may traditionally not get with an agency."

In spite of the fact that administrators highlighted openness and flexibility of goods and services as positive attributes, they also noted the administrative challenges posed by reporting and funding. An administrator in the Southeast reported that even with a specific class of goods, communication devices, there was such high variability in unit cost, that it was unfeasible to create a standard cost to incorporate into a participant's budget calculation. Many states reported having to create lists of varying length of approvable and non-approvable goods and services. One administrator from the Northeast described the process as starting out with a few service codes encompassing many smaller services which became "bigger and bigger and bigger" as the approved service list became more specific. Multiple administrators related stories of particularly egregious uses of the goods and services category including fixing a roof on a house, "the Cadillac of ski passes," "a flat screen TV," "a trip to Geneva," among many others. Administrators expressed dismay that these were ostensibly justified through identified deficits on an individual's plan of care and related to specific treatment goals.

As a result of these issues, administrators described a process of moving from a very flexible and open system to one that is more restrictive. However, even after administrators had created a list of approved and unapproved services, the list was placed within provider manuals, which participants "have no particular reason to...wade around in." As a result, administrators reported that goods and services requests were often made on a "case-by-case" basis which increased administrative work. In addition to the decision-making process, goods and services posed a challenge for administrators in quality assurance, as unique requests and spending were difficult to compare from participant to participant. One state in the Southwest reported that goods and service had become so burdensome that it was discontinued.

*Target population/ needs to be addressed.* Administrators reported that the target population and specified needs served multiple purposes. At its most basic, these categories specify which disabilities are covered under the self-directed program. This changed historically, as one administrator related, when IDD was recently separated out into its own waiver after being served for a long period of time alongside individuals with AIDS, TBI, and other populations. Individuals with IDD, according to administrators, are sometimes served under programs that are designed for other populations, particularly acquired brain injury, traumatic brain injury, and medically fragile waivers. For some administrators, this overlapping in service populations was a challenge, particularly around the competency of individuals with IDD to engage in the process of employer and budget authority.

In other cases, the need was less tied to specific diagnoses and classes of disability and rather to a specific need in the policy environment. One administrator specified that the limitations of the 1915c waiver criteria disallowed them from reaching individuals who did not meet the ICF/ID level of care specified by CMS. As a result, they started a 1915i which is more flexible about the population to be served. Additionally, an administrator tied the purpose of self-direction with compliance with a consent decree. Individuals who were in privately operated residential facilities would be served first, as they were the plaintiffs in the litigation, and only after they were offered the opportunity to participate in community-based self-directed supports would the state be able to service individuals from the waiting list.

*Multiple waivers/programs/options.* While some states implemented self-direction as part of a single waiver, the majority of states reported having multiple self-directed programs. Administrators reported that this was not a conscious decision at the outset but rather the result of making implementation decisions within an environment that already contained existing

programs that offered self-direction. For some administrators new programs were designed to eventually replace older programs, particularly those that predated the Cash and Counseling studies. In other cases, new programs were designed to reduce the waiting lists and comply with consent decrees related to previous programs. Successful implementation of self-direction with one population often resulted in infusing self-direction into other populations, as one state in the Southeast did expanding self-direction from an adult services waiver to the children services waiver. Most administrators reported that these programs functioned well as a coherent whole, especially the interactions between 1915b and 1915c waivers for states that worked under managed care. Different waivers and programs were sometimes implemented by separate departments, which resulted in DDPA's not knowing as much about certain waiver programs even though they served the IDD population.

*Medicaid waiver rules from CMS.* Administrators reported that rules from CMS were impactful throughout the implementation process. CMS regulations governed who would be accepted into Medicaid programs, based on medical and financial eligibility, and which services were likely to be covered, based on a medical need. The difficulty of communicating Medicaid waiver rules to families was described as contributing to more difficult relationships with families. Many administrators reported that families had difficulty understanding that self-direction operated within the Medicaid context, and as a result, would not be able to pay for everything. An administrator in the Northeast related the frustration that “the bigger picture, the more systemic issues are difficult to impress upon people. Sometimes individuals in families have an increased difficulty in understanding what is truly a need and what is a want in terms of services and funding for services.” The regulations that govern what is covered and not covered under self-direction are explained in Medicaid regulations that were described by one

administrator as “byzantine.” One administrator from the Northeast reported that these regulations were difficult for the department itself to interpret, resulting in putting “more requirements in place than what is absolutely necessary” based on the CMS regulations. The need for ongoing conversation with family members about what is appropriate for a Medicaid program was often described as a source of distress for administrators, as documentation and reporting requirements were identified as important parts of participating in self-direction.

*Waiver type.* The majority of states in the sample used 1915c Medicaid waivers in order to implement self-direction. Choosing a 1915c was not identified by administrators as negatively or positively impacting implementation of self-direction, but deviations from that pattern—choosing a 1915j, 1915k, 1915i, 1915b, or 1115 demonstration waiver—were identified as important in the implementation process. For example, choosing a K waiver was seen as a benefit by an administrator in the West because of the 6% matching funds increase the federal government provided as an incentive for states to use the K waiver. Transitioning from an 1115 waiver to a J waiver was also seen by one administrator as creating a more permanent program, as the designation shifts from a demonstration project to a permanent state plan. The restrictions on the C waiver, particularly those around the ICF/ID level of care requirement, were seen by more than one administrator as barriers to meeting unmet need in the environment, and as a result, were important factors in using a K or an I waiver. There are some states who continue to use 1115 demonstration waivers and report that the rules of that waiver allow them unlimited funds for individuals who meet the eligibility requirements.

*Waivers that blend traditional and self-directed supports.* Another choice administrators were faced with, either historically or in the present, was whether to implement self-direction as part of an existing waiver that offers traditional supports or to create a new program that only

offers self-direction. The majority of states in the sample chose to combine traditional and self-direction on the same waiver or program. An administrator in the Midwest related:

“Our self directed waiver, it was a smaller waiver. I don't remember the exact capacity. I think it was 150 people is what we had for capacity. We had extended services self directing. We had in home support, environmental modifications equipment and supplies. What we were ... We just really just kept it to self directing services. What we were finding is that people wanted to be able to access other services, like our day support, day habilitation, that type of thing. They couldn't, because that wasn't in that waiver. It was in our traditional waiver. We already had all of the self directed services in our traditional waiver, as well. It was just a matter of let's just ... We moved the slots over, and we just made it all one waiver.”

When waivers combine traditional and self-directed supports, administrators termed this an “option” rather than a separate program. Within self-directed options, states varied in the number of services that were available for self-direction. In one state, self-direction was only available for personal care services while other states reported parity or near-parity with the services available via self-direction and traditional supports. The relationship between self-directed and traditional supports was reported as a continuum, where self-direction enabled the purchase of non-traditional items and participants could choose self-direction for one service item and traditional supports for another, depending on their preference. Many states described the difference between traditional and self-directed supports as matter of small changes to administrative service codes.

*State-funded plans.* While almost all of the programs in the sample used the Medicaid waiver structure for funding, many states reported that there were additional opportunities to



engage in self-direction via state-funded plans. State plans were largely used for services and goods that were not covered under Medicaid waivers. Multiple state administrators reported that they were careful in the design and administration of their waivers to not “supplant” services covered under existing state plans. A state in the Northeast reported having to create budgetary control mechanisms for the purpose of preventing individuals from using waiver funds to pay for items that should be covered under the state plan. This was unpopular in their service area, as waiver funds provided the ability for participants to “shop around for whoever they want, [but] sometimes with the state plan, you’re limited to who that could be.” State funds were also used for populations that did not match the eligibility requirements for Medicaid waivers. This flexibility of funding sources was valued by one administrator in the Southeast, saying, “We really strongly have a stance that everybody that has intellectual disabilities, whether they have Medicaid or not, need assistance, and that's what we're here for.”

**Resources.** Implementation of self-direction requires economic and instrumental resources in order to achieve program outcomes. The most important resources highlighted by administrators were staffing and money. The most important staffing resource identified by program administrators was case managers. Case managers were described in almost all interviews as the “first line of defense” for monitoring and quality assurance as well as the representatives of the administration that knew the participants best. An administrator in the Southwest underscores:

“I think we have strong case managers. I think that they are very immersed in ensuring choice in self-determination, because our case managers are state workers. I think that our supervision of them, and being on message, and having a consistent workforce that really follows people through the years, I think that's a real strength”

Themes of “passion,” “institutional knowledge,” and “consistency” were common among administrators, and the effect was largely focused on the interaction between the implementing department and the participants and families served by self-direction. In states utilizing support brokers, administrators spoke highly of having support brokers “who are pretty seasoned and have been working in this field for a while.” An administrator in the Northeast highlights that having enough support brokers ensures that caseloads are low. An administrator in the South found that “good support brokerage...and financial administration [FMS] is what makes...our program go smoothly.” In addition to having a committed workforce, administrators highlighted the importance of having positions within the implementing department dedicated to implementing and promoting self-direction. An administrator in the Northeast describes their role as “push[ing] back against the larger system to make sure that what we’re doing is open and [ensuring] flexibility for families.”

The desire for more staffing resources was a recurring theme in many interviews. Most administrators reported that having more case managers would reduce the workload for existing staff, helping the system to keep pace with growing numbers of participants without “carrying a caseload that is not efficient [or] in compliance with our requirements.” Hiring new case managers was not a simple solution, as new staff lacked institutional knowledge as well as understanding of self-direction “as a different animal.” “High turnover” of case managers was also reported as a problem in some states.

While one state did report that monetary resources were not a large problem, the majority of administrators reported a desire for more monetary resources from the legislature. Cuts in funding were commonly reported by administrators. One administrator in the Northeast described how this affects service delivery:

“In some years, this year will probably be one of those funding cycles where the money is cut so we were not able we have to delay when we can offer that so instead of starting it on July 1 of our budget cycle we tell families that the money won’t be available till October or perhaps January. Um unfortunately last Friday our day budget was cut 3 million dollars that might this might be one of these years”

Administrators, when pressed to identify their “dream world” of self-direction and HCBS services, often mentioned more economic resources, or as one administrator quipped “an unlimited checkbook.” Yet, DDPAs contextualized the desire for greater resources within the economic forces within the state. One administrator in the Southwest captured it thusly: “We’re like any other discipline or field in the state. We wish all the money could come to support those with intellectual or developmental disabilities but we have to share the pot with those who are elderly and children’s issues and those with AIDS and those with cancer and those that also benefit from other state programs that are state funded. We always are vying, all of us, for limited funding.”

**Authority.** Administrators reported that authority was usually exercised with families and participants when participant spending did not match with administrative policies, including hiring unapproved family members, purchasing disallowed goods and services, and engaging in fraud. Exercising statutory authority occurred in many ways from direct interactions between administrators and families through directives to the intraorganizational network. Administrators reported using regional staff and case managers to enforce program regulations through providing technical assistance to families. For some administrators, authority within the program was used for creative and unique approaches to problems. An administrator in the Southwest described an innovative approach to ensuring regional administrators promoted self-direction:

“ A few years ago we, as part of our formula for how every area agency would actually get their wait list allocation the factors we put in there was number of [self-directed] arrangements an area agency had. That became one of the leading factors. We also put in employment as a weighted factor as well. That was one of the ways we tried to incentivize and then we also did a little bit of an incentive like if agencies had traditional services for individuals and those families converted to [self-directed] and those budgets were lower, we allow the area agency to use the gaps in funding, so if the traditional service say costs \$75,000 but then a family went into a [self-directed] arrangement and it cost \$50,000 that \$25,000 we allowed them to assign to other people that maybe needed additional service or services that were being provided that an agency wasn't able to bill on because the funding was capped.”

Authority, according to one administrator from the Northeast, is to be used with caution. They gave an example of instituting more training requirements for family members who provide paid support work.

“Let's say if I said everybody has to have CPR training, right, everybody's got to have it. Here's your source and what we're going to except and yada yada... You might have a situation where a family member or participant says ‘I really don't want my SSW to be trained in that. My mom's here 24 hours a day or something like that ... She knows CPR, or whatever.’ We don't want to start dictating to them just like we would a traditional provider. Part of the reasons for that too is because if you think about a lot of training requirements, a lot of training requirements are really designed with a congregate care setting in mind. That's not what's happening here. We're talking about real people living real lives.”

## Critical actors.

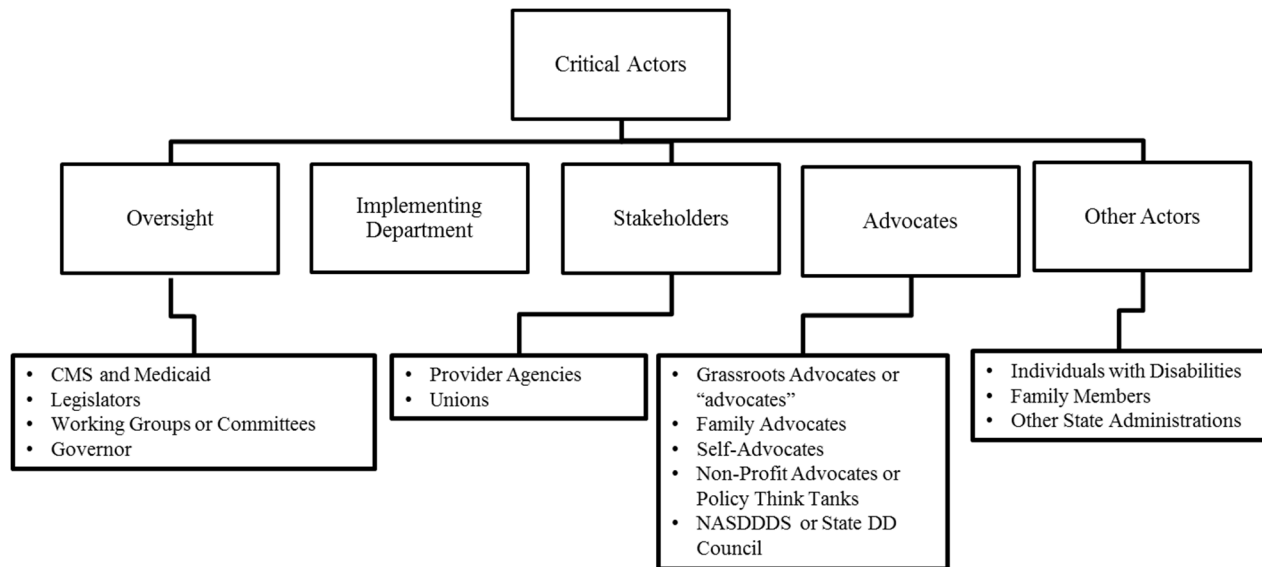


Figure 12: Critical Actors

### ***Oversight.***

*CMS and Medicaid.* The role of CMS in the implementation of self-directed supports lies in the supervisory and regulatory responsibilities that undergird Medicaid waivers. While some states offer self-direction independently of Medicaid through state plans, the vast majority of self-directed programs are implemented using Medicaid waivers. Administrators underscored the importance of billing correctly, monitoring and ensuring quality of services, ensuring compliance with CMS regulations, and remaining proactive about new CMS rule changes. Of particular importance at the time of the interviews were transition plans submitted to CMS to cope with new rules related to congregate settings and community integration. These plans are an example of the negotiation that occurs between state and federal authorities as part of implementation for self-directed Medicaid waivers. Administrators’ descriptions of federal oversight and new initiatives are described in the political environment section of this report and will not be repeated here.

*Legislators.* Administrators largely reported positive relationships with legislators. Implementation of self-direction relies on legislators to pass legislation in order to begin a program, appropriate funding for existing programs, raise or lower funding rates for programs, and phase out programs that have outlived their usefulness. Funding of self-direction is a contentious issue, as many states are undergoing significant budget cutbacks. As one administrator from the Southwest described, “we wish we could serve more than we do, but it’s all tied to legislative funding as to how many people we can allocate to a waiver at any given time...we only have so many funds that we can use to do that.” Many administrators reported that advocacy from the implementing department as well as formal organizations was important in building political consensus for legislators to create self-direction and raising and maintain funding for existing programs. At times, administrators specified particular legislators that were important in the implementation process. One administrator from the Midwest reported that the “minority leader in our state House of Representatives had a daughter with a developmental disability...and was one of the people that was able to put [self-direction] in state statute,” but this was not repeated by other administrators. More often, participants and families are reported to lobby legislators about “certain rules [or] interpretations of definitions of services in the home.” Administrators in these states reported responding with technical assistance or making changes to programs where possible.

*Working groups or committees.* Many administrators reported working with formal advisory groups composed of different stakeholders as part of the implementation process. These groups are convened on both the state and regional/local levels and fulfilled multiple functions including: increasing the utilization of self-direction, making changes to existing programs, providing feedback about how programs are functioning, engaging in policy decisions,

writing new waiver applications, designing outreach and training materials, creating survey materials for participants, and advocating for greater flexibility and funding for self-direction. One administrator spoke positively of a newsletter disseminated to their advisory council members as important in “updating what’s going on as it relates to our services [and] the people receiving services.” Administrators expressed appreciation for the “incredibly important” input of committee members and many underscored the democratic and diverse composition of stakeholders on state committees. One administrator who deviated from this pattern described a more contentious relationship with a workforce council, having to push back on many of the demands of provider agencies and unions as part of a unionization initiative.

*Governor.* Many administrators reported positive and supportive relationships with governors, and largely describe that support for self-direction through continued appropriations money to self-directed programs and signing legislation for new programs. An administrator from the Southeast reported that the governor is sensitive to the increasing waiting list in the state for services and has made additional appropriations, though new resources have not substantially reduced the number of people waiting. Initiatives from governors were also a source of stress for a few administrators, as new governors brought a vision for unionization or managed care that forced administrators to work with stakeholders and arrive at a workable solution. Changes in governors were also reported by one administrator who described “bumpy” relationships working with “acting directors and deputy directors” instead of “new directors, new deputy directors” appointed by the governor. The transition between administrations “slowed us down a little, and we’re not clear internally on the directions we need to go.”

***Implementing department.*** The implementing department refers to the administration tasked with implementing self-direction. Many administrators highlighted the importance of

having “top-down” support from “visionary administrators” who are committed to the philosophy of self-determination and self-direction as instrumental from program inception through implementation. Self-direction is a complex program that requires constant supervision and maintenance, so the “willingness” of administrators in the implementing department to endeavor to improve programs and satisfy the desires of multiple stakeholders was identified as an important factor in the implementation process. Implementing departments often delegated specific staff to promoting and enacting self-direction, which was seen as an important benefit. “Customer service” and “open-door” philosophies were identified by administrators as key in maintaining positive relationships with participants as well as a solid understanding of how self-direction was working or not working for participants and providers. Collaboration within the implementing department as well as leadership were identified by administrators as key to program success. Depending on the state, the implementing department either delegated outreach and training tasks throughout the intraorganizational network or report driving themselves throughout the state to provide technical assistance and outreach services to current or potential program participants.

***Stakeholders.*** Stakeholders refer to individuals and entities in the implementation environment that have a stake in the outcome of self-directed supports. Administrators defined stakeholders broadly, including “providers, coordinators [ed: case managers], individuals with disabilities, administrators,” as well as the state’s Developmental Disabilities Council, grassroots advocacy organizations, self-advocacy organizations, family advocacy organizations, unions, and working groups or committees. Thus, stakeholders are generally speaking formal organizations or members of formal organizations who organize to influence the implementation process. Their effects on the implementation process are detailed in more specific subcategories below.



*Provider agencies.* Hasenfeld hypothesized that the centrality of the stakeholder to the implementation process will determine their relative power in the implementation space. For provider agencies, this hypothesis is largely upheld, as provider agencies are described as a “strong trade group.” Administrators use the feedback of provider agencies, acquired through formal committees, vendor surveys, as well as informal feedback mechanisms, to create and modify self-directed programs. These interactions direct impact features of the service delivery system. One administrator in the West described using the feedback of traditional provider agencies to create a control mechanism that allows individuals who had a previous relationship with a DSW from a provider agency to hire them through self-direction without violating the agency’s non-compete clause, and at the same time, honoring the investment that the agency spent in training that worker. An administrator in the Midwest highlighted the importance of provider agencies as innovators, “trying to think of new types of services” for participants. This view of provider agencies was not shared by all administrators, as one DDPA from the Southeast reported that in their state, “the providers...seem to be the least heard.”

The practicalities of doing business as a provider agency mean that individuals with IDD who live in remote areas are less likely to be served by traditional providers due to service costs, which administrators cite as a major impetus behind creating a self-directed program that does not rely solely on traditional providers. While administrators expressed understanding of providers’ economic situation, they reported opposition from provider agencies during the implementation process. Because self-directed participants may choose DSWs from family members, friends, or independent practitioners, administrators reported that provider agencies “feel threatened...because they feel that it’s taking away from the consumers who would normally come to their day program and their residential program.” Residential providers, in

particular, are in opposition because “the way [residential] service is being provided now can’t remain the same” under the new CMS community rule. An administrator in the Northeast reported the transition from traditional supports to the individualized supports in self-direction as less of a conflict and more a matter of philosophical and technical change:

“I meet with 20 providers we just started a recent group that um is working on developing in home supports and so they have to go you know most of them have traditionally run group homes and group day services and so this is a really new way of doing business to provide individualized services. That’s the first step that you have to understand that individualized model of support and if you don’t understand that model and the implication of that model then you’re really not able to understand self-directed services. And a lot of agency providers I think they think because of course we’re person centered and of course we want to do what’s right for the individual they don’t necessarily understand that there’s still another leap you have to take and transform that kind of thinking into your daily operation.”

*Unions.* Very few administrators reported interactions with unions. These interactions were largely a source of stress, as one administrator reported that the case manager’s union “asked their members not to participate because it was more work, [but] that’s really changed over time...[as they see people grow and develop” under self-direction. Another administrator reported having to “push back” on the changes proposed by unions to self-direction that would have limited the discretion of participants to set wages for employees and blurred the boundary between the participant as employer by introducing the state as a “quasi employer” of support workers.

*Advocates.*

*Grassroots advocacy/ “advocates”*. Administrators spoke generally about advocates and grassroots advocacy within the state. When they specified the work of self-advocates and family advocates, it was categorized under these subcategories. When they spoke generally of advocates or grassroots advocacy, it was classified under this category. The words of an administrator from the Northeast best summarized the influence of advocates on the implementation process: “on one hand, they help us really understand what’s going on. And then on the other hand, when we’re screwing up, they’ll put us in our places.” The former function, information and feedback, runs bi-directionally between the implementing department and the individuals and families participating in self-direction. Advocacy organizations are present in program planning. As administrators related, advocates “helped the department workers developing this option” and “help in developing new services.” Advocates also relate administrative information to participants as well as promote self-direction by recruiting new participants.

The second function of advocacy groups in the implementation process is to apply pressure to the implementing department on behalf of the participants. Administrators often reported this pressure as helpful in the implementation process. When asked about the origin of self-direction within the state, many administrators related the pressure from advocacy groups as instrumental in building the will to enact self-direction within the implementing department and in the legislature. Administrators also reported relying on advocacy organizations to engage with legislators to dispel myths about individuals with IDD as it relates to pending legislation or existing programs. Pressure by advocacy groups was not always experienced as easing implementation, as administrators reported dissonance between the implementing department’s vision for self-direction and advocates’ vision. Advocates are described as desiring more

flexibility and higher budgetary allotments for participants which ran into conflict with administrators' "obligation for the health and safety of participants" and "cost-effectiveness." Administrators discussed these conflicts as part of a "give-and-take" process that pushes administrators to make changes to programs they may be "hesitant" to do.

*Family advocates.* Advocacy from families is highlighted by administrators as an important source of information and pressure in the implementation process. When asked why their state began offering self-direction, many administrators stated it was because "this is what families requested." Families expressed frustration to administrators about "not having control over who was working with their family member [and] wanting to break out of the box of traditional services," according to an administrator from the Northeast. Family advocates, as a subset of advocates in general, were specifically associated with developing training and outreach tools, advocating for greater funding in the legislature, and lobbying CMS to maintain existing service definitions to better match "how our lives work."

*Self-advocates.* Similar to family advocates, self-advocates or self-advocacy groups are identified as instrumental in the origin of many state's self-directed support programs. One administrator underscored the confluence of the rise of the self-advocacy movement in the late 1990s and early 2000s and the Robert Wood Johnson demonstration grants as creating the political will to implement self-direction. Administrators spoke positively of the ongoing impact that self-advocates have on the implementation of self-direction, detailing how they are empowered through inclusion in the program planning process and even mentioning the desire for greater self-advocacy within the state. In addition to planning and program feedback, self-advocates provide a human story of what the experience of service delivery is like for

participants. As one administrator from the Northeast explained, the process of making progress on self-determination is a personal story that is hard to understand from afar:

“That's hard to impart to people. That's how it's hard to grow. It's only when you have people in front of you that tell you their stories and really give you examples about what has happened to them that you see...it's not just a list of services you can pick from. It has a whole other dimension.”

*Non-profit advocates or policy think tanks.* Almost all administrators who mentioned non-profit advocates emphasized the role of the Robert Wood Johnson Foundation. RWJ grants to states are reported to be foundational in the creation of self-directed programs in providing technical assistance and financial support to train state workers throughout the intraorganizational network—from state-level administrators to front-line case managers. Present involvement of RWJ was not reported by administrators, but other non-profits have continued to provide support during implementation. The National Resource Center for Participant Directed Services was identified by some administrators as important sources of technical assistance, in particular for one administrator whose state was transitioning to managed care. Another sources of technical assistance was the American Association on Intellectual and Developmental Disabilities (AAIDD). As the developers of the Supports Intensity Scale (SIS), AAIDD is identified by administrators as instrumental in some of the more recent changes to the budgetary processes in self-direction across states. Additionally, one administrator highlighted the importance of an AAIDD Supporting Families Communities Practice grant in promoting community integration and responding to the implementation of the Able Act.

*National Association of State Directors of Developmental Disabilities Services (NASDDDS)/ state Developmental Disabilities (DD) council.* A few administrators mentioned

either the state's DD Council or their parent organization NASDDDS as important influences on the implementation process. DD councils are identified as important stakeholders in current implementation, providing solutions for problems in implementation. Present influence of DD councils builds on a history of assistance with program implementation, as one administrator in the Midwest identified grants from the state's DD council as instrumental in promoting adoption of self-direction. NASDDDS was also identified by one administrator as a valuable source of technical assistance and keeping administrators "aggressive not only with what is going on [on] the federal level but other states."

***Other actors.***

*Individuals with disabilities.* At the center of self-direction is the individual with IDD who engages in the process of directing their own supports. As an administrator from the Southeast defined self-direction as when an individual with a disability has "the authority to you know decide what service that they want. They're in control of their service delivery. They are in control of who provides the service, when they provide it, how it's provided to them. They're the ones making decisions." Self-direction, according to administrators will appear different from person to person, as each participant's supports are provided based on an individual support plan that incorporates the individual's needs, natural supports, and preferences—facets that vary from participant to participant. For example, "if an individual is prioritized for day services, we would have an allocation, and they could self-direct" that allocation. In addition to which services will be provided, individuals with disabilities also make decisions about the quantity and frequency of supports. How much of a given service or support an individual with IDD receives "depends on the individual and their family...they can purchase more [of a service] depending on the capabilities of the individual and sometimes how active the family is in helping them."

This flexibility and individualization is reported as a strength of self-direction, as it better accommodated the unique needs of “someone who might typically be fairly difficult in the traditional environment...who are challenging...to agencies.” Meeting the unique needs of individuals with disabilities who were not well-served in the traditional support system is reported as a benefit of implementing self-direction, but this individualization makes it difficult for administrators to generalize in the abstract what individuals with disabilities use self-direction to accomplish. As one administrator from the Southeast explained:

“A lot of people like to just simply go out to enjoy leisure events, things like that. There are some that are goal-based— that are participating in it in a very focused sense. I think majority of people tend to, not necessarily ... just use it as simply the focus to improve upon self-independence. I must sound redundant in a sense I guess, but just depends, I should say.”

Engaging in self-direction, according to administrators, requires that individuals with disabilities “grasp the concept of what kind of services are at their disposal” and “take on that role of looking for employees and managing employees.” The individual coordinates with a number of other parties, including a representative or proxy who is authorized to make decisions on their behalf, a case manager who ensures compliance with program rules, a support broker who assists with employing and budgeting, and the employer of record who may be an agency or a member of their natural support system. An administrator from the Midwest reported concern that within this network of other parties, they fear individuals “are not driving the services as much as parents, guardians, or others.” Administrators often reported that individuals “manage their budgets well,” “are very savvy” with their purchases, and “think of the state dollar, too.” However, there were also many administrators who reported difficulty imparting the strictures of

Medicaid regulations to individuals with disabilities. As one administrator from the Midwest explained, “individuals...don’t necessarily care about fiscal stewardship unless it impacts them personally.”

*Family members.* According to administrators, much of the services provided within self-direction are designed to occur in the family member’s home. Administrators’ vision for self-direction revolved around the individual with IDD and their family being “in control” of their supports and “promoting” that vision in their service area. A few administrators reported that younger families and those who are more well-informed about supports often choose self-direction as they are generally more well-informed about service options. In addition, family members often fill formal paid or unpaid support roles for participants in self-direction, including employer of record, representative or proxy, and direct support worker. This can be an important benefit, as one administrator in the Midwest related, “seniors were able to hire their adult sons and daughters to provide assistance, [and] because they had that option to be able to pay [the family member], they were more apt to ask for help when they needed the help...they felt good about the fact that they were giving them a job or helping them out.” Competencies of families to engage in self-directing their own supports were demonstrated by parents seeking out online training and resources from the implementing department as well as “looking or good staff...somebody who really knows their child.” Families were reported to be a strength of the service delivery system, as one administrator from the Northeast described:

“I truly also believe our family member participants working with the consultants have a huge role in the success of the program. Were it not for them, taking on their responsibilities as they’re required, remaining accountable, asking for help when they need it, getting guidance when they need it, meeting their obligations to stay eligible for



the program, monitoring their own program, monitoring their budgets, we would definitely not have an effective program.”

Complicating this vision of families as competent allies in the service delivery system, many administrators reported having difficulty “getting our families on board with our practices, our trainings, [and] our mission.” Administrators’ views of individuals with IDD are reported to clash with “family practices that are more punitive in nature [or] very high [or] very low expectations of individuals.” Family members were also mentioned alongside improper purchases or misuse of self-directed funds. An administrator in the West related that families normally do not engage in behavior that is “intentionally fraudulent,” but that “sometimes families will do things because they don’t understand the program or don’t understand the limitations.” Becoming an employer of record or engaging in budget authority as a representative can be challenging or “intimidating” for family members, and administrators reported these as obstacles within the service delivery system. More perniciously, an administrator in the Midwest described concerns that families “are keeping individuals at home just for the income that it generates through both the SSI payment and being able to become a provider and having us pay them to maintain the individual.” An administrator in the Southeast reported that “when any new service rolls out...there’s a lot of initial attempts to take advantage of the situation [by] directing the care of their children in ways that they would get paid for.” Largely, administrators reported coping with these issues through technical assistance and trainings administered by the implementing department or the case managers. Creating rules about where the family’s responsibilities begin and the state’s responsibilities end were also a result of this conflict between families and the implementing department.

Regardless of the positivity or negativity of the family/state interactions, the family environment remains a vital part of self-directed supports as the individual with IDD because the supports provided through self-direction are seen as filling in where family support cannot. In a simple example, this might involve “a temporary increase in the amount of hours [authorized]...if a mother went into the hospital...to have surgery.” Within the system as a whole, however, “getting the right supports in there” is a facet of “the more complicated dynamics of supporting someone with an intellectual disability or related condition in your home.” Administrators reported that they conceptualize self-direction as one among many programs that meet a family’s dynamic needs. The “burden” and “stress” that family members report as caregivers can accrete to something more complex when they may be unable to manage the workload of engaging in self-direction. An administrator from the Northeast explained her guilt and empathy for families who no longer feel they can self-direct their family member’s care:

“Things change and I think the hardest part about that is that families who enter into [SELF-DIRECTION] sometimes have a hard time feeling like they’re failing if they no longer can manage the program and they need to go to a traditional program. When you enter the door of [SELF-DIRECTION] sometimes it’s kind of like there are families who have been promoting it for a really long time and they may even talk about the traditional services maybe not being up to par but then they someday reach the time where it no longer works for them and people feel tremendous guilt. What I would hope is that we can get to this place where people recognize that [SELF-DIRECTION] is a continuum and alternate arrangements are going to work at different times for different people and you can weave in and out of those options at any time and without guilt or fear of failure.

I think we have some work to do in that area because I think our big thrust have been really promoting [SELF-DIRECTION]. I think that in retrospect it wasn't really communicated as a continuum. It was really communicated as this Utopian option and without really communicating that you know what? There's going to be times in life that this is going to be perfect and it's going to work great and it's going to be good for your family, it's going to be good for you but it's normal that things change and that it's okay to choose a traditional service arrangement.”

*Other state administrations.* The implementing department often works in tandem with other state departments during the implementation process. Because self-direction is common to many populations, including individuals with physical disabilities and those of advanced age, some administrators reported that multiple departments operate within the same strategic plan, coordinate on previous implementations of self-direction, and provide new client referrals to self-directed programs. Important departments highlighted by administrators include the Department of Child and Family Services, which may interface with families of children with disabilities to aging into DD or Medicaid services, Adult Protective Services and law enforcement, which handle claims of abuse or neglect of participants in self-direction, and regional Medicaid offices, which act as part of the intraorganizational network providing oversight and interfacing directly with participants. State Information Technology departments were also seen as crucial in transitioning the implementing department from paper to electronic records.

Administrators balanced these reports of coordination with other state departments with stories of challenges from other departments. In some cases, the reporting in the interviews themselves were hampered by the siloing of departments. Details of self-directed programs that

served individuals with IDD were sometimes difficult for DDPAAs to relate, as the program was housed in another department. These programs were sometimes state plans run through a department of health or other waivers housed in a Medicaid services department. Additionally, while some states reported that strategic planning was a consensus-based process, one administrator reported that after engaging in programming for one waiver type their office had to “jump in” and change to another waiver type in order to “align” how different departments funded their services. Another administrator singled out their legal department as openly hostile towards self-direction:

“We hear that all the time, and it's especially true for our oversight groups, like our program integrity bureau. There's a lot of fraud. There's a lot of fraud. What I usually come back is look, you need to try to convince me. I've worked in program integrity and oversight. If there's fraud in participant direction, there ain't no more or less than any other level of fraud out there... That's a big thing we have to challenge.”

When asked for reasons why their legal department did not like self-direction, the administrator offered:

“Probably for, maybe not the exact same reason as much as is a lot more difficult to try to defend something that we're doing. It's because it's human. It's nebulous. ... For instance, our support service workers don't sign any type of provider agreement. They're not Medicaid providers. The common law employers don't get anything. They're not paid, so they're certainly not providers in any sense of the word. You're talking about like your dentist who is botching your records and botching your documentation, and maybe needs to be sanctioned or terminated from the program. From a legal perspective, that's easy.

We've got books of regulations that say here's all the ways that we can take care of this.

Not so much the case in participant directed services. I think they're real resistant to it.”

### **Driving forces.**

In transitioning from the previous three domains to driving forces, the focus of the analysis speaks at a higher level of abstraction. Instead of the rote program elements (which services are covered, target population) or individuals and agencies in the network, driving forces refer to the conceptual connections between program elements and how they drive implementation forward or impede its progress.

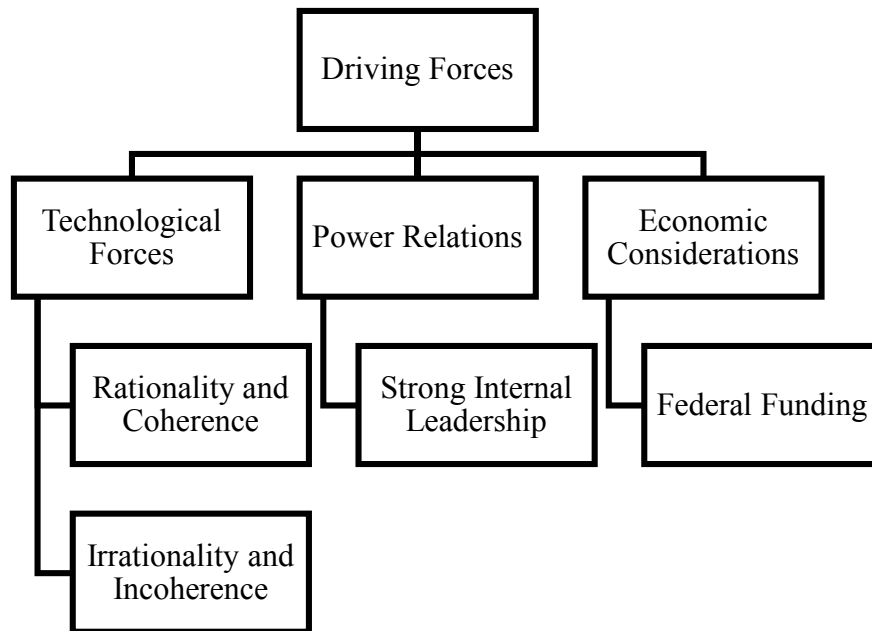


Figure 13: Driving Forces

***Technological specifications.*** Technological specifications refer to the specific components of the service delivery system—control mechanisms, the interorganizational network, the intraorganizational network, and the technical core—that are supposed to operate together. In creating technological specifications, administrators distill the program design into distinct parts that are arranged in a logical sequence in order to achieve the intended goals of the

program. It is unsurprising that technological specifications and its subdomains were the among the most common codes in the data set because of their centrality to implementation. They define what is to be implemented, and their effects are therefore substantially important to understanding implementation. Each administrator interviewed described a system with both rational and irrational components.

*Rationality and coherence.* When the components of the service delivery system—from individuals, families, support workers, and contracted companies— are performing their functions correctly in tandem with each other, the system is identified as having rationality and coherence. This rationality is importantly not a function of the performance or competence of specific individuals but the rationality and coherence of the system design that assigned them their task. A simple example of technical rationality is found in the comments from an administrator in the Southwest explaining the rationality of spending restrictions for participants. When asked why they decided to exclude services provided outside of the home from the state’s self-directed programs, the administrator cited the department’s desire for “folks to have the ability to manage those services that are coming into their environment” which matched the department’s goal of serving as much of their service population as possible within their own homes.

The rationality that holds together the various components of each state’s unique implementation of self-direction was identified as the most important driving force impacting implementation. Administrators generally agreed with the theory of change in self-determination theory that through opportunities for self-determination, individuals with disabilities will make healthy choices about their supports, individualize and personalize services, and experience greater satisfaction with supports—among many other positive outcomes. This general theory of

change for self-direction is complicated, however, in the responses related by administrators. Because administrators have their own incentives and motivations, rather than the singular “theory of change” posited by Hasenfeld, administrators described many theories of change based on the outcomes they wished to produce. Within a rational system, these goals mutually reinforce one another.

For administrators, a compelling sign of a system with rationality and coherence is that money flows to the correct places via the correct people or agencies. In assessment, individual support needs are assessed by the case manager in the person-centered planning process and transformed into a budget that embodies equity across participants—ensuring budgets are not “too high” or “too low” for assessed need—as well as the state environment—budget levels are economically sustainable for the state, for example. Once individuals receive their budget, they engage in spending and contract with providers based within the parameters set by the program regulations, making changes where they see fit. An administrator from the Southeast explained the process thusly:

“Let's say I want to just simply change a service, if I want to move some hours from personal care into respite or let's just say I want to take personal care out of the equation all together. I just want to create respite. I can certainly do that. It's just a matter of with respite, do I have a primary care giver named on my plan of care somewhere? Respite is considered relief of a primary caregiver. As long as you fit certain parameters and service definitions, there's really not much of an issue when it comes to shifting dollars around. Shifting hours around, to make it more personalized for the person.”

If support needs increase, a reassessment will occur in a timely manner and is forwarded to regional or state-level officials for review. The FMS provider will provide proper payment to

support workers and provide reporting to the case manager, participant, and the implementing department.

The proper allocation and spending of money is conceptualized by administrators as largely serving other outcome-related goals. In a rational system, participants should also have their support needs satisfied. Case managers conduct in-home assessments to ensure services are being delivered properly and that participants are satisfied with the services they are receiving. The FMS provides payment to providers and tracks spending for the participant. Family members or friends employed as support workers allow participants in remote areas to have their needs met. Unique needs, such as therapeutic camps or vehicle modifications, can be purchased through economizing on spending in other areas and receiving the proper authorizations from the implementing department.

As a result of their loved one's service needs being met, family members providing natural supports can engage in employment on the marketplace, rather than having to sacrifice working to provide supports full-time. The ability to control "the people coming into their environment" helps family members to feel more secure in that their relative's needs are being met inside the person's home by a responsive support worker who will be consistent across a longer period of time. Provided they remain within regulations, individuals and families can also make "day-to-day changes" such as "when your worker comes, what they do, who your worker is" without consulting other parties. Altogether, these improvements foster satisfaction among participants, and through word of mouth, more participants will enter services.

Ultimately, the rationality and coherence of technological specifications impact implementation by fostering positive program outcomes on the participant, administrator, and system levels. The recursive effects of these outcomes on the implementation process are



difficult to generalize across state implementations but serve as a virtuous cycle wherein each component mutually reinforces the next to create a more robust system.

*Irrationality and incoherence.* The many theories of change that administrators expressed are the technological mechanisms through which the program takes inputs, processes them through components, and produces outcomes. Within an irrational system, this process is subverted, threatening implementation through the production of negative outcomes and their redounding effects across the system.

The most common theme associated with irrationality is confusion about roles and responsibilities of participants, support workers, and other staff—termed “blurred lines” by one administrator. Self-direction is a complex program, one that breaks down the traditional service relationship between provider and participant into multiple component parts. Administrators reported that participants often misunderstand the roles of support brokers, case managers, and department staff, and even if they do comprehend those roles correctly, they might ask all three staff members and receive three different answers to the same question. One administrator from the Southwest reported that without codifying the “core competencies, of providers, of families, and implementing a training program around that... there’s a lot of drift...in practice.” The roles and responsibilities of participants, likewise, are a source of irrationality in the responses of some administrators. Administrators reported having to fight to preserve the existing employer-employee relationship between participant and support worker, which is under threat from multiple sources including restrictions on wages, negotiations with unions who would rather bargain with the state, and federal labor laws that increase the cost of employing support workers without providing funds to assist with the change. Moreover, unclear regulations about proper and improper spending for participants requires “case-by-case” approval by administrators for

purchases of goods and services that do not neatly fall into preexisting categories. Thus, although these roles are delineated in the model of self-direction, in practice there is a drift away from rationality.

Relatedly, administrators reported that because of the decentralized structure of self-direction it can be difficult to monitor and ensure quality. Because fiscal intermediaries handle payroll functions, they provide some monitoring functions, but an administrator from the Southeast related that “they don’t have on-the-ground eyes and ears support and assistance for the individuals and the family members who are receiving the services [which] makes it very difficult to evaluate.” Furthermore, if a problem is discovered such as “meth use or fraud...who is on the hook for it? In the self-directed model where the participant is the employer, you don’t have the pockets of an agency to go back to” in order to recoup fraudulently spent funds. Ensuring the health and safety of participants can also be a challenge, as one administrator from the Southeast found participants are “less likely to tell you about problems and less willing to monitor the problem...when they’re hiring their own family members.”

Many administrators reported transitioning from a relatively open program with few limitations on spending to one with many regulations around spending. In this early state, “it was really getting a bit out of control with some of the things that were being purchased...beyond what I think the average taxpayer would feel comfortable supporting—big screen TVs, things like that.” Self-direction’s theory of change should provide for fiscal stewardship by participants as well as effective monitoring by case managers and the implementing department, but without more stringent regulations on spending, they were unable to end improper spending. Even when participants spent money on items that were genuinely related to support needs, spending did not always embody rationality. An administrator from the

Midwest described “purchasing vans for transportation [that] the family couldn’t afford to maintain” or request a higher budget that might “replace natural supports” with paid supports funded by the government.

When restrictions are put into place to avoid misspending, the resulting paperwork and enforcement reside with administrators, case managers, and the implementing department. Multiple administrators described overwork in their department from “manual data entry” and “paperwork processing” to ensure that money is matched with support needs, an individual service plan, and a specific Medicaid service code. One administrator from the Northeast described:

“We were stupid... It's just so overwhelming. We have how many different codes? Like 90 some different codes. Everything is categorized by codes....As I said, we started extremely flexible and wanted people to be able to direct anything. We became more restrictive. I mean it doesn't look like it when you look at the list. We did actually. We had to unbundle a lot of the services, per our waivers. We would have a service code that might encompass a couple of different services and we had to unbundle them. It just got bigger and bigger and bigger.”

If service definitions do not present a “black and white, yes and no for every single thing” , administrators report “spending a lot of time with [regional administrators] about what is allowable and what is not allowable...depending on what’s going on for the individual” making the request. Administrators often referred to case managers as the front-line staff of the implementing department, though they are often private contractors. With the administrative goal of increasing participation in self-direction, case managers are reported to become “overwhelmed [by] carrying a caseload that is not efficient or in compliance with our

requirements” because of lack of funds to hire new case managers in some states or the additional training in self-directed support required for case managers in other states.

Keeping the many working pieces of self-direction functioning properly can be a source of stress for administrators; however, that force is also felt by participants. The “paperwork burden” is described by administrators across states as an important issue in implementation. Administrators reported that self-direction” is not for the fainthearted...you really have a lot of work to do to manage their budgets.” While there are components of the system designed to assist with participant budgets, such as FMS providers, they too are overworked and stressed by changes in the system. An administrator from the Northeast described:

“an absolute nightmare with handling...federal unemployment tax from year to year. What happens is, those percentages are adjusted on a retroactive basis and the FMA's have already processed claims to have those percentages associated with those wages that are provided by employers. You have an issue there where there could be more dollars that are charged to the consumer, if that tax spikes. Say it goes from 1.9% to 2.2%, then the consumer is responsible for those dollars. If the consumer is pushed up against regulation limits on what they're paying their employees, then they have to reduce wages and employees in order to fit those taxes into the billable rates. Just to capture what is current. If they calculate it properly, then they may have to reduce it even further to capture the dollars that would be issued in that spike for the previous year. That's just one example. It gets really complicated, unfortunately.”

As one administrator succinctly put it, “there’s a lot more that goes into working with an individual who directs his or her own services.”

***Power relations.*** According to Hasenfeld, the power of a particular actor or group of actors is determined by its centrality to implementation. A monopoly provider of a service in implementation holds great power in the implementation space because the program cannot be implemented without its approval. Within a polycentric and complex policy like self-direction, multiple actors could potentially withdraw their support and abruptly end implementation. CMS, as the federal department overseeing most self-directed programs via Medicaid, is a central player in power relations. That power is expressed through the ability to change state implementation features, such as transitioning from a voucher-based system to an FMS-based system, determining the parties present during the writing of a participant's individual service plan, and approving transition plans based on new CMS initiatives, like the new community rule. The power is expressed through individual interactions between DDPAs and CMS administrators as well as the written applications that DDPAs must use to apply for CMS funding. Should DDPAs choose to disregard or oppose a CMS recommendation or provision, as one administrator from the Midwest described, they can use other powerful allies such as family advocates and self-advocates whose power within the social space may force CMS to defer to the state.

Another set of actors with centrality in the implementation space are the governor and legislature within the state. A governor's power may be demonstrated by expressing support for self-direction in the public space as well as by appointing administrators and signing legislation that facilitates implementation. Governors also bring new initiatives, such as unionization and managed care that must be acted upon by DDPAs and incorporated into new or existing self-directed programs. Contrastingly, the legislature's power largely lies in appropriations of funding and in creating working groups or committees, which administrators report as useful for

strategizing about emerging problems and increasing the number of participants using self-direction.

According to administrators, provider agencies express their power both during the inception of a program as well as throughout its implementation and renewal. Provider agencies advocate for their own interests during implementation by creating favorable regulations and opposing changes that might harm their business interests. While classified in this study under the intraorganizational network, states often contract with private providers for case management services. One administrator recounted that case managers' centrality to participant recruitment into self-direction was expressed by turning away participants who expressed interest saying, "we don't do that." As another administrator from the Northeast described, "it's not so easy when we tell 48 business partners 'Hey, we think you should promote this.'" Although case management and other agencies were highlighted by many administrators as central, one administrator from the Midwest offered that provider agencies "seem to be the least heard." Advocates, while not a direct part of the service delivery system, are highlighted by many administrators as central in the implementation process. An administrator from the Southeast states that "if something wasn't working or if people weren't happy...we would hear from advocacy loud and clear." Similar themes of "taking us on" and "back-and-forth" between the implementing department and advocates show that while they are less central to the implementation itself, they remain powerful as evidenced by accomplishment related by administrators including the origins of self-direction in states, the expansion of pilot programs to state-wide programs, and reductions in waiting lists.

The most central actor to the implementation process is the implementing department itself. Most often, the implementing department uses its programmatic authority to ensure

compliance with existing regulations and create new regulations in self-directed programs. An administrator from the Southeast reported that when issues arise in the case manager- participant relationship, the department will “serve as a neutral party...to advocate for the person [but not] destroy the relationship that the case manager and the family have.” On a larger scale, the power of the department is substantial, as it creates self-directed programs and worked on amendments and renewals of those programs. This power was not universal, however, as one administrator from the Midwest describes a strong commitment by their administration to self-direction, self-determination, and person-centered planning “for quite some time” that did not produce tangible results. While a strong commitment to self-direction was identified as an important factor—described later in a subcategory—this administrator described power that was limited “where the rubber meets the road....It’s harder to develop things and get it through legislation and get it through CMS...all of those things.”

Power relations, regardless of the particular agents involved, were largely expressed within the context of coordination and negotiation between parties. An order from the governor to support unionization of the DSW workforce originated in coordination between governor and implementing department and ended in negotiation between the department and the newly formed union. This process is also mirrored in the description of advocacy to legislators by an administrator in the Southeast. Advocates and participants are “very quick to call the governor’s office or their state representative to complain about whatever...they feel is their issue.” The outcome of this process is negotiated between the department and the participant in part based on the relative power of each player in that interaction. Although issues of conflict are highlighted in some administrator’s responses, coordination was the more salient theme in power relations. Administrators described the importance of stakeholder input, advocacy assistance, and political

support to building a sustainable self-directed program—elucidating a view of power as a less adversarial force.

*Strong internal leadership.* An important subcategory that emerged in the data is strong internal leadership. Many administrators reported that programs originated from the work of “strong” or “visionary” leadership that expressed dedication to the self-determination philosophy and the self-directed model of service delivery. This power was exercised through helping regional administrators and provider agencies “overcome the fear and resistance” to providing participants with greater control over supports. Even among states that were not early adopters of self-direction during the RWJ pilot projects and Cash and Counseling, administrators reported that self-direction is “not checking a box...[it’s] more of a culture shift.” The idea of organizational culture was also key to sustaining the momentum through the life of the program. Multiple administrators reported that administrators in their department, other state departments, and individuals in the intraorganizational network express a commitment to self-direction that assists in solving problems. As one administrator from the Northeast related:

“A couple of us fall on very different sides about what we should do to promote participant direction. [My colleague] will testify, every week we have some very contentious calls with people about what are we going to do and what we think is best. The one thing I will say for each and every one of them is I may think their idea is the dumbest thing I’ve ever heard, but I know that they believe in participant direction and want to promote it.”

*Economic considerations.* In the original Hasenfeld model, economic considerations are an operationalization of the transactions cost branch of implementation theory. The experiences of administrators revised somewhat the definition of this code to encompass not just the search,



information, bargaining, and enforcement costs of the transaction cost model but also the economics underlying the program itself.

One of the more important themes in economic consideration was the opportunity for administrators to reduce costs by implementing self-direction. Self-direction was referred to by some administrators as a cost-saving measure. An administrator from the Southeast explained that self-direction allows administrators to “knock out some that middle money that goes to the provider that helps cover their overhead and you give that to the client...and they’re getting more services for actually less money than what it was taking on traditional waiver service.” Self-direction also brings cost savings in other programs by reducing stays in nursing homes and hospitals and reducing staffing needs in residential facilities, according to administrators. Administrators also solicit competitive bids for contracted services like FMS providers in an effort to economize. Additionally, participants themselves help to reduce costs by “thinking of the state dollar” when making purchases. Even when reducing the overall amount of spending is not the goal of administrators, making better use of existing economic resources remains important. An administrator from the Northeast described self-direction as “very enticing for some families” who are in traditional services as “we can actually double a person’s services just by pulling their money and using it in a more cost effective way through self-direction.” While economic concerns are important to administrators, two administrators in the Northeast expressed dismay at the notion that “fiscal authority” and “how money [was] spent” were “taking away from the person-centeredness...and the dreaming and the planning part” of self-directed supports. Another administrator described fighting economic forces even when they support arguments for their program’s success:

“Personally, I'm really getting sick and tired of everything in this world having to do with money. This is about incomes. This is supposed to be about what is best for these people. This is supposed to be about making their world a better place. I've said before, I'll be damned if I sit in some meeting and try to sell this because it's going to cost 10 percent less. The accountants ... Human services are run by accountants and computers nowadays, and we try to prevent that as much as possible.”

These negative cases reinforce the idea that economic considerations and the cost of programs are vitally important to the implementation of self-direction. Implementation requires monetary appropriations from the state government, and administrators expressed gratitude for the amount they were given while also desiring greater appropriations to reduce unmet need. As an administrator from the Northeast related:

“We also wish we could serve more than we do, but it's all tied to legislative funding as to how many people we can allocate to a waiver at any given time and so we'd all love to serve more people but we know we only have so many funds that we can use to do that.”

Program funding is contingent on the larger economic health of the state. For a state with “good budget revenue coming in” there are fewer “hard choices to make.” When the “money is tighter...our funding priorities get tighter.” Federal funds were also important in reducing state costs and maintaining financial viability for self-directed programs, though one administrator reported opposition among conservative legislators for seeking additional Medicaid funds. Administrators described severe consequences for spending too much money. One administrator recalled that after coming up “100 million dollars over, we were forced to make a change in our system or the company wouldn’t be around.” In the face of more challenging economic environments, administrators responded by creating additional control mechanisms in the

program, reducing or postponing funding, or removing specific services from self-direction that are more costly, such as residential homes or “goods and services.”

After funding is received by the implementing department, it is disbursed to participants in the form of individual budgets. The metric used to calculate budgets is important, as it helps retain costs to a predictable level, maintain equity between program participants, and ensure there are enough program funds for new participants. Administrators used multiple mechanisms for achieving predictability in costs, including having discrete levels of budget based on assessed needs, universal caps for budgets regardless of level of need, or using algorithms that compared individual needs with the average cost of services within the state. Once established, administrators reported a concern for maintaining existing budget levels for participants. When regulation changes on the state or federal level occur, economic pressures may occur on participants’ budgets that might imperil their participation in the program. An administrator in the Southeast described the consequences of shifting costs from the state to the participant for a specific line item.

“Something that we pushed on to the consumer, say around four years ago, was the costs that are associated with these background checks and training's and screenings. That's caused a pretty significant blow to those who are looking into participate in the waiver. The numbers are growing still, but there's a lot of people that argue that this is a barrier. The costs are, basically gone from... about \$30, maybe \$40, upwards to say \$250 per employee. It's a heck of a spike, and my concern is we're going to start pushing people out of participant direction with these standards.”

Once participants receive the money from their individual budgets—though it should be noted that the money is actually transferred to an FMS provider who disperses money on behalf

of the individual or family—they contract with support providers to meet their needs. The state regulates to varying degrees how much participants may pay providers, and these wage ranges also impact the implementation environment. An administrator from the West relates a story of how cost control mechanisms brought about by “tough” economic times on the state level led to “not being able to attract enough providers...limiting our availability in certain areas.” Provider agencies are not mandated to serve clients, and thus must determine whether serving a particular individual or geographic area is economically viable. An administrator in the Midwest underscored that “individuals [that] had a need for a lesser amount of services, the agencies were kind of overlooking them because they didn’t bring a lot of money with them...It was harder for them to staff four hours a day versus staffing an eight-hour shift.” Self-direction is viewed by administrators as ameliorating this problem by allowing participants to hire non-agency staff. Providing money to family members is described by one administrator in the Midwest as vital for ensuring that support needs are met.

“With some of the seniors, they were able to hire their adult sons and daughters to provide assistance. Because they had that option to be able to pay for part of the care that they were giving them that allocate burdens that they were more apt to ask for help when they needed the help than they did before when they weren't a paid provider. They felt good about the fact that they were giving them a job or helping them out.”

The ability to pay support workers for non-medical assistance is a common benefit cited by administrators; however, one administrator from the Midwest noted that existing pay rates for providers create perverse incentives for skilled medical workers, support brokers, or case managers to engage in direct support work instead due to higher pay rates, causing a reduction in important segments of the workforce.

“One thing we notice with [certified nursing assistants] across the state of Kentucky and the average rate there is \$12 an hour. They're doing a medical task or medical duties associated with the individual say, nursing in a hospital, and yet you've got people working for \$20 an hour and providing non medical care. They're only working one on one, in a social setting. It really skews the job market to a pretty significant degree, if you think about it.”

While economic forces could create negative incentives in the implementation of self-directed supports, an administrator reported using positive economic incentives to promote the adoption of self-direction among their regional administrations.

“A few years ago we, as part of our formula for how every area agency would actually get their wait list allocation the factors we put in there was number of [self-directed] arrangements an area agency had. That became one of the leading factors. We also put in employment as a weighted factor as well. That was one of the ways we tried to incentivize and then we also did a little bit of an incentive like if agencies had traditional services for individuals and those families converted to [self-direction] and those budgets were lower, we allow the area agency to use the gaps in funding, so if the traditional service say costs \$75,000 but then a family went into a [self-directed] arrangement and it cost \$50,000 that \$25,000 we allowed them to assign to other people that maybe needed additional service or services that were being provided that an agency wasn't able to bill on because the funding was capped. We really created these financial incentives for the agencies to be able to really help promote [self-direction]”

*Federal funding.* An interesting subcategory in economic considerations was the particular effect of federal money on implementation. According to multiple administrators,

federal money obtained through the Medicaid system is vital to ensuring the economic viability of self-directed programs. States, according to an administrator in the West, do not have “unlimited money;” relatedly, an administrator in the Southeast described his department looking “at Medicaid as this infinite bank.” In this state’s implementation, the force of federal money operates by transitioning individuals from “state programs and into Medicaid.” Federal money also comes with stipulations that states must follow—Medicaid regulations that ensure funds are being spent on the medical needs of participants. Moreover, there is a politics attached to taking Medicaid funds, according to one administrator in the Southeast, based on the conservative values in the state. Another administrator highlighted that when cost savings are achieved on the state level, the state is not able to retain those financial resources to serve more people, a missed opportunity to use economics to create positive incentives as in the previous paragraph.

### **Aim 3: What Effect Do These Salient Forces Have on the Service Delivery System?**

#### **Policy environment.**

*Federal issues.* Administrators reported two main issues in relation to the federal government—coping with federal administrative initiatives and the oversight of CMS. The new CMS community rules states are charged with complying with urged changes in control mechanisms that regulate provider standards for residential homes. This initiative is also likely to change the interorganizational network within those states that allow self-direction within group homes, as the current service relationships between the participants and the group homes cannot stay the same. Administrators described these rules as affecting self-direction only slightly, if at all. Contrastingly, the federal department of labor regulations are likely to impact the service delivery system to a large degree. Administrators described the uncertainty waiting for litigation to resolve itself and provide more clarity to the states about how this might affect

support workers in self-direction. For those states who have taken proactive approaches to this problem, administrators reported tightly restricting overtime to forty hours per week or tracking overtime usage to ensure that the costs of compliance with potential increases in salary will not be financially unsustainable.

Administrators described the oversight role of CMS as largely impacting control mechanisms. Specifically, feedback from CMS was reported to strengthen oversight mechanisms both in control mechanisms and during case management visits. Because state departments must ensure proper billing and reporting to CMS, case managers and employers of record must ensure documentation links services provided with medically necessary support needs. Multiple administrators described the impact reporting requirements had on the bundling and unbundling of supports as a result of CMS oversight. Additionally, CMS was responsible in one state for transitioning towards using an FMS versus providing money directly to participants.

***State issues.*** Waiting lists in the state were reported to affect the assessment and screening procedures case managers implement with participants before they enter the programs. These control mechanisms become more stringent when waiting lists are present, as fewer individuals can be allowed into the program and prioritization by level of need or crisis occurs. Additionally, waiting lists affect budget tiers, as tiers are used to economize on scarce economic resources. Other cost control mechanisms affect the service delivery system in a similar manner, as administrators report that any savings will be used to serve unmet need in the policy environment. Indirectly, waiting lists also affect the intraorganizational and interorganizational network by not overwhelming the system with too many new participants. States in which participants were added in an expeditious manner often reported high caseloads for case managers and support brokers, which can negatively impact service delivery.

Litigation also affects the service delivery system by changing the prioritization requirements in states with consent decrees. Based on the reports of administrators, consent decrees mandate that the state serve a particular population that falls under the class in the lawsuit. Consequently, the screening and prioritization mechanisms must change to accommodate these new participants. In one state, an administrator explained that individuals in residential homes were going to gain access to services before individuals on the waiting list, reflecting a change in the previous prioritization criteria. Additionally, litigation may create entirely new programs to comply with the litigation that have unique features, such as not including residential supports in one state, that limit how participants may spend their money. Important socioeconomic factors in the state included budgetary issues and large rural populations. In states reporting budget issues, administrators report introducing cost control mechanisms such as budget algorithms, wage limits, and budget caps in order to reduce the overall cost of the program. This change in control mechanisms also indirectly impacts the interorganizational network, as administrators reported that participants with fewer resources are less able to attract providers to fulfill their support needs. In states with large rural populations, finding providers to service rural participants was a challenge in traditional supports. Administrators with sizable rural populations reported that participants were more likely to use family DSWs and that the introduction of these workers expanded the pool of available workers in the interorganizational network. Rural participants were able to exercise employer authority and self-determination by recruiting, training, and employing a family member or friend as a support worker. However, administrators also noted that quality assurance and monitoring was a challenge in rural settings. They stressed the importance of case management, but many describe these monitoring mechanisms as needing further improvement.



These effects are particularly important in states that have a shortage of DSWs in the policy environment. When participants do not have a robust pool of providers to choose from and natural supports are unable to fulfill support roles, the support relationships that emerge may be of inferior quality. Poor service relationships affect the provider-participant relationship, a key component of the interorganizational network. Additionally, these supply constraints impinge on the ability of participants to exercise self-determination in choosing an employee, as they have fewer options from which to choose.

Administrators also explored the effects that previous experience with self-direction pilot projects had on implementation. The service delivery system benefited from previous investments—usually through RWJ grants—in training case managers, support brokers, and families on self-direction. In addition to promoting health among the interorganizational and intraorganizational network, this training also helped to ingrain the philosophy of self-determination in participants, assisting in capitalizing on opportunities for self-determination. Although these programs had benefits for the present day service delivery system, many administrators described early programs as having far fewer controls on spending. As states expanded access to greater numbers of participants, administrators described introducing more stringent controls on spending, impacting opportunities for self-determination, and in some cases, negatively affecting the linkages between the state and family.

The impact of managed care on the service delivery system was important in that it introduced a new part to the intraorganizational network, the managed care organization. Managed care's effect on control mechanisms is difficult to discern in the data, though one administrator described the managed care structure as affording the state the opportunity to serve

all individuals with IDD without the use of a waiting list, eliminating the need for prioritization in screening.

The state's school system is another force that impacts the service delivery system. Families who were used to exercising self-determination in the school environment—administrators described these as largely younger families—are more likely to choose self-direction so they may continue engaging opportunities for self-determination. The school calendar is also important for states that provide self-direction to children with IDD. Self-direction allows parents to use their budgetary authority to purchase care outside of school hours as well as pay for camps over the summer—though the latter is only available in states with budgetary authority, individually directed goods and services, and control mechanisms that permit spending on camps.

***Cultural issues.*** Deinstitutionalization and community living had a direct impact on the interorganizational network by reorganizing participant services away from group homes and residential settings and into individual and family homes. Administrators reported that the “group home mentality” was found in provider agencies and administrators who worked in institutions. As a result, administrators engaged in training of staff members in the intraorganizational network as well as provider agencies to acclimate them to the “cultural shift” that self-direction represents. Additionally, administrators linked the deinstitutionalization movement with the self-determination movement, which formulated much of the technical core in the service delivery system.

Similarly, paternalistic attitudes towards individuals with IDD were reported to affect how participants interacted with traditional provider agencies as well as some state staff. These linkages were stressed when staff did not acknowledge the self-determination of participants.

Paternalistic attitudes were also reported to occur within the family home, and administrators described the “struggle” of bringing families along with their mission of participant self-determination through increased training. Families with more paternalistic understanding of the support needs of individuals with IDD were described as preferring congregate residential settings. One administrator described that the voluntary trainings designed to achieve this conceptual change were proving ineffective, leading to increased use of case management to provide technical assistance.

Administrators related another cultural issue, the demarcation in support needs that should be provided by families and needs that should be paid for by the government. This cultural debate is reflected directly in the regulations for family DSWs. In one relatively restrictive state, the administrator described their regulations as congruent with the state’s values system regarding family support. These restrictions also affect the interorganizational network and the degree to which individuals can exercise self-determination and employer authority. States that are more wary of family DSWs also reported the need to guard against potential fraud and abuse through monitoring by the case manager. Finally, regulations on participant directed goods and services reflect these values, as items that could be used by family members, such as iPads, were described by one administrator as being restricted.

### **Policy instruments.**

The program design chosen by each administrator greatly impacted the service delivery system within each state. In delineating which supports and services are available for participants, program design limits and enables the opportunities for self-determination and the exercising of employer and budget authority. Administrators described choices between bundling and unbundling service types, which turn into restrictions on budgetary authority in the

service delivery system. For example, a single category on the program design level might include multiple service types that encompass various tasks related to ADLs—chore, personal care—that participants requisition through budgetary and employer authority. When these are unbundled into specific service types administrators attach a specific purpose to each and create controls that reflect those purposes and limit the degree to which participants can move money from one service type to another.

Another important program design choice is the inclusion or exclusion of participant-directed goods and services. For administrators whose states included these services, they described complex control mechanisms that are necessary to ensure proper spending. Cost standards, pre-approval processes, and lists of approved and disallowed goods and services are necessary to ensure that rules are consistently applied across the service area and that participants spend money correctly. Administrators emphasized that all rule-creating and spending were based on assessed medical need in the individual support plan. The interactions between participants and the state related to goods and services often occurred through the intraorganizational network, and the tenor of those relationships could be affected by the lack of clear “black and white” answers to spending questions. Denying purchase requests, particularly after rule changes, was characterized as damaging relationships between the family and the state. The area agency or state department approving purchases was also reported to suffer from overwork from staffing the often unusual requests of participants. Administrators desired for better training materials for participants on purchase rules as well as more simplified service codes on the administrative level.

Program design also specifies the target population and the needs to be addressed by the program. These specifications were directly addressed in the assessment tools states use to

determine needs as well as the screening criteria that determine eligibility. Administrators reported that by targeting individuals with IDD or by including them in previously existing programs, they were more likely to require a representative and an employer of record to properly exercise employer and budget authority due to “cognitive limitations.” In this way, the interorganizational network differs within self-directed IDD programs.

Other program design decisions also impact the service delivery system, particularly those related to Medicaid waivers. States that reported using multiple waivers often use different screening criteria and assessment procedures to determine which waiver program would be most beneficial. In some states, this is delineated by level of need, with a comprehensive waiver covering individuals with higher needs. Additionally, a few administrators reported transitioning participants off of older programs created during the Cash and Counseling era and towards programs that have more robust implementation of employer and budget authority. A related program design choice is whether to separate self-direction onto its own waiver or offer both traditional and self-directed options on a single waiver. Administrators reported that blending traditional and self-directed service delivery models was beneficial for participants, as they were able to exercise a greater degree of self-determination by purchasing traditional supports while self-directing other supports, particularly goods and services.

Choosing the type of waiver is also important. Administrators reported that assessment procedures helped to determine whether a participant would meet the ICF/ID level of care required for a 1915c waiver or whether they might be better suited to a state plan or 1915i, 1915k, or 1915j option. One administrator reported that by remaining with the 1115 demonstration waiver, the state was not limited in the amount of funds it could request and therefore did not have to prioritize people by level of need. For all of the Medicaid programs,

administrators explained that Medicaid waiver rules determine the screening mechanisms and inform assessment tools to ensure that participants are eligible for the program. Additionally, Medicaid rules inform restrictions on spending for goods and services, often a point of contention between administrators and participants—determining what is “truly a want and a need.” Although administrators expressed that these distinctions should be covered in training with the case manager, many recounted that improvements were necessary to ensure better compliance with these standards.

Not all self-directed programs in the sample used the Medicaid waiver system, though most did. State-funded plans were largely described as filling in holes that waiver programs created in terms of services and populations covered. Administrators described that goods and services that were not covered under Medicaid were able to be covered in state plans, ensuring that participants were able to exercise self-determination and use budget authority to purchase goods. Control mechanisms were used, however, to prevent participants from spending waiver money on goods that should be covered under the state plan, in one state. This was a source of discord in the relationship between participants and the administration, as the state plan limited the ability of participants to engage in employer and budget authority in a robust manner. In addition to program design, another component of policy instruments is the resources that administrators have at their disposal. They described having robust providers for case management, support brokerage, and FMS as key to the success in the service delivery system. Having trained case managers who have institutional knowledge was crucial for a well-functioning intraorganizational network that is able to engage in monitoring and interface directly with participants on behalf of the state. Good relationships with FMS providers help to ensure that participant relationships with employees are functioning correctly and that self-

determination can be exercised through purchasing goods within the individual budget. Additionally, strong internal leaders in the intraorganizational network were identified as key for promoting self-direction and providing technical assistance. Although many administrators reported have a robust system of case management, a few administrators report having difficulty with high caseloads which overburdens the intraorganizational network and may detrimentally impact the relationship between the state and participant.

The final component of policy instruments is the authority granted to the administrators to elicit compliance. Administrators often mentioned authority implicitly by talking about enforcing compliance with rules after people did not fulfill their function appropriately. For example, when participants misspent money, administrators used the area agency and case management to engage in technical assistance but also created control mechanisms that would disenroll participants that repeatedly violated spending rules. Administrators were sensitive to the effect that exercising their authority has on participants, in one case, weighing additional training requirements with the countervailing burden it would impose on families whose needs did not neatly match up with those requirements. In demonstrating this understanding, administrators demonstrated the importance of maintaining positive relationships between the participants and the state.

### **Critical actors.**

***Oversight.*** In the critical actors domain, oversight bodies create a multitude of effects on the service delivery system. CMS and Medicaid are among the most influential critical actors. In addition to providing the very structure upon which self-directed programs are built, administrators highlighted the influence of CMS on the billing and monitoring systems in the service delivery systems. During oversight, the administrators reported being “dinged” for

various issues with these aspects of the control system being the most relevant. Additionally, the new rules for congregate settings are likely to change the way that the interorganizational network functions by directing resources away from congregate settings and into more community and integrated settings.

Legislators and governors also perform a supervisory role in self-direction. Both parties are responsible for appropriating money to be spent on self-direction and the degree to which each makes self-direction “a priority” can affect the budgetary restrictions that a state has in place. For example, states with tighter fiscal environments may be forced to screen participants for level of need, using waiting lists or funding priorities to determine access. Additionally, budget caps and subcaps were specified as ensuring the cost-effectiveness and therefore viability of self-directed programs in states with tighter fiscal environments. Legislators and governors are also the target of lobbying by advocacy groups which in turn impacted the control mechanisms within the program. According to administrators, this may mean the department changes rules when possible, or advocates might work towards dispelling myths about individuals with IDD in an attempt to preserve and extend self-determination. Finally, the governor has the some unique powers including beginning new initiatives and appointing directors in departments implementing self-direction. Initiatives such as unionization of the support workforce and managed care were mentioned as originating the governor’s office, and these altered the interorganizational and intraorganizational networks in those states.

The role of working groups in affecting the service delivery system was described as important by many administrators. These groups often include participants, family members, providers, FMS providers, Medicaid review agencies, other state administrations, in addition to the implementing department. By engaging many parts of the service delivery system,



administrators utilized the lived knowledge of people in the system to reform it through making changes, usually to control mechanisms, or reformulate it by creating a renewal or new waiver application. The effects most often described by administrators included designing outreach and training mechanisms and advocating for greater flexibility and more funding for supports—each of which affects the control mechanisms and indirectly the ability of participants to exercise self-determination.

***Implementing department.*** The department implementing self-direction is described by administrators as impacting the service delivery system largely through the training process. The department mandates trainings that participants and employees are responsible for attending, sometimes delegating that responsibility to area agencies or engaging in a “roadshow” of trainings around the state. Additionally, when problems arise in the course of service delivery, many administrators emphasized the importance of customer service, having an open door policy, and dealing with participant complaints as quickly as possible. These efforts again underscore the importance of the relationship between the state and the family or participant.

***Stakeholders.*** Provider agencies and unions were the primary stakeholders discussed by administrators in their interviews. Provider agencies, as members of the interorganizational network, were influential in crafting control mechanisms that allowed them to continue parts of their business model, while some traditional residential supports necessarily had to change. Additionally, administrators reported that providers were starting to offer new support options to adapt to the self-direction marketplace, including FMS services, support brokerage, among others. Administrators also reported that the interorganizational network had more of a change in culture or philosophy with self-direction. As part of the policy refinement process, administrators described dispelling myths and fears about self-direction and acclimating them to

a model that provides for greater participant self-determination. Similarly, the advocacy role of unions was focused on creating control mechanisms that were favorable to their interests. Specifically, an administrator in one state reported that unions wanted to eliminate the ability for individuals to set wages for their employees, strictly defining wage rates with the state, and excising that component of employer authority. In another state, the union representing the case managers urged them not to participate in self-direction as it required more work for the same amount of pay, limiting the supply of labor in the intraorganizational network. In both cases, the administrators were able to work with the unions to overcome these issues and the effects on the service delivery system were only temporary.

***Advocates.*** The effects of grassroots advocates were not only in the creation of the program in general, but also on specific aspects of the service delivery system. Administrators described relying upon advocates for information about how services are impacting participants and families, and the changes advocates requested largely reflected the control mechanisms in the program. Specifically, advocates described the need for more flexibility in budgetary control, less restrictive budget caps, and the elimination of subcaps for specific services and supports. These features impeded the ability of participants to more fully exercise self-determination as part of the technical core.

Family advocates fulfilled a similar function as grassroots advocates, in that they transmitted knowledge to the implementing department about problems in the program. Family advocates were instrumental in creating self-directed programs in the first place that allowed family members to be hired as personal support workers, expanding the pool of labor in the interorganizational network and furthering participant self-determination. Additionally, family advocates were also helpful in creating outreach and training materials in concert with the

department to better educate new participant in how to succeed in self-direction. The desire for greater funding and larger budgets was emphasized by administrators as a common issue in family advocacy. Finally, family advocates were particularly useful in one state, advocating for the bundling of services when CMS wanted those to be unbundled—a change that would have imposed additional spending restrictions and documentation requirements on families.

Non-profit advocates and think tanks are also influential on the service delivery system. In the beginning of self-directed programs, these entities and in particular the Robert Wood Johnson Foundation provided technical and financial assistance to train the intraorganizational network and create trainings for participants. More recently, other non-profits like the National Resource Center for Participant Directed Services (NRCPDS) have been helpful, according to administrators, in providing technical assistance on how to integrate managed care into the intraorganizational network and control mechanisms. As administrators described increasingly moving towards the SIS assessment tool, they cited the influence of the American Association on Intellectual and Developmental Disabilities.

***Other actors.*** As the target of the service delivery system, individuals with disabilities were often mentioned as influential by administrators. The individual's needs form the basis of the individual support plan, around which all services and supports are based and authorized. Within the technical core, they exercise self-determination and individualize supports through employer and budget authority and hire individuals in the interorganizational network to provide supports. The aggregated preferences of all individuals with disabilities form the interorganizational network that emerges for the system. These preferences are also reflected in the control mechanisms in the service delivery system, as individuals who request items that are not medically necessary are described by administrators as leading to the creation of long lists of

approved and unapproved goods and services. Administrators' perceptions of individuals with disabilities also influence the training that they receive whether the case manager will emphasize the need for an employer of record or representative to engage in self-direction.

Family members are also highly influential in the service delivery system, as they are generally conceived of by administrators as maintaining the living environment and providing natural supports to participants. These functions bound where administrators believe paid supports should fit in and support individuals with disabilities, informing the regulations around family DSWs, limitations on respite, and the role of the employer of record. The informal support roles are also important when family members pass away or become ill, which inform the exceptions procedures in the control mechanisms. Administrators reported that family members often acted as employers on behalf of participants, and that they were generally the ones engaging in employer and budgetary authority on behalf of the participant. When they spent money incorrectly, administrators responded by creating additional control mechanisms and reaching out through intraorganizational network with technical assistance. The level of paperwork and documentation required by administrators was described as daunting, and administrators reported building electronic billing systems in order to lessen his requirement.

**Driving forces.** As described in the previous research question, driving forces move up a level of abstraction from previous implementation domains. Moreover, they aggregate the effects of various domains and subdomains and propose specific channels by which they impact the service delivery system and other subsequent implementation domains. As a result of this abstraction, their effects on the service delivery system are difficult to specifically describe. Technological rationality and irrationality, for example, speak to how well the components of the service delivery system work together as designed. Generally rational systems require no

changes or only incremental changes, though the effects will differ greatly from implementation to implementation. Similarly, irrationality describes a service delivery system in which components function incorrectly or are implemented incompetently because the theory of change does not hold for the implementation environment. These effects are better described in the preceding sections wherein dysfunctions in the system are brought to light by advocates or through CMS oversight, for instance. Power relations describe the abstract mechanism through which critical actors influence the service delivery system, but their effects have already been described in the previous sections. Finally, the effects of economic considerations are better described in the budget issues section as well as the resources section of this analysis. Without more concrete and generalized effects for the driving forces, it is difficult to analyze how they affect the service delivery system across state implementations.

#### **Aim 4: What Concepts Are Important for DDPAs in Assessing Success in Self-Directed Programs?**

**Participant outcomes.** In the interviews, DDPAs were asked directly, “what outcomes are important for you in assessing the effectiveness of self-directed supports?” When administrators answered this question, they largely focused on the effects that participants and families experience as a result of participating in self-direction. Primarily, opportunities for self-determination and flexibility comprise the most frequent codes in the responses. Administrators described flexibility in self-direction as participants being able to make choices, adapt supports to fit their unique needs and contexts, and engage creatively in the process of service delivery. For example, if a family member or caregiver falls ill, the flexibility in self-direction allows the participant to request additional funds temporarily in order to maintain the current level of supports.

In many responses, flexibility and self-determination are also mentioned alongside participant satisfaction. Administrators described satisfaction as largely the result of the employment relationships between support worker and participant. Because participants are able to have greater control over who provides services and how those services are provided, participant satisfaction improves—particularly for participants whose needs were not well served in traditional supports. Administrators learned about participant satisfaction through official channels, such as case manager reports and formal advocacy, as well as through informal channels, such as positive or negative word of mouth for participants. Participant dissatisfaction was mentioned less often in the responses of administrators, and mostly arose from the control mechanisms in the service delivery system—caps on specific services, budget algorithms, restrictions on large purchases.

Another important participant outcome for administrators is community participation and inclusion. In the descriptions of administrators, community inclusion is a function of where a person lives and what they do during the day. For many administrators, it was a source of pride that a sizeable portion of their service population was living outside of large institutions and group homes; moreover, participants who require institutional services stay there for short periods of time and are able to translate easily into the community. Additionally, community integration speaks to participants' freedom to spend their days as they desire. Administrators spoke positively of reducing the use of day treatment and increasing the amount of leisure events and community activities in which participants can engage.

In addition to these service goals, administrators underscored the importance of providing the supports to participants that match their needs—termed the correspondence index in the conceptual model. Participants with unique support needs should, according to administrators,

be able to have them met through the flexible spending allowed by self-direction.

Administrators also described a successful system as one in which participants are able to get their support needs met with a minimum of hassle. Administrators focused on the ease with which participants can hire family members, lowering the paperwork burden, providing supports through case management and support brokerage, having clear rules for authorizations of large purchases, and the flexibility of budget authority as contributing to ease of service delivery. Comparisons between self-direction and traditional supports regarding ease of use often favored self-direction, with administrators often stating that those who had difficulty under traditional supports experience self-direction more positively.

Although mentioned less often in the direct questioning of important outcomes, difficulty with service delivery is an important component of how administrators understand program success. Difficulty can arise in many facets of the service delivery experience. Within the employment relationship, participants can become overwhelmed with the volume of paperwork, confused about their roles and responsibilities, or be unable to find consistent providers. Other sources of difficulty derive from control mechanisms that administrators may not be able to change, including budgetary caps, restrictions on transferring funds within a budget, and inadequate wage ranges to attract employees. In some cases, these control mechanisms were put into place after years of relatively liberal spending restrictions, and the transition to operating under these restrictions created difficulty for participants. Finally, breakdowns in specific components of the service delivery system, such as unresponsive FMS providers and area agencies that deny access to self-direction were also sources of difficulty.

Many signs of success occur within the family or participant's home. Administrators highlighted the importance of improving the quality of life for participants as an important gauge

of program success. Quality of life is often described with the ability to receive services within the home, another important gauge of success for administrators. Because services are located within the home, administrators report participants are more likely to be satisfied. The additional control over those supports through employer authority also engenders an improvement in the quality of the provider-participant relationship as well as the quality of the services overall. Administrators described this development as speaking to the success of self-direction, particularly as compared to traditional supports in which participants had less authority in the support relationship. Although it was mentioned in fewer interviews as a specific indicator of success, the reduction in caregiver burden is important to some administrators as a sign of success in self-direction.

While many of the preceding goals were reported by administrators to be shared by participants themselves, administrators also described some aspirational goals that they impose on the program. Participant employment is a particularly important outcome for administrators, and many DDPAAs report revising their programs in order to provide more employment supports. Similarly, administrators also focused on whether participants are meeting the goals stated in the ISPs as a measure of program success, though some admit difficulty in tracking those measures for all participants. Both employment and goal attainment involve another desired outcome, participant independence and autonomy. Administrators' responses describe this autonomy as an independence from provide agencies as well as the ability to live in an independent home.

**Administrative outcomes.** While administrator depictions of program success focus largely on the participant realm, some concepts relate more to outcomes on the administrative level. Administrators often reported that growth in program size is an important indicator of a successful program. Growing the program's size is described as the impetus behind dedicating



staff members to popularizing self-direction, training case managers, securing contracts. In the minority of states where the size of the program does not meet the expectations of administrators, one administrator, for example, expresses “embarrassment” in comparing their numbers to the years of effort it required to build the program. They continue that the goal behind reforms to the system is to eliminate barriers for participants and increase the numbers of individuals who participate in self-direction. When asked about the future of their self-directed programs, many administrators express a desire to increase the number of participants.

Some administrators, though not all, related the desire to increase adoption of self-direction with the potential cost savings that self-direction offers the state. The administration saving money is another important outcome that administrators identified as denoting success. Administrators differed on the degree to which they value cost savings. Many administrators described cost savings as integral to the continuation of the program, particularly in states where exceeding the budget allotment had been a problem historically. However, a few administrators expressed reluctance about “touting” cost savings in self-direction. One administrator contextualizes this in terms of “getting sick and tired of everything in this world having to do with money” while the reasons of other administrators remain unexplored.

A final code that ties both participant and administrator realms together is word of mouth. Administrators explained that once participants achieve positive outcomes in self-direction, they often tell other individuals and families about the program. Once “word gets out,” the number of participants in the program is likely to increase as people in traditional supports will talk with their case manager about exploring self-directed options. Although word of mouth is generally described as positive, when administrators described negative word of mouth the opposite effect

can occur. Participants who have difficulty in receiving services will, according to some administrators, direct others to traditional supports or agency with choice options.

#### **Aim 4: What Innovations Would DDPA's Propose to Improve Policy Output?**

Many of the interviews questions were designed in order to better understand the conceptualization and thought process of program administrators and how those affect program implementation. In the process of collecting this information, information about program innovations were shared with the researchers. These innovations can be described as furthering the purposes of engaging families and participants, increasing the number of participants in self-direction, simplifying the budgeting process, and simplifying the employment process.

**Engaging families.** Many administrators described the experience of engaging in self-direction as “daunting” and “challenging” for participants and families. While formal training administered by the department and case managers is the most commonly reported approach to ameliorating this issue, a few administrators also offered that using self-advocates and family members as trainers is a useful intervention. Peer-facilitated trainings can not only reinforce the training provided by the state but provide more tailored strategies to ensure program success. The two administrators who reported currently operational peer-facilitated training programs described them in terms of teaching how to “work the program” and “how best to use the program to their advantage.” Given that many administrators describe participants as “creative” and “impressive” in their use of budgeted funds, peer-facilitated trainings might be an opportunity to harness that resource and provide greater support to self-direction participants.

Another opportunity for self-advocate and family input is in the creation of training materials, including manuals, guides, and workbooks. A few administrators discussed the importance of these workbooks in assisting in the person-centered planning process as well as

training and orienting participants to program expectations. An administrator from the West highlighted the importance of family input into the creation and revision of those curricular materials. Because families understand what other families might need and have been trained using previous materials, they may be a helpful source of input on future workbooks.

Training requirements for families vary between states, with some focusing solely on the case manager, and others mandating specific trainings, particularly for families who want to engage in paid support work. For the more extensive states, the implementing department is often tasked with engaging in the “roadshow” or regional staff is required to conduct periodic trainings.

Some administrators described this process as an overwhelming workload. One administrator reported that by recording trainings and posting them online, workload can be reduced in the intraorganizational network and potential barriers for participants and families can be reduced.

A final innovation that is mentioned in one interview is the use of a “justice center” for individuals with IDD if they or another person in their care network believes they might be the victim of abuse or neglect. This system is integrated with the law enforcement and protective services. The administrator characterizes this system as a “final safety net” in the monitoring system, when the case manager, support broker, regional administrator, and FMS are unable to catch abusive or neglectful practices.

**Increasing the number of participants in self-direction.** Administrators in multiple states described the importance of having specific staff on the regional level to promote self-direction and increase adoption during the early stages. In one state, these administrators were all participants in the interview, and they described their process of dividing regions of the state and specific tasks as contributing greatly to the adoption of self-direction throughout the state. Because self-direction is described as a “cultural shift,” training must according to these

administrators go deeper into showing how self-direction was “different from the way we did business previously.” These administrators acted as “system change agents” without ordinary supervisory responsibilities of regional administrators. Two other states reported using regional administrators in a similar manner when implementing self-direction on a state-wide basis. For states that are considering self-direction and those whose implementation has only recently started, positions such as these may help promote self-direction across the state and provide immediate support for implementation problems.

Area agencies, though often described as a source of rationality, can also contribute to irrationality and incoherence in the service delivery system. Many administrators reported that although area agencies and case managers are required to promote self-direction, low or non-existent participation numbers in some service areas indicate that area agencies are not fulfilling this function. One administrator reported using positive financial rewards to incentivize area agencies to promote self-direction. By allowing the area agency to internalize the cost savings for any participants who switched from traditional to self-direction, the administrator reports using the area agency’s desire for more resources to fulfill the state’s desire for more self-directed participants:

“A few years ago we, as part of our formula for how every area agency would actually get their wait list allocation the factors we put in there was number of [self-directed] arrangements an area agency had. That became one of the leading factors...That was one of the ways we tried to incentivize and then we also did a little bit of an incentive like if agencies had traditional services for individuals and those families converted to [self-direction] and those budgets were lower, we allow the area agency to use the gaps in funding, so if the traditional service say costs \$75,000 but then a family went into a [self-

directed] arrangement and it cost \$50,000 that \$25,000 we allowed them to assign to other people that maybe needed additional service or services that were being provided that an agency wasn't able to bill on because the funding was capped. We really created these financial incentives for the agencies to be able to really help promote [self-direction].”

**Rationality and budgeting.** Many administrators pointed towards budgetary control mechanisms as a source of technological irrationality. For example, participants may overspend money and without the prompt redirection of the FMS, case manager, or support broker, may be left with no money to pay for necessary supports at the end of the fiscal year. While multiple administrators reported working on electronic billing, a few administrators with currently operating systems described the rationalizing effect these have on service delivery. Because authorizations for budgetary decisions often need to be approved by the case manager or regional authority, electronic budgeting allows them to do so with a minimum of paperwork. “When [the case manager] hits the submit button, that should go through automatically, without review from anybody. The computer system already knows they’re within budget. That’s fine.” Electronic billing systems connect each component in the system with the necessary spending information, including FMS Providers. Another administrator described that “a case manager can click on a view transaction button and it will bring up all of the expenditures, the employees, how many hours they worked, what they were paid, any goods and services that were purchased, anything that was placed into savings. It's real time.” When a participant desires to purchase an unusual good or service, case managers can provide the necessary information for the participant to make an informed decision based on the health of their budget.

In addition to approving budget changes during the service year, electronic budgeting also assist with the annual budgetary review process. Case managers, armed with correct information, can review utilization with the participant and their families during the past year, compare it to previous years, and make decisions about what might be best for next year. After the participant and case manager agree on the budget for the next year, electronic billing systems allow regional and state authorities to approve budgets automatically, reducing the overwork that comes with manually processing “thousands” paper applications. In the words of one administrator, if “nothing’s really changed in their life, they’re not out of budget,” then automating approvals makes sense.

Another trend in the interviews of administrators is the increased adoption of the national assessment protocols like the SIS and ICAP as well as budget algorithms. These innovations are designed to counteract the irrationality that can occur when budgets are inconsistent across participants with the same level of need. While a few administrators reported using the SIS on a statewide basis, many others report piloting its use in self-directed programs including those that are not focused on IDD. Administrators described the SIS and ICAP as helping to making sure “we have...the right services at the right time, because right now we have people who are...their needs are low and they have high budgets and some people whose needs are high and they have low budgets.” For states using the SIS or ICAP in the assessment process, the results can feed directly into the budget algorithm which determines an individual’s allocation based on the average cost providing the services indicated in the assessment. Administrators identified budget algorithms as contributing to the predictability of budgets, helping with cost containment, but also potentially leading to lawsuits from advocates. More states report using budget algorithms

than the SIS or ICAP, though the increased adoption of both may help to bring uniformity to self-direction within and across states.

**Rationality and employment.** While many administrators identified employment relationships between participants and support workers as a strength within the service delivery system, there are important external pressures that may contribute to irrationality. Foremost in many administrators' minds are the new federal Department of Labor regulations that may substantially increase the cost of employing support workers. One state reported that by eliminating overtime, they were able to reduce stress and uncertainty about the future of the department of labor regulations. Another source of potential stress in the employment relationship comes from state employment regulations. Multiple administrators reported having to push back against the state becoming too involved in the regulation of providers, as they become almost joint employers along with the participants. One administrator in particular worried about the liability implications of de facto joint employment, with the state potentially having to provide health insurance and other benefits to an expansive workforce. This administrator proposed, though is not in the process of enacting, changes to the employment relationship that would reclassify support workers as contract employees, rather than traditional employees. If this change were made, participants would no longer have to worry about unemployment claims or deducting taxes, as this responsibility would fall to the support worker. Additionally, the state would be relieved of its role as bargaining and regulatory intermediary between support workers and participants. Although contract work may be attractive in this state, states in which robust union bargaining is a part of the implementation process may find this change too radical for the political climate.

## **Chapter 5: Discussion**

### **Introduction to Discussion Section**

The following section discusses the major findings from each aim in the study, highlighting important and unexpected findings in light of the existing literature. Subsequently, major implications for future research, policy, and social work practice will be explored. The section closes with a reflection on the strengths and limitations of this study and future directions for research on self-direction.

### **Aim 1: Assess the utility of Hasenfeld & Brock's Political Economy Model of Implementation**

The Hasenfeld and Brock model (1991) was chosen for this analysis because it had previously been used to analyze the implementation of self-directed supports in New York (Sciegaj et al., 2008). However, the goal of that study was to understand how political and economic forces caused New York to not move forward with their implementation of self-direction as part of the Cash and Counseling experiments. The analysis included only the critical actors, policy instruments, and driving forces in its theoretical model. Because the present study investigated successful implementations of self-direction, it was necessary to include all of the domains from the political economy model. Other sources (e.g. McGrath, 2009) used incomplete versions of Hasenfeld—omitting certain implementation domains or using an earlier version of this model—demonstrating the need for a comprehensive understanding of program implementation.

The majority of codes from the Hasenfeld and Brock (1991) Political Economy Model of Implementation were well grounded in the data set. Moreover, their utility was demonstrated by providing a corral in which emergent codes were derived through inductive reasoning. This



interpretive work, part of the directed content analysis process, assisted in modifying Hasenfeld's model from a more mechanistic model to one in which human action was present. In this way, Hasenfeld's original model should be understood as a "view from a distance" approach to understanding implementation. Although the model synthesizes many empirical articles about policy implementation, the domains in the final model do not explain how administrators actually implement programs. While critical actors are included in the implementation domains, actors do not behave as individuals; rather, they affect the implementation process based on the category to which they belong and their relative power in the implementation space. Through the inclusion of administrator conceptualization and policy refinement, the present study provides a more detailed understanding of implementation from the perspective of the administrators themselves.

The inductive category of administrator conceptualization also helped to incorporate some subdomains derived from the DDPA literature review. The wants and desires of administrators were incorporated into the subdomain of preferences. The relatively few preferences derived from the literature review—avoiding scandal, limiting state liability, and meeting participant need—were expanded significantly through the interpretive process, providing a more comprehensive understanding of the mindset of administrators implementing self-direction. Preferences were conceptualized using a political economy framework, highlighting the importance of self-interest and the principal-agent relationship in the provision of public goods (Ostrom, 1989; Niskanen, 1994). Although it is in the self-interest of administrators, for instance, to increase the size of self-directed programs, make administrative work easier, and acquire more resources, these desires also benefit current participants and

potential participants in self-direction. Indeed, the self-interest of administrators that is reflected in their revealed preferences aligns highly with the interests of participants.

The administrator conceptualization domain also includes the knowledge and opinions that administrators have about self-direction. Only one deductive category was derived from the DDPA literature review, philosophical agreement with self-direction, and the domain of knowledge and opinions was expanded significantly through the use of inductive data analysis. Many of these categories reflect the deep penetration that self-determination theory has made into the administrative realm. Administrators regularly described self-direction as a cultural shift in how services are delivered to individuals with IDD. Additionally, administrators reported that self-direction was particularly helpful for individuals who were dissatisfied with traditional supports or whose needs did not fit neatly into the traditional model—a finding supported in the previous study of self-direction administrators (Walker et al., 2009). These cross-cutting themes were present in many of the descriptions of self-direction provided by administrators and reflect the degree to which administrators have absorbed the importance of self-determination for individuals with IDD.

The policy refinement domain addresses another limitation of the Hasenfeld model and its application to the implementation of self-direction. The model stops at policy output. Once services are provided to the target population, no other actions take place in implementation. This contradicted one of the deductive categories that was well-grounded in the data set—improvement of service delivery and innovation—derived from the program administrator literature review. The inductively derived category of policy refinement reflects the impressions of administrators that their implementation work is ongoing and constantly evolving based on outcomes, conceptualizations, and interruptions. Engaging in monitoring and quality assurance

and acting upon those results were described as important to administrators, and policy refinement provides a subsequent step in the implementation process in which this administrative work takes place.

Policy refinement also provided an apt corral for deductive themes derived from both the self-determination literature and the administrator literature review. The responses of administrators reinforced the importance of coordination between the individuals and agencies in the interorganizational and intraorganizational network. Abery and Stancliffe (2003) emphasize the importance of coordination among actors in the mesosphere, as individuals' self-determined behaviors are nurtured when support organizations share knowledge. Moreover, self-determination theory highlights the training of staff in provider agencies and in government departments on self-determination as an environmental factor that facilitates self-determination. The reports of administrators concurred with this aspect of self-determination theory, as administrators reported having to bring along all members of the system—providers, administrative staff, and even family members—to their philosophy of self-determination for individuals with IDD.

## **Aim 2: Describe the enacting of self-direction by DDPAs**

**Features supported by the literature on self-direction.** For self-determination theory, the most important aspect of the service delivery system is the provision of opportunities for individuals to engage in self-direction. Once these opportunities are provided, individuals can make decisions about the degree to which opportunities are important to them and engage in self-determined behavior. This process, conceptualized by Abery and Stancliffe (2003), also varies across time as preferences, contexts, and opportunities change in an individual's life. The primacy of opportunities for self-determination in the responses of administrators demonstrates a

high degree of agreement with self-determination theory. Moreover, the idea of self-determination was conceptualized similarly to Abery and Stancliffe's model. Administrators conceptualized self-determination in part as having the flexibility to meet life's changing needs and the ability to engage in decision-making and choice. More significantly, another important component of Abery and Stancliffe's model, the individualization of supports, was found in many administrators' descriptions of self-direction. The ability to individualize supports is key for individuals with disabilities, as the lack of personalization was a main critique that self-determination theory posited in relation to traditional supports.

One component in administrators' descriptions of self-determination that challenges the self-determination literature is the concept of responsibility. Administrators often mentioned self-determination in tandem with responsibility for participants or family members. Self-determination was viewed by administrators as laborious, and they emphasized the importance of participants having the capability to engage in self-direction. Self-determination theory describes individual capability in a different manner, focusing on specific skills, knowledge, and attitudes that individuals possess (Abery & Stancliffe, 2003). The capability described by administrators is focused solely on the ability to engage in the tasks necessary for employer and budgetary authority. This discrepancy is not surprising, as administrators are concerned with the capability of participants to exercise the specific duties that traditionally are performed by administrators and provider agencies, rather than the capabilities of self-determination more broadly. Administrators described transitioning to self-direction as removing many of the safeguards that come with using provider agencies to deliver supports, and by entrusting these responsibilities to participants, they wanted to ensure that participants' health and safety would

not be compromised. Walker and colleagues (2009) describe accountability as often emerging in tandem with individual budgeting and monitoring of employment and budgetary decisions.

Another result within administrators' descriptions of the service delivery system that is supported in the literature is the trend towards increased use of the Supports Intensity Scale (SIS). While only a handful of states reported presently using the SIS statewide to evaluate participant need in self-directed programs, many more administrators reported that the SIS was in use for other populations or that the state was piloting the SIS for eventual statewide implementation. This process demonstrates a trend within the states of moving budgetary processes towards those supported by empirical evidence. The SIS has been validated across multiple studies (e.g. Wehmeyer, Chapman, Little, Thomson, Schalock & Tasse, 2009; Weiss, Lunskey, Tasse & Durbin, 2009) and presents administrators with a standardized way of assessing participant needs that is designed to dovetail with a person-centered planning process (American Association on Intellectual and Developmental Disabilities, 2008). States that adopt the SIS are promoting self-determination in clients by providing individualized budgets, rather than providing a uniform amount to each participant.

The use of the SIS is associated with the formulation of budget algorithms in the literature, and there were some states that conformed to this aspect of best practices (Smith & Fortune, 2008). However, given that many states are still working on adopting the SIS on a statewide basis, budget algorithms were often used with other assessment tools. Generally, assessments were based on assessed hours of need and multiplied by the average cost of services in the state. Budget algorithms reflect a focus on individualization of supports that is important in self-determination theory and the best practices literature. Additionally, they represent a break from the trend previously identified in the self-direction administration literature towards the use

of budgetary caps for all participants and towards a more individualized model of containing costs (Walker et al., 2009). In comparison to states that provide for strict budgetary caps or budget tiers, the use of a budget algorithm ensures that the individual budget amount is directly derived from individually assessed need. Severance and Campbell (2008) argue that the use of budget algorithms helps to ensure fair and equitable distribution of support dollars; however, the use of standardized resource allocation methods may make the system resistant to change which may undermine the extent to which opportunities for self-determination grow over the long term. Crisp and colleagues (2010) as well as Moseley, Gettings and Cooper (2003) describe retrospective budget methodologies as providing for greater individualization in budget creation than those that rely on statistical regression. As state administrators transition in greater numbers to the use of prospective assessment and budget methodologies—SIS and budget algorithms—self-determination may be minimized by reducing the use of retrospective budget methodologies.

The use of electronic billing systems was another emerging trend in the reports of administrators. While they were not fully implemented in the majority of states, administrators in states where they were operational described them as bringing rationality to the system and helping communicate knowledge efficiently. This represents a slower implementation than recommended by previous studies of self-direction, in which information technology systems were seen as critical to best practices (Walker et al., 2009). Electronic billing is mentioned by the NRCPPDS as part of best practices for participant-direction with populations other than IDD, including veterans (Schoeps, 2015). Although not directly related to IDD, the use of electronic billing in Medicaid services has a strong evidentiary basis (e.g. Dennis & Blanchard, 2013; Nietert, Bradford & Kaste, 2005). Moreover, administrators report that it reduces the workload of each individual and agency in the service delivery network, a key incentive from a political

economy framework. For participants, electronic billing systems have the promise to further minimize workload.

Administrators also reported that managing risk was an important component of implementing self-directed programs. This focus is reflected in their descriptions of escalation procedures and backup or contingency procedures. Crisp and colleagues (2010) recommend the use of individualized backup and contingency plans, rather than a universal plan for each participant in the state. All administrators reported that contingency plans were created in this way, allowing participants to determine who to call in the event of an emergency. Additionally, the use of participant monitoring and case manager supervision as part of escalation procedures is grounded in best practices for self-direction. Although only one state mentioned having a dedicated hotline for abuse or neglect, many administrators described their escalation procedures as critical components of the service delivery system and underscored the importance of relationships with protective service departments on the state level.

The direct support relationship, for administrators, was described in a similar manner to the empirical literature on self-direction. In particular, administrators reported that participants were often more satisfied with support workers recruited from friends or family members. Family DSWs are associated in the literature with greater satisfaction with the support relationship, with greater satisfaction with the specific support received and fewer unmet support needs (Bogenschutz et al., 2010; Foster et al., 2005; Simon-Rusinowitz et al., 2005). Similarly, administrators described that participants were also better able to remain in their own homes and reduce the use of group homes as a result of self-direction, an outcome that is also found in the literature (Fox & Kim, 2004). In-home supports were valuable to administrators in that they

supported the goal of keeping individuals in private homes, rather than residential settings—a goal shared by Crisp and colleagues (2010).

Within the interorganizational network, administrators emphasized the importance of working with family members to clearly delineate the roles of employer of record and direct support worker. Avoiding conflicts of interest between these roles is also reflected in Crisp and colleagues (2010), which speaks to best practices. However, many states also report barring certain family members from engaging in paid support work for similar reasons. Parents of minor children and spouses were reported to be part of an individual's natural supports and are therefore unable to engage in paid support work. These restrictions are not born out in the best practices literature. The National Participant Network's (2010) guiding principles state that overreliance on natural supports can fundamentally alter the relationship. Family DSW restrictions are based less on evidence than, as one administrator reports, values around what should or should not be paid for by government. In this way, administrator preferences and incentives are in conflict with those of participants—a principal-agent problem common to public administration. Administrator incentives to be good stewards of public funds entails reducing or maintaining costs as well as paying for services in a manner that is congruent with the prevailing values in the state. When these incentives promote overreliance on natural support or impose arbitrary restrictions on who may become a paid support worker, self-determination of participants may be undermined.

In the intraorganizational network, the role of the case manager was paramount in the descriptions of administrators. They were portrayed as the most important source of monitoring, assessment of participant needs, and compliance with spending regulations—results that are mirrored in other nationwide studies (NRCPDS, 2014) as well as the Crisp and colleagues



(2010). The importance of monitoring and quality control is emphasized in the best practice literature (Walker et al., 2009), and it is interesting to note that this task is generally accomplished through case management. Additionally, the case manager was often described as the person recruiting and training participants for self-direction. The best practices literature dictates that this is recommended when case managers have been specifically trained in self-direction; however, not all administrators reported having a specially trained case management workforce (Crisp et al., 2010). Indeed, case managers often were reluctant to recruit participants into self-direction due to misgivings about program features. Some administrators reported overcoming this issue by selecting specific case managers to train, which reflects best practices in the Crisp and colleagues (2010).

**Features challenged by the literature on self-direction.** In the responses of administrators, the dominance of employer authority over budget authority in definitions of self-direction and its essential component parts was a surprising finding. Although administrator definitions of employer and budget authority did not differ from what is found in the literature, administrators defined self-direction largely in terms of employer authority. Crisp and colleagues (2010) define self-direction as encompassing both employer and budget authority. Although most participants spend their budgets by engaging in employment relationships, the additional authority to determine wages and purchase goods and services increases the degree to which self-determination can be expressed. The diminution of self-determination caused by not offering budgetary authority may be lessened in state implementations by allowing participants to determine wages for their employees as part of employer authority. There were few states that mandated a single rate of pay for support workers, and administrators reported that although budgetary authority may not be offered, an individual may be permitted to determine the wage of

their employees. This represents a challenge to how employer-only states are conceptualized within the literature and reflects a greater potential for self-determination within these programs (Crisp et al., 2010).

Another aspect of the technical core, person-centered planning, was mentioned in only a few of administrators' definitions and explications of self-direction as well as their discussions about implementation more broadly. Person-centered planning is a key component of self-direction and predates self-direction as a policy innovation (Crisp et al., 2010). Assessment processes, when they were described by administrators, were generally a depiction of how many hours were needed in a specific service category. One group of administrators expressed dismay that self-direction and fiscal planning had eclipsed person-centered planning in their minds, and this observation was applicable to the responses of administrators throughout the data set. The idea of person-centeredness and the personalization of supports was a more common theme in the descriptions of administrators, but the assessment and planning process deviated significantly from best practices and self-determination theory.

Administrators also reported "blurred lines" between components of the interorganizational and intraorganizational networks were common among participants, workers, and administrators. For some administrators, the functions of support broker and case manager were described as somewhat interchangeable. Walker and colleagues (2009) previous study on administrators implementing self-direction described the use of combined support broker/ case manager and the use of distinct support brokers and case managers. They emphasize the importance of separating out the support broker role based on evidence from state pilot projects. While some responsibilities, such as oversight and training, do overlap in Crisp and colleagues (2010), there is a clear distinction in the literature between the case manager as an agent of the

state and the support broker as an agent of the participant. A similar blending of roles occurs with regional or county administrators, sometimes referred to as “area agencies” by administrators. Depending on the state, these entities provided a combination of oversight on behalf of the implementing department, employment of case managers, employment and training of direct support workers and other providers, and support brokerage. There is little information in the best practices literature on the proper role of area agencies, except when they provide services through agency with choice. Further research is needed to better understand whether these multiple roles result in conflicts of interest that may negatively impact participants.

**Features that have mixed support in the literature.** The components of agency with choice (AWC) and employer of record (EOR) are generally defined by administrators in a similar manner as they are in the literature. However, some administrators described EOR as “true self-determination” and agency with choice as an inferior option along the self-determination continuum. According to Crisp and colleagues (2010), participants who engage in EOR are participating in the “hallmark of self-direction” by exercising a higher degree of choice and control (p. 7-5). Administrators more commonly conceptualized the difference between AWC and EOR as a continuum for participants who wanted to have some control or a great deal of control over their supports. While this distinction for participants is found in Crisp and colleagues (2010), the concept of a continuum of support options was valuable to administrators and represents an implementation of Walker and colleagues (2009) recommendation for using AWC to lessen the burden of engaging in self-direction. Administrators reported that by offering a continuum, they were lowering obstacles for individuals who wished to engage in self-determination over some aspects of their supports but were concerned about laborious paperwork requirements if they became an employer of record.

Crisp and colleagues (2010) mention the use of wage ranges and subcaps for specific services, explaining their origins in the budget allotments provided to state administrations and collective bargaining agreements with providers and unions. These are often the target of advocacy by grassroots organizations, according to administrators, as they limit the degree to which individuals can exercise self-determination. It is difficult to argue as to whether these undermine best practices in the literature, as they are often the result of forces outside of the control of administrators—budgetary problems in the state or contracts with unions. Similarly, many administrators reported that their states were forced to use waiting lists in order to ration services to those most in need, echoing previous studies of self-direction administrators (Walker et al., 2009). In this way, self-determination conflicts with the political and economic framework in which self-direction is implemented. Although administrators demonstrate a high preference for participant self-determination, they must ensure that programs continue to be viable in the implementation environment—a necessity that can limit the expression of self-determination.

Training requirements are another concept in the descriptions of administrators that have somewhat mixed support in the literature. There is variation between states as to how extensive training requirements are for family DSWs. Some states allow the participant to determine all training requirements, while others require minimal or significant trainings provided by the state. According to Crisp and colleagues (2010), these state variations all fall within the umbrella of best practices in self-direction. For providers that perform tasks requiring more extensive training, the descriptions of administrators followed best practices by requiring providers to meet more stringent state requirements. For more everyday tasks, participants are the best informed on what training requirements are needed. However, some administrators expressed that training requirements were less related to expertise and more related to parity between traditional and

family DSWs—with untrained workers viewed as unfair competition for those who already completed training requirements through a traditional provider agency.

There were some results where best practices are difficult to discern in the literature. For example, the use of regional administrators to promote self-direction was reported in multiple interviews, but these change agents are not present in the self-direction literature. Another ambiguous result was the relationships that administrators described with FMS providers. Strong relationships with FMS providers were reported by administrators to be crucial to successful implementation. It seems logical that strong relationships would be helpful, but there is little evidence to support this assertion in the literature. Competition between FMS providers would, in self-determination theory and political economy, provide for greater choice—an opinion that is expressed by more than one administrator. However, future research would have to determine whether competition between FMS providers will result in better outcomes for participants or systems.

### **Aim 3: Describe the Salient Forces that Influence DDPAs in the Process of Administering Self-direction**

**Policy environment.** Although the categories in the original coding matrix were largely grounded in administrators' descriptions of the policy environment, there was also significant interpretive work done that elicited surprising results. The most common code for federal issues was what other states are doing. Administrators were far more concerned with state-to-state learning than was anticipated. These results were buttressed by the expressed desires of administrators to keep up with the latest trends in self-direction and make changes to their service delivery system to better accommodate national trends. Within the original coding matrix, administrators were expected to desire to improve their programs; however, the focus on

other state implementations of self-direction was not expected (Infield, 2005; Schmitz et al., 2005).

Part of keeping up with national trends is the interaction that states have with federal administrations, particularly CMS and the Department of Labor. State-to-state learning was also important in this domain, as administrators reported looking towards other states to better understand how the new labor regulations would affect their residential homes and other congregate settings. While there was some turbulence reported with CMS regulations, most administrators reported that the new community rules were not likely to impact self-direction—an unexpected finding. Administrators linked this sense of calm with the tendency of self-direction to help participants avoid congregate settings and engage in community integration. Because the new community rules are designed to increase the use of person-centered planning and reduce the use of residential homes, this initiative will support the expression of self-determined behavior. The NRCPPDS (2012) emphasizes that person-centeredness will have to be incorporated into congregate settings and that participants will be given more choices within their residences, providing greater opportunities for self-determination. Furthermore, the CMS regulations again demonstrate the degree to which self-determination theory has been influential in shaping policy for individuals with IDD.

Contrastingly, the results around new labor regulations from the federal government were sources of significant uncertainty and turbulence in the policy environment. While this result was an emergent code in the final coding matrix, there is significant evidence in the literature that new labor regulations will have a significant and possibly detrimental impact on self-direction. The Department of Labor standards, according to an NRCPPDS webinar (Murphy & Cucu, 2015), propose a set of factors to be interpreted by the courts as to whether a self-directed

participant is subject to regulations. Because many of these tests, such as wage setting, recruitment, and making hiring and firing decisions, are key aspects of engaging in self-direction, it is likely that these regulations will have a significant impact on the future of self-direction. Moreover, based on the design decisions made by administrators—determining wage ranges, setting employee qualifications, determining services in the plan of care—states may be considered third-party employers and therefore be liable to provide more extensive monetary benefits to support workers. Although these rules have been significantly limited by the courts during 2015, the Department of Labor may still win on appeal—underscoring the significant uncertainty that comes with federal administrative initiatives (Murphy & Cucu, 2015).

Within the state policy environment, the effects of waiting lists and unmet need, highly interconnected categories in the data set, were largely negative, causing turbulence in the environment. Administrators reported that advocates are often unhappy with longer waiting lists, and that litigation was a possible outcome if the unhappiness persisted. In their descriptions of waiting lists, administrators often expressed dissatisfaction with the size of the unmet need in the environment and feelings of inefficacy at reducing the size of the list despite additional funds appropriated by the legislature. These problems are common within the literature, as the waiting lists for 1915c waivers alone totaled near 350,000 people with IDD in the year 2014 (Kaiser Family Foundation, n.d.). The political economy incentives of administrators are to increase program size and promote access to programs, but when waiting lists are used, these preferences conflict with the amount of funds available to provide services. Administrators often reported desiring to fund more people than they currently do, but they report that economic realities necessitate using a waiting list.

Both the DDPA literature review and self-determination theory indicated that litigation related to IDD would be an important code in the dataset. Self-determination theory often points to the importance of litigation in creating self-directed programs and for adding legal authority to the calls for greater self-determination for individuals with disabilities. In the reports of administrators, litigation was viewed as both a source of turbulence and calm within the environment. Some administrators reported having to fight advocates in the court system when they made changes to programs, particularly when budgetary regulations changed. However, one administrator reported that consent decrees ensured that self-directed programs remained funded during difficult financial times for the state budget. In both cases, litigation was portrayed as a vehicle for increasing or maintaining self-determination, a finding supported by self-determination theory.

Another category derived from the DDPA literature review was well grounded in the reports of administrators—the effect of socioeconomic factors on self-direction implementation. Subcategories within socioeconomics included the effect of rural populations and budget issues. Budget issues were commonly mentioned by administrators in their descriptions of implementation. Even in states with relatively healthy budget environments, administrators emphasized that overall health does not necessarily translate into increased funding for self-direction. This result was expected, as budgetary issues are commonly described in the literature as affecting implementation, particularly regarding rules for individual budgets and budget authority (Sciegaj et al., 2008; Walker et al., 2009). Administrators confirmed this influence in their responses. The influence of rurality is also found within the literature, as Infield (2005) describes the utility of self-direction in closing service gaps in rural areas. Administrators valued



this feature of self-direction, as it helped them to reduce the unmet service need in their environment, a revealed preference in the data set.

Administrators also highlighted the shortage of DSWs within the state as a potential problem for implementation. In particular, for some states, the lack of “knowledgeable” and “consistent” providers was noted as an ongoing problem. The DSW shortage is a well-acknowledged problem in the self-direction literature, and administrators confirmed that it continues to affect present implementations (Trtiz, 2004).

Many administrators described the importance of having previous experience with self-directed pilot projects, particularly the Cash and Counseling demonstrations, as important factors in implementation. In states where pilot projects took place, administrators reported that their workforce received specific training on self-direction, a key environmental component that supports participant self-determination. Additionally, the funding and cultural change that was garnered through participating in those projects assisted in carrying the self-direction forward through the years. Over time, however, many of these programs had to become more restrictive and impose more spending regulations, a finding also common to previous studies (Walker et al., 2009). A unique and unexpected finding occurred in a few administrator’s interviews, in which they described having to terminate these pilot projects and transition participants into more modern implementations. These findings about what administrators do to the original self-directed programs in their state provided a richer understanding of the lifespan of self-directed implementations.

The impact of other programs for individuals with IDD, a deductive code based on self-determination theory, was likely understated in the dataset. Because of the intensive focus on the implementation of self-direction, administrators often focused solely on these programs rather

than the entire spectrum of administrative interventions for individuals with IDD. Consequently, it is difficult to surmise based on this data set how self-direction interacts in with other programs for individuals with IDD to promote self-determination. Emergent codes around managed care and the impact of schools presented some interesting findings. Managed care was seen in one state as a structure that ensures each person who qualifies for the program is able to be served; whereas in another state, the transition towards managed care had yet to be implemented and was described with uncertainty. This dissonance is reflected in the literature on managed care and self-direction, as researchers highlight potential confluences between managed care and economization in self-direction but also difficulties in merging the two philosophies of service delivery (Sciegaj et al., 2014). The impact of managed care on self-direction merits further study with more directed questions about how the two program philosophies operate in tandem.

Similarly, the impact of schools on self-direction was also likely understated due to a lack of direct questioning. For administrators who mentioned the impact of schools, the effect was generally positive as schools provided younger families with more opportunities for self-determination. Once families transitioned out of school-based programs, they generally wished to continue exercising the same degree of control over their family member's supports. Incorporating self-determination into special education curricula for individuals with IDD is considered part of best practices (Wehmeyer & Schalock, 2001), but the link between these programs and self-determination-based programs like self-direction outside the school environment points towards a fertile area for future research. Administrators in IDD programs did not speak of partnerships with school administrations, and further research is needed to evaluate the extent that these departments coordinate on transitioning children with disabilities through self-determination.

The cultural issue that occurred with the greatest frequency in the data set was deinstitutionalization and community living. Self-determination theory describes these cultural forces as important macro-level impacts on the ability of individuals with disabilities to express self-determination. Administrators mirrored these assertions within the data set, tying the origin of self-direction to deinstitutionalization and the movement towards normalization, or living “everyday lives.” Moreover, the penetration of self-determination theory was further evidenced by the pride with which administrators described the reduction in institutionalized populations and the increase in the number of individuals living in their own homes or in the homes of family members.

Deinstitutionalization was driven in part by the self-determination movement which rejected previous notions of benevolent paternalism towards individuals with IDD and affirmed the right of individuals with IDD to make important choices about their lives (Doty et al., 1996). The responses of administrators indicate that paternalism is still an active force in the implementation environment. Administrators described interactions with family members, providers, regional administrators, and state administrators where they had to work on changing deficit-focused attitudes towards individuals with IDD. Self-direction was conceptualized by administrators as a cultural shift in service delivery, similar to the descriptions of self-determination scholars (e.g. Nadash & Crisp, 2005). Unfortunately, some administrators believed that self-direction was crowding out self-determination from the minds of administrators and other individuals in the service delivery system. Too much focus was being placed on spending and the hopes, dreams, and everyday choices of individuals were buried underneath hourly service authorizations, wage rates, and other financial negotiations. This represents a challenge for self-direction moving forward and may point to a crest in the

movement towards greater self-determination. While CMS continues to formally push for greater self-determination and person-centeredness in all HCBS programs, the practicalities of administration might continue to draw focus towards spending rather than human potential.

A final cultural issue that affects implementation is how administrators draw the line between where natural supports end and state-funded supports begin. Administrators describe this tension as an ongoing problem in implementation. The use of natural supports is key to the success of self-direction, as individuals often engage family members for both paid and unpaid support roles. Administrators desired to validate natural supports while at the same time not replacing them with paid support. The literature points to the tendency of natural supports to be relied upon too greatly in supporting individuals with IDD (National Participant Network, 2010). Families of lower income are likely to lose out on the benefits of engaging in paid support work, including increased income and better mental health outcomes, in states where restrictions are tighter (Heller et al., 2012a; Heller et al., 2012b).

**Policymaking.** Administrators did not often describe the policymaking environment in their interviews. The structure of self-direction as a joint program between state and federal officials complicates the policymaking process envisioned by Hasenfeld, wherein policy problems and solutions are coupled in a legislative body. Moreover, the programs under examination in this study had already completed the process of policymaking, and when revisions needed to be made or future programs created, these processes were largely accomplished in the implementing department rather than the legislature. The legislature was described by administrators as largely a source of funding and occasionally a source of oversight, but the coupling of problems to solutions occurred largely in the policy refinement domain inside the implementing department.

**Policy instruments.** The subdomains within program design derived from Hasenfeld’s model were well grounded in the experiences of administrators. Administrators described each program as specifying the particular services and supports that could be self-directed. Two issues emerged within this category—bundling and unbundling of service types and the inclusion of goods and services. Unbundling services was described by administrators as impeding the self-determination of participants, as it created more restrictions on participant spending. Administrators reported having to balance this with the political and economic demands of their position in which CMS directives and spending accountability are important. Though one administrator reported that self-determination was impeded by unbundling service types, it is unclear from the literature as to whether bundled services would be considered to impede self-determination in all cases. This distinction is far clearer, however, regarding self-directed goods and services. Crisp and colleagues (2010) define goods and services as part of full budgetary authority and therefore full self-direction. Administrators commonly reported the need to create approved or disapproved lists for these purchases, a practice which is also described by Crisp as inhibiting true self-determination.

Other decisions reported by administrators that relate to program design were better described using emergent codes. Administrators made decisions about the type of waiver to use, whether to single out self-direction on its own waiver or blend it into existing traditional waivers, maintaining state-funded plans, using a single waiver or multiple waivers, and how to incorporate Medicaid waiver rules from CMS. Administrators agreed with previous reports in the literature that Medicaid rules were onerous and often confusing—“byzantine,” in one administrator’s terms (Infield, 2005). While there is no best practice literature on which waiver to choose—the answer depends largely upon the population served and the specific needs of the

administrators—but the present study presents a unique understanding of how those decisions are made. State-funded plans were largely conceptualized as filling in gaps where Medicaid funding is prohibited from flowing, including when participants did not meet eligibility criteria or particular goods and services could not be converted into a Medicaid billable service.

Administrators report often having to fit new programs within the context of previously existing programs, including earlier self-directed pilot projects and traditional HCBS waivers. For states that operate under managed care, there is a difference between those that operate under the 1915b authority alone or those that also have a 1915c that works in tandem with the b waiver. These states did not report differences in implementation or satisfaction based on these design decisions, and further study is needed related to participant outcomes to better understand how waiver types impact participants. Finally, many administrators describe the utility of combining traditional supports and self-direction on a single waiver program. Administrators valued being able to provide participants with a continuum of support options, and by combining traditional and self-directed supports within a waiver, participants were able to engage in greater self-determination about what level of control they desired over their supports.

The other two subdomains from Hasenfeld's model, resources and authority were also well grounded in the data set. Within resources, the desire for greater monetary resources was paramount, as was the desire for more case managers and support brokers. The need for more funding of self-directed programs is reflected in the literature, as the waiting list for HCBS services for individuals with IDD is quite lengthy (Kaiser Family Foundation, n.d.). Coupled with the budgetary issues throughout many states, the result is reduced access to self-direction and fewer resources for administrators implementing self-direction (Cubanski & Kline, Holahan et al., 2002). When resources were not forthcoming from the legislature, administrators reported

making reductions to reimbursement rates or delaying the distribution of funds until legislative appropriations were secured. These actions were reported as possibly compromising self-directed support arrangements, a finding supported in the literature, but administrators felt they had little choice in the matter (Bachman et al., 2012; Simon-Rusinowitz et al., 2014). These decisions also serve to describe the authority component, in which implementing departments used their power to elicit compliance. A common complaint of administrators, and one that is supported in the literature, is the recalcitrance of regional authorities and case manager to recruit individuals into self-direction (Crisp et al., 2010). By using their authority to bring members of the intraorganizational network on board with self-direction, administrators are expanding opportunities for self-determination and ensuring that it is present across the participant's ecosystem. However, administrators cautioned against using that authority too heavily on participants and families, as when new rules are created, they affect the everyday lives of individuals.

**Critical actors.** Because the majority of self-directed programs are enacted through Medicaid waiver programs, it is unsurprising that the primary oversight body reported by administrators was CMS. This deductive code from the DDPA literature review was well grounded in the data set. Aside from the CMS initiatives and oversight described previously, there was little else in the relationship that is of note for future research. Most administrators report that CMS plays a central role in implementation, and therefore in accordance with Hasenfeld's theory, has a central place within the power dynamics influencing implementation.

The oversight responsibilities of the legislature and governor were also described by administrators. Although administrators often described a supportive environment within these branches of state government, support was generally defined as financial appropriations with a

particular emphasis on increased appropriations to minimize waiting lists. Simon-Rusinowitz and colleagues (2001) find similar roles for governors and legislatures during the Cash and Counseling demonstration projects. When new governors took office, a previous nationwide study on self-direction found that it could either bring more funds and attention to self-direction or may cause uncertainty in the implementing department—results that were both echoed in the reports of present administrators (Walker et al., 2009). Some administrators also highlighted the importance of partnering with the advocacy network in the state to combat more paternalistic views among legislators. This process is designed to increase awareness and support for self-determination in the ecosystem, a key goal of ecological self-determination theory.

The role of working groups and committees was an emergent code within the data set, though the use of formal advisory groups is common in the self-direction implementation literature (Crisp et al., 2010). Administrators described the purpose of these groups as communicating information throughout the system—with state-level information flowing downward to participants and participant feedback flowing upward to state administrators. Furthermore, administrators demonstrated a preference for participant input into the decision-making process as well as strong advocacy support for programs. These goals were accomplished through working groups, which helped administrators create new training and outreach materials, provided feedback on what was working, assisted with problem solving, and generated new ideas for program refinement. Crisp and colleagues (2010) emphasize the importance of accessibility in facilitating participant involvement, an aspect of committee work that was not explored in detail in this study, but speaks heavily to the ability of participants to exercise self-determination and control over the programs that affect their lives. Finally, some



administrators reported that on some committees or working groups, such as those negotiating with unions, administrators acted as agents for participants—advocating on their behalf.

Within the final model, the role of the implementing department was broken down into multiple component parts. In a complex, polycentric program such as self-direction, there is no one entity charged with implementation; instead, there is a network of local, county, state, and private agencies that act on behalf of the implementing department. This revision to Hasenfeld's model did not eliminate the role of the implementing department—conceptualized as the state-level entity responsible for implementation—as a critical actor. The themes described by administrators, including “customer service” and “open-door” policies, are echoed in the literature (Crisp et al., 2010). These themes spoke to a preference of administrators to be accessible to participants and to respond to issues quickly. Administrators spoke proudly of accessibility, that there was not wrong door for participant complaints or issues, and the speed with which issues were resolved.

Hasenfeld's category of stakeholders was comprised mainly of provider agencies and unions. Feedback from these actors was garnered through stakeholder advisory committees and other negotiating processes, such as collective bargaining. These processes largely followed Hasenfeld's self-interested bargaining model, in which providers and unions advocated for their own interests. Walker and colleagues (2009) and the Crisp and colleagues (2010) recommend including providers on committees with participants and advocates to more easily reach compromise, but that advocates should be more represented on committees to counter the strength of provider bargaining. This overrepresentation was not found in the responses of administrators, though there were no direct questions about it in the data set. However, the reports of administrators challenge the Crisp's (2010) idea that advocates and participants are

more peripheral to the implementation process than providers. Providers have greater centrality in traditional supports and therefore may need to be countermanded on committees by an overrepresentation of advocates; conversely, in self-directed supports, administrators described participants and family members as the core element, the most important critical actor within the space. This tentative result speaks to the power of self-direction in fomenting a cultural change within service delivery systems that enables self-determination throughout the ecosystem.

The role of advocates in the implementation process was described by administrators as twofold—to bring knowledge from the bottom up and to hold administrators accountable. Administrators spoke positively of both of these roles that advocates embodied. The preference for more knowledge communicated across the system was a common code in administrator conceptualization, a part of their self-interested desire to improve programs. In addition to the welcome, though sometimes contentious, relationship described previously, administrators also described a preference for strong advocacy support for programs. Administrators reported working with advocates to ensure program features allowed for greater self-determination and to dispel myths within the legislature about the ability of people with IDD to engage in self-determined behavior. These complementary roles challenge Hasenfeld's model of political economy, wherein bargaining is largely self-interested and adversarial. The ability for factions to form based on common interests is an extension of this theory and one that fits well within the subsequent interest group literature (Cummins, Byers & Petrick, 2010). Additionally, administrators' desire to be held accountable by advocates highlights the importance that administrators attach to participant self-determination and control over supports. Participants and families were invited to create and revise outreach and training materials, providing a

mediated version of the peer-to-peer learning process that is considered part of best practices in the literature (Crisp et al., 2010).

Advocates were also instrumental, according to administrators, in the process of creating self-directed programs. Administrators highlighted the importance of non-profit organizations and think tanks, particularly RWJ, in creating the political will and financial ability to create and train a service delivery system. The centrality of RWJ to the creation of self-direction is also found within the literature, as they were the primary funders behind the Cash and Counseling demonstration projects and the subsequent transformation grants (Doty et al., 2012; Walker et al., 2009). Subsequently, administrators also emphasized the importance of AAIDD and NRCPPDS in providing technical assistance on implementation issues, a critical actor relationship that is not based on self-interested bargaining contra Hasenfeld. The role of AAIDD in developing the SIS assessment is of particular interest, as it helps to balance the interests of administrators and participants by retaining person-centeredness in assessment while also balancing the administrator's preferences for economic predictability and equitable distribution across the service area.

The roles of the individuals with IDD were described as central to the implementation process. Administrators' descriptions mirrored self-determination theory as well as the self-directed literature more broadly on the importance of self-determination in decision-making, though the lack of focus on person-centered planning in assessment remains a challenge. Based on their responses, it is evident that administrators have significantly adopted the tenets of self-determination theory and its predecessor normalization theory—with one administrator reciting Nerny and Shumway's (1996) values-based principles for self-determination in their response.

Administrators described the roles of family members often interchangeably with the role of the participant. This reflects an ongoing conflict in the literature as to whether self-direction for individuals with IDD is more of a family support program, rather than an individual support program. Administrators were apt to describe family members as the central components of self-direction, influencing the level of supports in the assessment process, performing employer of record and DSWs functions, and advocating for the interests of their loved ones. Many administrators focused more on the family unit than on the individual with IDD. For example, administrators often spoke of the paper work burden in self-direction as adversely affecting family members, rather than individuals with IDD. In this way, the true definition of “participant” is somewhat unclear in the data set. For some administrators, individuals with IDD are the participant—with family members acting as formal and informal sources of support. For many others, family members are participants, directing funds and making employment decisions. This was often reflected in the language that administrators used to describe the provision of supports, denoted by an emergent code in administrator conceptualization. Self-determination theory describes increasing the autonomy and choice of individuals with disabilities. However, in self-direction, administrators often demonstrated that the realities of program implementation—accountability, responsibility, and capability—require that a more family-centered decision-making process is in effect.

Within critical actors, the influence of other state administrations or departments was significant. Administrators described having to advocate forcefully against misconceptions that self-direction was prone to abuse and misspending, often with legal departments. This was a cross-cutting theme across many parts of the interviews, and administrators report this persistent misconception as an important though not insurmountable barrier to successful implementation.

Another challenge within other state administrations was the lack of communication between departments that ran parallel self-directed programs. Some states housed self-directed programs in different departments, and administrators evinced a lack of knowledge about how programs outside of their department functioned, despite the fact that they target the same populations—individuals with IDD. This problem is compounded when individuals with IDD are served under waivers that do not directly target this population, posing a substantial challenge for IDD researchers.

**Driving forces.** The driving forces hypothesized by Hasenfeld were well grounded in the data set. Importantly, the idea of technological rationality and irrationality was deepened through the qualitative reports of administrators. Administrators implementing self-direction complicated the simple “theory of change” that Hasenfeld hypothesizes. Self-direction contains many theories of change based on the outcomes that administrators want to achieve. As such, technological rationality and irrational are perhaps better conceptualized as properties of the service delivery system itself rather than entirely exogenous forces. On paper, self-direction contains a list of component parts, such as FMS, support brokerage, or employer of record, and a specific way they should be combined. However, administrators report making unique choices about how those component parts should be put together. For example, some administrators choose not to use support brokerage or to perform FMS services within the implementing department rather than contracting out. As such, the “theory of change” underlying self-direction shifts as the purpose and configuration of the components changes. Administrators reporting irrationality are actually describing a service delivery system whose components are malfunctioning, not due to user error but due to a problem in how these components are thought to fit together. In this way, the present study deepens and revises Hasenfeld’s understanding of

technological rationality as both a driving force influencing the service delivery system as well as an output of the actions of components within the service delivery system.

Similarly, the definition of economic considerations shifted due to inductive processes. In the reports of administrators, economics drifted away from the transactions cost model of economics that Hasenfeld uses and towards a focus on costs and payment. The transaction costs model emphasizes the importance of centralization of decision-making and the creation of decentralized hierarchies to balance control and emergence (Calista, 1987). While these considerations were certainly a part of the reports of administrators, when administrators mentioned economic forces, they often focused more on the quantity of funding in the environment, the sufficiency of funding to ensure a robust provider pool, and the size of individual budgets. Indeed, the desire of administrators for greater funding to serve more participants is unsurprising given the number of people on waiting lists (Kaiser Family Foundation, n.d.); moreover, administrators revealed a preference of wanting to reduce the unmet need in their service area—a desire they linked to the need for increased funding. Ultimately, transaction costs issues were subsumed within the technological rationality and theory of change in the final model.

Hasenfeld's subdomain of power relations, unlike the previous two forces, did not evolve as a result of the data analysis. Power relations between various critical actors were largely influenced, in accordance with theory, by their centrality to implementation. CMS, the implementing department, case managers, individuals, families, among many other actors all played highly central roles in the implementation process, and centrality was difficult to generalize across interviews. An unexpected result was the centrality of advocates to the implementation process, as advocates are often described as marginalized voices in

implementation. In the reports of administrators, advocates were described as having significant power—taking administrators to court over rule changes, providing coalition support when administrators advocated to CMS, and holding administrators’ “feet to the fire.” Although administrators may have been trying to portray their relationships with advocates in a more positive light due to observer effects, their descriptions of even adversarial interactions as both necessary and positive were noteworthy.

#### **Aim 4: Describe DDPA Perspectives on Policy Output and the Degree to which Participant Needs are Being Met by Self-Directed Programs**

Many of the categories from self-determination theory were important for administrators’ perception of program success. Success was largely defined by the ability of participants to engage in self-determination in order to have their needs met. Administrators also emphasized the importance of community integration and inclusion. These results demonstrate the high degree of agreement between administrators’ understanding of self-direction and self-determination theory. However, this study is limited in its ability to test administrator assertions against the actual reality of service delivery experienced by participants. Ultimately, future research will have to compare the descriptions of administrators with the experiences of self-direction participants to determine the extent to which self-determination can be exercised in HCBS service delivery.

Important outcomes for administrators can be contextualized with larger ongoing trends. In particular, transitioning individuals with IDD into employment was an important sign of program success for administrators. The new Department of Labor restrictions on sheltered workshops are an important contextual variable that is likely shaping how administrators understand community integration. Additionally, the CMS community rules also emphasize the

importance of community integration, and this is reflected in the focus of administrators on inclusion as a metric for program success. To the extent that these developments cause administrators to offer choices and opportunities for individuals with disabilities that were not present previously, they may have the effect of increasing participant self-determination; however, these federal administrative initiatives may limit the choices offered to participants as they transition systems away from previously existing models of service. This tension in the data is reflected by administrators who highlight the importance of being an “employment first” state while also emphasizing that new opportunities should be chosen rather than forced upon participants.

In addition to participant-focused outcomes, administrators describe system outcomes that are important to measuring success in self-direction. These outcomes are well grounded in the political economy understanding of administrative decision-making. The revealed preferences of administrators for larger programs, reduced costs, intraorganizational coordination, and meeting participant need are all reflected in their definitions of success as larger, less expensive, predictable, and consistent programs. By incorporating these individual preferences into the political economy model of implementation, the present study extends the knowledge of program implementation proposed by Hasenfeld through accounting for individual preferences and actions.

Administrators endeavoring to foster better outcomes across the implementation system centered around increasing the use of technology in self-direction. Administrators spoke about moving training materials online, using electronic billing systems, and transitioning to using the SIS and budget algorithms to determine individual budgets. These components were



conceptualized as bringing greater technological rationality to the system. The evidentiary support for these interventions is explored previously in this section.

### **Implications for Research, Practice, and Policy**

The present study utilized a unique theoretical and methodological approach. The deductive categorization matrix combined self-determination theory, which is rooted in the disability rights movement, and political economy, which is rooted in rational choice approaches to policymaking. By using these two theories in tandem, a dialogue emerged that provides a unique insight into the present and future of self-direction for individuals with IDD.

The most salient result from this research study is the extent to which the philosophy of self-determination has permeated the consciousness of public administrators. Opportunities for self-determination were described as the most important part of self-direction, and its components such as flexibility, individualization, and variation across time echo the self-determination theory of Abery & Stancliffe (2003). Administrators demonstrated a strong preference for systems that would expand participants' choices and draw more participants into self-directed options. Often, present implementations were contextualized within the history of the self-determination movement more broadly and framed in terms of the effects on community integration and human potential for individuals with IDD.

Given these desires, the present study contextualizes these preferences within the political and economic environment in which administrators act. Moreover, the inductive categories derived from the experiences of administrators provide a more comprehensive understanding of the institutional forces that impact their decision-making. The results indicate that although administrators often desire to increase opportunities for self-determination in their target population, the realities of public administration often obstruct their ability to do so. Moreover,

the political and economic forces within the public administrator space impact how public administrators understand what self-determination is and how it can be expressed. Self-determination was often mentioned synonymously with choice, control, autonomy, independence, self-sufficiency, and authority. Although these concepts are conceptually related to some degree, they also reflect the values present within the administrator's cultural milieu. Self-determination, as conceptualized by Abery & Stancliffe and Wehmeyer, speaks to a more foundational concept than "who comes into your home" or "how much your support worker will be paid." Self-determination is determining how one's life should be lived within an ecosystem that supports one's definition of the good life. While some administrators reported that the considerations of everyday decisions were important in self-direction, these were largely overshadowed by the descriptions of fiscal issues. Tellingly and presciently, an administrator from an early interview in the Northeast lamented that self-direction had overtaken self-determination in the minds of administrators. Although self-determination could be expressed within the allocation of fiscal resources, the characterological and spiritual trait of self-determination was eclipsed by the flow of resources and power. Many administrators spoke highly of transformational leaders that were inspired by the self-determination movement and provided the groundwork for self-directed programs many years ago. Unfortunately, the present day may represent a retrenchment against these rights-based and philosophical arguments. For advocates of self-determination for individuals with IDD, the results of this study should provide further evidence that more work remains in the self-determination movement.

In addition to describing their understanding of self-determination, administrators also revealed how technological forces are likely to impact implementations of self-direction moving forward. As states increasingly turn to the use of electronic billing, budget algorithms, and

standardized assessments like the SIS, there is a concern that the uniqueness of individuals will become lost. Future directions for research should explore how individuals with self-determination experience these more technologically sophisticated systems. For individuals who do not fit neatly into the algorithm or assessment process, how administrators will cope with outliers is an unanswered question. Administrators are tasked with a difficult balance—to weigh the importance of individuality and person-centeredness for each participant with equitability and fairness across participants in the system. Although technology holds promise for the latter goals, it is the role of advocates and researchers to ensure that the dreams and hopes of each individual are honored, as well.

Another important implication of the present study is to better understand the motivations and understandings of administrators. Hasenfeld's model of implementation was demonstrated to be reductionist and devoid of human cognition and action. Similarly, the literature review that informed some of the deductive categories in the original coding matrix were derived from the perspective of administrator as a self-interested actor. The inductive categories that emerged from the experiences of administrators presented a more complex and nuanced understanding of how administrators think and behave. Administrators revealed preferences for a system that is accessible and responsive, provides for greater self-determination, is flexible in how it interprets rules, keeps up with important trends in service delivery, garners more resources and choices for participants, and reduces the unmet need in the environment. While there were some examples of the principal-agent problems in the data, many of these preferences align well with the best interests of individuals with IDD and their families. Moreover, the knowledge and opinions that administrators bring to the implementation process signified their thoughtfulness on the purpose and outcomes of self-direction. Although some of the opinions on self-direction were self-

interested or related to external conditions, such as medical necessity and CMS reimbursement, administrators reflected on the purpose of self-direction, incorporated their own personal experiences, and used these constructions to fight back against other critical actors who believed self-direction was prone to abuse or scandal. In this way, the present study uses self-determination theory as an entrance into the conceptual world of program administrators, revising and deepening the more reductionist models of political economy.

### **Strengths and Limitations**

The present study provides a comprehensive and in-depth understanding of how administrators implementing self-direction make decisions. Of the forty-one states that have implemented state-wide programs that include self-direction for individuals with IDD, this study included interviews from thirty-three state administrators—just over 80% of the states. While some states were inevitably left out of the dataset, the present study is based on a robust sample of a unique and difficult to access population. Additionally, the format of the interview lent itself well to the directed case analysis method, as it provided the opportunity to test the applicability of previous literature on self-direction, program implementation, and self-determination. Trustworthiness of the final research product was fostered through the help of other researchers in the auditing, peer review, and research team coordination process. At each step in the direct coding analysis, the categorization scheme was checked by the peer reviewer in accordance with the coding consistency plan.

The most important limitation in the data set is the potential for social desirability bias in the interviews with administrators. Administrators may have altered their answers to the interviewer's questions based on wanting to appear more responsive to families or individuals or more satisfied with their relationship with the state legislature, for example. Interviews were not

conducted in an adversarial manner to ensure objectivity and to build trust with administrators who may be skeptical that their words might be used against them. Administrators operate in a political environment in which advocates are pressuring them to provide for greater self-determination, and it was important within this study to ensure that administrators did not believe the researchers had an advocacy agenda. As a result, the researchers were careful not to undermine administrator's descriptions of relationships with other actors or bring up experiences of individuals who may be unsatisfied with service delivery. This adversarial process should form the basis of future research where the reports of administrators contained in this study are compared against those of participants, families, and support workers to arrive at a deeper understanding of self-direction.

In addition to social desirability bias, systematic error may be present in the sampling process. Administrators who declined to participate in the study may be systematically different from those that chose to participate. Specifically, administrators in states with contentious implementation environments may be reluctant to participate in a study that examines their state's implementation in detail; however, that information would provide a more complete picture of the challenges of program implementation. Similarly, studying administrators in state that chose not to implement self-direction would provide for more robust detail in future research on the political and economic conditions that foster successful implementation.

Finally, the deductive reasoning in directed content analysis may have introduced confirmation bias into the analytical process. Whereas other methods of qualitative data analysis rely only on inductive processes, directed content analysis uses a deductively-derived categorization matrix as a starting point for analysis. In choosing theoretical frames before the analysis is performed, the researcher may have biased the analysis process by seeking to verify

pre-existing ideas rather than inductively creating new ideas that are better grounded in the data set. Elo and Kyngas (2008) contend that deductive analysis only makes explicit the theoretical frames that all researchers performing qualitative research bring to the analytical process, including those who solely use inductive reasoning. In the present analysis, the deductive categorization matrix and Hasenfeld's model provided an initial starting point around which inductive categories, which comprised a majority of the final coding matrix, were derived. The emergent categories represented unexpected findings, indicating confirmation bias was not a dominant process within the analysis. Furthermore, the use of peer review, auditing, and research team collaboration throughout the analysis process helped to ensure the confirmability and trustworthiness of the final research product.

## **Conclusion**

In previous chapters of this manuscript, Connor and his family were considering whether to remain in traditional waiver services or pursue self-directed waiver services to meet Connor's support needs. The process for both traditional and self-directed supports was described as somewhat similar—a case manager's assessment, an individual budget, support workers, and case management supervision. However, the differences that exist between traditional and self-directed supports—the authority to hire, train, and schedule support workers, determine spending on an individual budget, and engage with a support broker—may be significant to a family who is dissatisfied with previous service through traditional supports. By choosing self-direction, Connor and his family may be better able to meet Connor's support needs and help him lead a more fulfilling life by expanding his opportunities for self-determination.

The present analysis provides context for how Connor's opportunities for self-determination are created in his environment. His desire for supported employment is tied into goals of living semi-independently, which is captured through person-centered planning in the assessment process. With this goal on his individual support plan, he is able to allocate money from his individual budget for supportive employment and interview and select a supported employment provider—with the assistance of his support broker. Regularly, a case manager monitors Connor's progress with his employment goals and ensures that the services he is receiving meet the standards provided by the state. These are the processes that Connor and his family see, but his service experience relies upon a complex, interdependent network of individuals, agencies, administrations, and systemic forces. The ecosystem in which Connor's services are delivered and the extent to which it supports self-determination may mean the difference between frustration and a life well lived.

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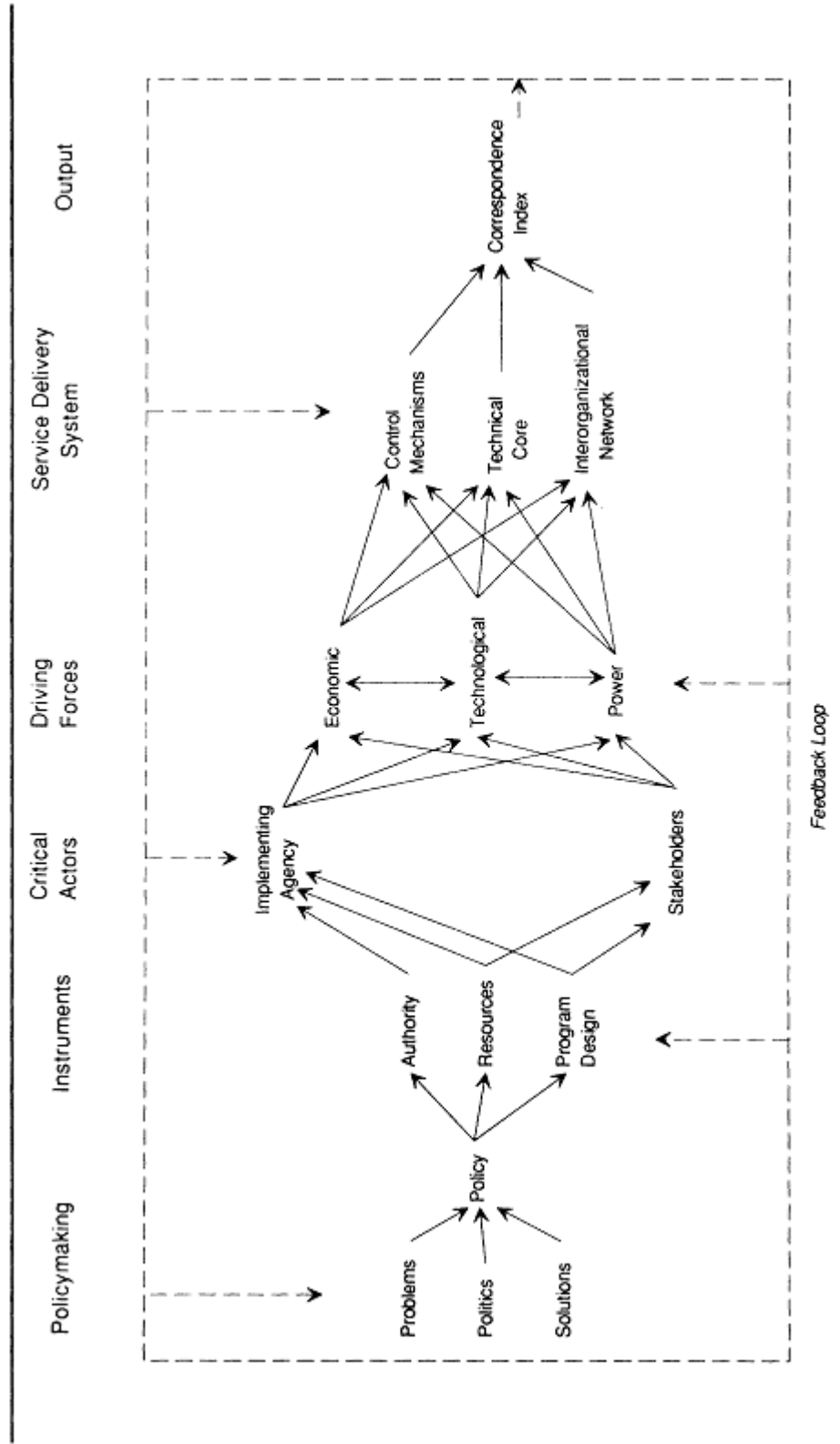


Figure 1: A Political Economy Model of Implementation

## Appendix B: Self-Directedness—Variations in State Implementations of Self-Direction

### Self-Directedness—A Scale Based on Design Choices

<b>Design Choices</b>	<b>Low Self-Directedness</b>	<b>Moderate Self-Directedness</b>	<b>High Self-Directedness</b>
<i>Planning</i>			
Does the care plan development involve a person-centered planning process?	Professional determines plan		Participant's and family's role are emphasized
<i>Budgeting</i>			
Does the program/waiver/option offer budget authority?	No		Yes
Is budget authority available for all services and supports covered in the waiver?	No		Yes
How is the budget calculated?	Capped at specific dollar amount for all consumers	Statewide uniform assessment tool	Based on person-centered planning process
What is the level of consumer participation in the budget process?	Professional develops budget after assessment		Participant and family have significant input
Are consumers given the option of working with a support coordinator?	No		Yes
Does the program offer the option to self-direct more than five services or supports?	No		Yes
Does the program allow the consumer to reallocate funds independently?	No reallocation may occur	Approvals are required for reallocations	Approvals are required for large reallocations or

			not needed at all
Are individuals required to work with a fiscal intermediary?	No		Yes
Are consumers given a choice in fiscal intermediary providers	No	Limited options	Many options
How large are the permissible wage ranges for service providers?	Exact wages specified by state	Wage ranges specified by state	No maximum or minimum
Are participants able to purchase individual goods and services not covered under traditional waivers/programs/options?	No		Yes
Are participants allowed to reallocate unspent monies at the end of the year?	No		Yes
<i>Employing</i>			
Does the waiver/program/option offer employer authority, including the ability to hire and fire employees?	No		Yes
Is employer authority available for all services and supports on the waiver/program/option?	No		Yes
Does the waiver/program/option offer employer authority for at least five services or supports?	No		Yes
Are participants able to choose between co-employer and common law options when exercising employer authority?	No		Yes
Are individuals able to hire family members as paid support workers?	No	Yes, but only when all other options are exhausted	Yes, pending state approval
Are parents of minor children or partners of adults able to engage in paid support work?	No		Yes, under certain conditions

How involved are consumers in training support workers?	Not at all	Consumer's role is mentioned by state	Consumer's role is emphasized by state
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## Appendix C: Interview Protocol

1. In general, how would you define self-directed supports?
  - a. Programmatically, in your state, what are the necessary components for a program to be considered self-direction?
2. What factors lead to your state's decision to use a self-directed supports?
  - a. How have your interactions with stakeholders impacted your implementation of self-directed supports?
3. Is self-directed supports available to anyone in your state who has I/DD, or only specified sub-populations such as children, adults, people with ASD, etc?
  - a. Is it available statewide?
  - b. Is it available to anyone who meets eligibility requirements?
  - c. Is it offered as an option for individuals on the waiting lists?
4. In general, are there trends in what types of individuals are most commonly served in your state's self-directed supports?
  - a. Children versus adult?
  - b. Specific disabilities?
  - c. Are there any sub-populations who are excluded from eligibility for self-directed options?
5. In your pre-interview, you provided a list of goods and services covered in self-directed supports. How did you make the determination to include those services?
  - a. Did you make the decision to exclude other goods and services?
  - b. Have there been any issues in your state around what goods and services are covered in self-direction?
  - c. Have you received any feedback from self-directed waiver participants about goods and services?
  - d. Can individuals exercise budget authority for all goods and services?
  - e. Can individuals exercise employer authority for all goods and services?
6. Is there individualized budgeting in the self-directed supports?
  - a. How is the individual budget determined? Minimums and max—waiver program cap?

7. Can an individual hire a family member as a paid support worker?
  - a. Does that family member need to register with an agency?
  - b. Are there any training requirements family members must complete in order to become a paid support worker?
  - c. Are any family members restricted from becoming paid support workers?
8. If a participant needs to change how their budgeted funds will be used, does their revised spending plan need to be approved by the state?
  - a. If budget amounts are changed, does a user need to seek state approval?
9. What monitoring and quality assurance mechanisms are in place to support self-directed supports?
10. What is working well with self-directed supports in your state?
  - a. What outcomes are important for you in assessing the effectiveness of self-directed supports?
  - b. What strengths in your organization have been helpful in implementing self-direction?
  - c. What (internal and external) resources were helpful in implementing self-direction?
11. What are the primary challenges with self-directed supports in your state?
  - a. How has your organization overcome these challenges?
  - b. What (internal and external) resources were helpful in overcoming these challenges?
  - c. Are there any social, economic, or political trends unique to your state that have affected implementation?
12. In your opinion, what changes could be made to your state's self-directed service options to make them better?
  - a. What resources might be needed to make these changes?
  - b. What outcomes are important to you?
13. In some states, we have heard from administrators who are focused on fiscal stewardship of Medicaid dollars and others who are more focused on consumer self-determination. How you balance the goal of fiscal stewardship with the goal of self-determination for individuals with I/DD?
14. In your dream world, how would self-directed supports fit within the broader context of Home and Community Based Services for individuals with I/DD?

- a. Pragmatically, do you think that is possible to achieve?
  - b. Does your vision for self-direction correspond well to the economic, social, and political environment in your state?
15. How have the CMS community rules affected your state's implementation of self-direction?
16. Any additional information you would like to share about self directed supports in your state, or any additional comments on previous questions?

## Appendix D: List of Participating States

1. Alabama
2. Arizona
3. California
4. Connecticut
5. Florida
6. Georgia
7. Hawaii
8. Idaho
9. Illinois
10. Iowa
11. Louisiana
12. Kentucky
13. Maryland
14. Massachusetts
15. Michigan
16. Minnesota
17. Missouri
18. Nebraska
19. New Hampshire
20. New Mexico
21. New York
22. North Carolina
23. North Dakota
24. Ohio
25. Oklahoma
26. Oregon
27. Pennsylvania
28. South Carolina
29. South Dakota
30. Tennessee
31. Utah
32. Vermont
33. Virginia

## Appendix E: Final Codebook

### Key for code origins

Hasenfeld & Brock (1991)= H&B
Abery & Stancliffe (2003)= A&S
Program Administrator Literature Review= LR
Inductively-derived codes= IND

- Policy Environment (H&B): *stable or unstable environment in which self-direction policy is developed*
  - o Federal/National Issues
    - Federal administrative initiatives (LR): *administrative and bureaucratic initiatives, largely from CMS*
    - Federal oversight by CMS (IND): *actions taken by CMS to induce compliance in the states*
    - National Core Indicators Project (IND): *initiative across states to compare outcomes in HCBS services*
    - What other states are doing (IND): *the actions of other state administrations related to self-direction*
  - o State Issues
    - Budget issues (LR): *Concerns about general budget issues on the state level*
    - Calm (H&B): *Agreement between powerful entities within the policy environment*
    - Conservative/Liberal balance in the state (IND): *balance of state legislators who espouse conservative or liberal ideologies*
    - Experience with pilot projects (IND): *previous experience with other self-directed programs*
    - Litigation related to self-direction (LR/A&S): *state or federal litigation related to access to self-direction or other HCBS services*
    - Managed Care (IND): *use of the managed care service delivery method within the state's Medicaid program*
    - Other state legislation/programs for IDD (LR/A&S): *other programs, supports, or initiatives relevant to individuals in self-direction*
    - Poverty (IND): *very low income within a state*
    - Public Perception (IND): *How the general public perceives the self-directed program*
    - Rural populations (IND): *individuals outside of metropolitan areas who need services*
    - School and Self-Direction (IND): *related to the school environment and how that impacts self-direction*

- Shortage of direct support workers (LR): *Lack of adequate numbers of direct service workers in an area*
- Shortage of support coordinators (IND): *Lack of support coordinators in an area*
- Socioeconomic factors in the state (LR): *Aspects of the social or economic environment that impact policymaking*
- Turbulence (H&B): *Disagreement between powerful entities within the policy environment*
- Unmet need (IND): *individuals with disabilities who need services that they are not receiving in the service area of the department*
- Waiting lists (IND): *list of individuals who cannot access services at this time due to economic or program design reasons*
- Cultural Issues
  - Deinstitutionalization and community living (A&S): *movement of deinstitutionalization and community living for people with disabilities*
  - Family/informal support vs. paid support (IND): *finding the proper balance between what family/informal supports should provide and what the state should pay for*
  - Guardianship and Conservatorship (A&S): *Legal authority to make decisions for a person with disabilities*
  - Medical vs. Non-Medical Model of Care (IND): *contrasting views of the service needs of individuals with disabilities related to medical competence*
  - Paternalism/Perception of IDD Population (IND): *wanting to insulate individuals with disabilities from decision-making processes*
  - Self-determination movement (IND): *movement for individuals with disabilities to have more opportunities for control over the aspects of their lives they value*
- Policymaking (H&B): *the process of creating legislation creating, funding, and amending self-directed supports programs*
  - Policy problems (H&B): *how policymakers understand the problems self-direction tries to address*
  - Policy solutions (H&B): *how policymakers conceptualize self-direction as a solution*
- Policy Instruments (H&B): *components of the policy created in the legislature*
  - Program Design (H&B): *indicates policy specifications regarding the target population, needs to be addressed, and the services to be provided*
    - Available supports/services (H&B): *supports provided through the self-directed program (respite, PCA, etc.)*
    - Medicaid waiver rules from CMS (IND): *rules from CMS that impact program design*
    - Multiple waivers/programs/options (IND): *Use of multiple waivers within the same state to implement self-direction*

- Needs to be addressed/target population (H&B): *population and social problem to be addressed by the program*
  - Single Waiver (IND): *State uses one waiver to implement self-direction*
  - State-funded plans (IND): *self-directed supports are funded through state funds*
  - Waiver type (1115, 1915) (IND): *type of waiver used*
  - Waivers that blend traditional and self-direction: *Waivers that have both traditional and self-directed options on the same waiver*
- Authority (H&B): *Legal authority of the implementing department to elicit compliance*
- Resources (H&B): *money, personnel, expertise, skills, facilities, and incentives*
  - Respite for people on waiting list (IND): *additional provision of economic resources for individuals on the waiting list*
- Critical Actors (H&B): *Individuals and groups who affect implementation of the policy*
  - Oversight
    - CMS and Medicaid (LR): *people in the Medicaid and CMS administration*
    - Department of Labor (federal) (IND): *people in the federal department of labor*
    - Governor (IND): *executive officer of the state*
    - Legislators (IND): *legislative officers of the state*
    - Working groups or committees (IND): *Groups formed by or with the intraorganizational network that may include stakeholders and advocates*
  - Implementing Department (H&B): *individuals in the state administrative department tasked with implementing*
  - Stakeholders (H&B): *groups with their own interests that influence policy implementation*
    - Provider agencies (IND): *Agencies that provide supports to individuals in self-direction*
    - Unions (IND): *unions that represent Direct Support Workers and other health professionals that provide services in self-direction*
  - Advocates
    - Family advocates (LR): *family members who advocate for changes to self-direction*
    - Grassroots advocacy (LR): *local or state organizations that advocate for changes to self-direction*
    - NASDDDS or State DD Council (LR): *formal council of DD professionals within a state and their national oversight organization*
    - Non-profit advocates or policy think tanks (LR): *state-level or national non-profits that advise on policy matters*
    - Self-advocates (LR): *individuals with disabilities who advocate for changes to self-direction*
  - Other Actors

- Individuals with disabilities (IND): *participants in the self-direction program diagnosed with IDD*
  - Family members (IND): *family members of individuals with disabilities who participate in self-direction*
  - Other state administrations (IND): *individuals in other state administrations*
  - Other states (IND): *other US states*
  - Universities and colleges (IND): *higher education institutions*
- Driving Forces (H&B): *forces in the implementation environment that create rules and incentives*
  - Technological specifications (H&B): *specify the components of the program and how they are to be assembled*
    - Rationality and coherence (H&B): *technological specifications have an internal logic and coherence about what change should happen and how it will be accomplished*
    - Irrationality and incoherence (H&B): *technological specifications lack internal logic and coherence about what change should happen and how it will be accomplished*
  - Economic considerations (H&B): *issues related to cost and supply/demand*
    - Federal funding (IND): *money from the federal government*
  - Power relations (H&B): *bargaining positions and self-interested actions of individuals, administrators, providers, and others*
    - Strong internal leadership (IND): *Leaders within the department who are committed to self-direction implementation*
- Service Delivery System (H&B): *the existing model of service delivery as implemented by the administration*
  - Control Mechanisms (H&B): *structure, process, and outcome measures and regulations made by the implementing department*
    - Background checks (IND): *comparing a worker to formal registries as part of the hiring process*
    - Backup plans, contingency plans (IND): *formal plan to ensure care is provided during emergencies*
    - Budget based on average utilization/algorithm (IND): *Budget is based on an algorithm that calculates based on average utilization in the state*
    - Budget based on previous utilization (IND): *Budget is based on previous utilization for the participant*
    - Budget caps (IND): *formal limits on how large an participant's budget can be*
    - Budget tiers (IND): *use of budget tiers based on level of need*
    - Caps for specific services/supports (IND): *Capping expenditures for specific services*
    - Cost control mechanisms (IND): *aspects of program design that are designed to reduce costs*



- Documentation (IND): *process by which services are documented and passed on for payment*
- Electronic billing systems (IND): *payment and employee documentation systems that are electronic*
- Escalation Procedures (for abuse/crises) (IND): *protocols for escalating incidents in the intraorganizational network during abuse or crises*
- Exceptions Procedures (for budgets and spending) (IND): *protocols for requests for additional resources by participants*
- Families/participants training providers (IND): *process of participants training providers on their support needs*
- Family training on self-direction (IND): *process of family getting trained in self-direction*
- Individual support plan (A&S): *Plan created by participant and intraorganizational network that describes services to be provided*
- Pre-approval process (IND): *process by which extraordinary spending requests are approved by the intraorganizational network*
- Prioritization by crisis/level of need (IND): *use of level of need to prioritize who receives supports in self-direction*
- Regulations for non-agency providers (IND): *training and certifications required for non-agency providers*
- Screening of participants (IND): *interviewing participants before they enter self-direction*
- State's custom budget method (IND): *unique method of budget calculation for a state*
- Supports Intensity Scale/ Other validated budget method (IND): *using the SIS or other method not specific to a state to determine support needs/budget*
- Wage limits (IND): *limitations on how much participants may pay their employees*
- Interorganizational Network (H&B): *relationships between stakeholders, particularly support agencies, FMS providers, support brokers, unions*
  - Direct support workers (IND): *individuals who provide direct support to people with disabilities*
    - Agency DSWs (IND): *direct support workers from agencies*
    - Family DSWs (IND): *direct support workers who are family or friends of the participant*
    - Independent DSWs (IND): *direct support workers who are not from an agency but are also not from the informal network of the participant*
  - Employer of record (IND): *common law employer of paid support workers*
  - Families training other families (IND): *families training other families in events sponsored by the state*

- Financial management services (IND): *external agency who ensures compliance with employment law and provides payment*
- Medicaid review agency (contracted) (IND): *a third party reviewer that assesses Medicaid compliance*
- No FMS provider (IND): *the state does not contract with a third party for fiscal agents*
- Provider-family/participant linkages (A&S): *interactions between providers and families*
- Provider network (H&B/A&S): *Network of providers that provide supports to individuals in self-direction*
- Representative/Proxy (IND): *an individual the participant designates as able to make decisions on their behalf*
- Residential programs/group homes (IND): *residential homes for individuals with disabilities*
- Support Brokers (IND): *providers who assist the participant with the tasks of engaging in self-direction*
- Intraorganizational Network (LR): *Entities within the administering department: state administrators, county administrators, regional administrators, and case managers*
  - Case managers (IND): *individuals from privately or publicly owned entities contracted by the state to perform monitoring*
  - County-State relationships (IND): *relationships between county and state officials*
  - County/Regional officials (IND): *administrators on the county or regional level*
  - Managed Care organizations (IND): *organizations that control spending for medical supports needs on the state level*
  - State-family linkages (IND): *relationships between the intraorganizational network and the family*
- Technical Core (H&B): *program components that directly impact client outcomes*
  - Agency with Choice/Co-employer model (IND): *individuals from an agency provide supervisory functions for the provider*
  - Budget authority (IND): *participant makes decisions about how to spend their individual budget*
  - Common law/FEA model (IND): *individual provides supervisory functions for the provider*
  - Employer authority (IND): *hiring, firing, training, and management of employees*
  - Individual budgets (A&S): *setting a budget amount and service plan based on individual needs*
  - Opportunities for self-determination (A&S): *opportunities for the participant to engage in self-determined behavior*

- Person centered planning (A&S): *planning that utilizes the person-centered methodology*
  - Traditional/provider-managed services (IND): *services that are not self-directed but impact clients directly*
- Policy Output (H&B): *the actual services being provided to consumers*
  - Participant outcomes
    - Access to self-direction (IND): *ability to enter and engage in self-direction*
    - Adult/child balance (IND): *proportion of adults and children in the waiver program*
    - Community participation and inclusion (A&S): *integration with the participant's community*
    - Correspondence Index (H&B): *degree to which needs and services correspond and the degree to which eligible consumers were processed and served in the policy*
    - Decreased budgets for participants (IND): *lower budgets for participants*
    - Difficulty with service delivery (IND): *participants reporting problems with services*
    - Ease of service delivery (IND): *participants reporting few problems with services*
    - Employment of independent DSWs (IND): *employment of individuals not affiliated with an agency to perform direct support work*
    - Employment of family members or friends as DSWs (IND): *employment of family members or friends as direct support workers*
    - Employment of independent DSWs (IND): *employment of individuals not affiliated with an agency to perform direct support work*
    - Flexibility for participants/families (A&S): *participants and families able to customize services to their needs*
    - Fulfillment of support needs (A&S): *participants having their support needs met*
    - Fulfillment of unusual needs (A&S): *participants having unusual support needs met*
    - Higher wages for employees (IND): *Participants are able to pay employees higher wages*
    - Improve quality of provider-participant relationship (IND): *seeing improvements in the quality of the relationship between the provider and participant*
    - Improvement in quality of life (IND): *seeing improvement in participants' quality of life*
    - Increase understanding of self-direction (IND): *participants and families better understanding self-direction*
    - Increased budgets and services for participants (IND): *more resources and supports for participants*

- Participant dissatisfaction (IND): *participants expressing dissatisfaction*
- Participant empowerment (IND): *participants feeling empowered*
- Participant goal attainment (IND): *participants achieving goals*
- Participant safety (IND): *participants remaining safe*
- Participant satisfaction (IND): *participants expressing satisfaction*
- Reduce turnover/stability for families (IND): *providers and supports are consistent for families*
- Reduced caregiver burden (IND): *lessening of the stress associated with caregiving for individuals with disabilities*
- Reduced problem behavior (IND): *reductions in the “problem behaviors” of participants*
- Respect and acceptance (A&S): *participants feeling respected and accepted*
- Staying in family/individual home (IND): *participants are able to stay in family homes*
- Strengthen family relationships (IND): *family relationships are stronger as a result of self-direction participation*
- Support needs not met (IND): *Participants' support needs are not met*
- Administrative outcomes
  - Administration exceed budget allotment (IND): *program goes over its allotted budget*
  - Administration saves money (LR): *program reduces costs from previous implementations*
  - Administrative overwork (IND): *administrative staff report too many responsibilities*
  - Administrator dissatisfaction (LR): *administrator expresses dissatisfaction*
  - Administrator satisfaction (IND): *administrator expresses satisfaction*
  - Enforcement of rules (IND): *intraorganizational network or interorganizational network enforces program rules for participants*
  - Few participants (IND): *not many participants sign up for self-direction*
  - Improper spending by participants (IND): *participants try to spend money on unapproved services/supports*
  - Interorganizational coordination problems (IND): *implementing department and interorganizational network are “not on the same page”*
  - Intraorganizational coordination problems (LR): *implementing department and intraorganizational network are “not on the same page”*
  - More consumers sign on (IND): *self-direction increases in popularity*
  - Participants dropping out of self-direction (IND): *participants decide to leave self-direction for traditional services*
  - Retaining participants (IND): *Participants stay in self-direction and do not transition back to traditional supports*
  - Word of mouth (IND): *participants tell other people with disabilities about their experience in self-direction about self-direction*

- Administrator Conceptualization (IND): *how the administrator thinks about self-direction*
  - o Preferences (IND): *desires and wants of program administrators*
    - Accessibility/responsiveness to participants (IND): *capacity of the administration to respond to participant needs*
    - Avoiding scandal, fraud, and abuse of program (LR): *avoiding negative outcomes that might reflect poorly on the program*
    - Clear rules for programs (IND): *rules for program are clear to all participants, providers, and administrators*
    - Consistency (IND): *Consistency across service delivery system in how program is implemented by different parties and experienced by participants*
    - Ease of access to self-direction (IND): *individuals who desire self-direction are able access it easily*
    - Ensuring participant health and safety (IND): *desire to keep participants safe and healthy*
    - Ensuring quality supports/services (IND): *Making sure that supports are of good quality for participants*
    - Fiscal stewardship (IND): *monitoring the spending of state funds*
    - Flexibility in intraorganizational network (IND): *ability of intraorganizational network to adapt to changing conditions*
    - Growth in program size (IND): *desire to increase the size of the program*
    - Having enough supports for participants/families (IND): *wanting enough supports provided by the state to ensure participant and family success*
    - Individual participation in policymaking process (IND): *desire to have participants involved in the changing of self-directed policies*
    - Keeping up with the latest trends (IND): *desire to make one's programs similar to the cutting edge of other state's self-directed programs*
    - Keeping everyone happy (IND): *desire to maintain harmony between all parties in implementation*
    - Limiting state liability (LR): *desire to minimize the liability of the state*
    - Making administrative work easier (IND): *desire to make work easier for the intraorganizational network*
    - Making participant work easier (IND): *desire to make work easier for participants*
    - Meeting participant need (LR): *desire to meet participants' needs*
    - More control for participants (IND): *Desire to give participants more control over supports*
    - More choices for participants (IND): *Desire to give participants more choices in how they get their support needs met*
    - More knowledge communicated across the system (IND): *desire to have more knowledge about what is going on in self-directed programs*
    - More resources (IND): *desire for more resources to implement self-directed programs*

- Permanent, better, more resilient program (IND): *desire to create a better program that with withstand the test of time*
- Predictability (IND): *desire for predictability in program administration*
- Reaching challenging populations (IND): *desire to reach challenging populations in the service area that might not be well-served by traditional supports*
- Reducing costs (LR): *desire to the reduce the cost of the program on the state*
- Reducing unmet need (IND): *desire to reduce the unmet needs within a service area*
- Robust provider network (IND): *desire to have a number of service options for participants*
- Strong advocacy support (IND): *Desire for strong support for program among advocacy community*
- Knowledge and opinions about self-direction (IND)
  - “personal” or “intimate” nature of PCA work (IND): *opinion that PCA work is intimate by its very nature*
  - All should be given the opportunity to self-direct (IND): *anyone who wants to use self-direction should be able to*
  - Caregiver burden (IND): *difficulty that informal supports face in caring for individuals with disabilities*
  - Competency of participants (IND): *ability of participants to engage in the daily actions necessary for self-direction*
  - Continuum of programs/options (IND): *self-direction should be part of a continuum of options from traditional to fully self-directed*
  - Employment for participants (IND): *paid employment for self-direction participants*
  - Family-centered vs. person-centered (IND): *whether the administrator uses family-centered or person-centered language*
  - Family/informal/natural supports (IND): *the unpaid social supports for an individual with disabilities*
  - Family/participant relationship (IND): *related to the relationship between the individual with disabilities and their family members*
  - Family/participant taking responsibility (IND): *family having to take responsibility for the actions necessary to engage in self-direction*
  - Focusing on “in-home” supports (IND): *supports should be directed to inside private homes*
  - History of the department (IND): *what’s been done before in the department*
  - Large Purchases/One-time purchases (IND): *one-off, often high price supports or services*
  - Medical necessity/ relationship to plan of care (IND): *service needs as they relate to medical need and a written plan of care*

- Need for a representative/proxy (IND): *representatives/proxies that help individuals make decisions in self-direction*
- Participant independence/autonomy (IND): *Independence for self-direction participants, as defined by the DDPAs*
- Participants as fiscal stewards (IND): *participants through their actions economize on purchasing services*
- Participants request too much money/supports (IND): *Belief that participants will request too much money, at least initially*
- Person-centeredness (IND): *how much supports reflect the dreams and desires of the participant*
- Personal background of administrator (IND): *unique life experiences of each administrator*
- Philosophical agreement with self-direction (LR): *expressing agreement with self-direction on a philosophical and moral level*
- Protecting the rights of participants (IND): *belief that administrators need to protect participants from infringements on their rights*
- Purpose of self-direction (IND): *what an administrator believes is the purpose of self-direction*
- Relationship to other programs/waivers (IND): *how the administrator conceptualized the linkages between self-direction and other programs*
- Self-direction as the “first option”/ more popular (IND): *Self-direction should have the majority of participants and should be considered first, before traditional supports*
- Self-direction for people dissatisfied with traditional (IND): *self-direction is for people who are dissatisfied with traditional services*
- Self-direction is “not for everyone” (IND): *Based on their circumstances, self-direction may not be the best option for people. And it is their choice.*
- Self-direction is a cultural shift (IND): *self-direction implementation involves a cultural shift*
- Self-direction is prone to abuse (IND): *belief by others than self-direction is prone to abuse because of its design*
- Self-direction was “the wild west” (IND): *over the years, self-direction transitioned from a very liberal program with few spending limits to one with tighter controls*
- Self-sufficiency (IND): *ability of the participant to support themselves*
- Transition from child to adult services (IND): *transitional needs of individuals graduating from child to adult services*
- Policy Refinement (IND): *actions taken by administrators to change existing self-directed programs*
  - Adding services/supports (IND): *adding more supports to existing programs*
  - Bargaining with Providers/Unions (IND): *engaging in bargaining with providers on behalf of the state and/or consumers*

- Changing how providers think about supports (IND): *changing providers' mindset to be more compatible with self-direction*
- Clarify/Tighten rules for programs (IND): *making rules more stringent or at least more clear due to outputs*
- Contracting with new providers/agencies (IND): *process of contracting with consultants, new agencies in the intra or interorganizational network*
- Coping with CMS rule changes (IND): *process of dealing with rule decisions from CMS*
- Creating manuals, outreach materials, and trainings for families (IND): *creating materials for families to learn more about self-direction*
- Creating new administrative positions (IND): *creating positions in the intraorganizational network specifically for self-direction implementation*
- Creating new waivers/programs/options/renewals (IND): *creating new waivers or updating existing ones formally through CMS approval*
- Creating working groups or committees (IND): *creating a small group of people to study an issue*
- Decreasing self-directedness (IND): *moving the technological core further away from the textbook model of self-direction*
- Distinguishing one program/waiver/option from another (IND): *changing how one program operates in relation to another*
- Formal self-assessments/studies (IND): *commissioned studies by the implementing department about self-direction*
- Home visits (IND): *case manager visits to participants' homes for QA/monitoring*
- Identifying gaps in service (IND): *identifying areas for improvement in self-direction*
- Improving service delivery/innovating (LR): *improving self-direction, particularly with unique ideas*
- Increasing self-directedness (IND): *increasing the amount of self-determination that can be exercised by consumers, usually through adding services, increasing control, or providing more choices*
- Infusing self-direction into other programs (IND): *taking ideas of self-direction and using them in other programs for individuals with disabilities*
- Interorganizational coordination (A&S): *interfacing with individuals and entities in the interorganizational network*
- Intraorganizational coordination (A&S): *interfacing with individuals and entities in the intraorganizational network*
- Introducing new technology (IND): *using technology, particularly electronic billing, to make services better*
- Keeping elements from previous programs (IND): *process of keeping elements from previous programs when creating new programs*
- Learning from previous experience (IND): *taking knowledge from previous experiences with self-direction and using it with current programs*
- Listening to feedback (IND): *listening to critical actors*



- Lowering barriers to engaging in self-direction (IND): *removing existing obstacles for individuals to engage in self-direction*
- Lowering caseloads (IND): *lowering how many people are served by either support brokers and case managers*
- Not refining/stasis (IND): *Making a decision not to keep services at they are*
- Promoting self-direction (IND): *raising awareness and ensuring the intraorganizational network shares information about self-direction*
- Quality assurance/monitoring (IND): *studies of existing services performed on an ongoing basis at the consumer-provider level*
- Removing supports/services (IND): *taking out supports from service offerings*
- Rule-making (IND): *process of creating new rules and regulations for self-direction*
- Seeking outside help (IND): *from consultants or national organizations*
- Staff training on self-direction (A&S): *ensuring individuals in the intraorganizational network understand self-direction*
- State-to-state learning (IND): *learning from what other states are doing*
- Strategic planning (IND): *deliberate plans on how to improve services moving forward*
- Streamlining services (IND): *finding and creating more efficient practices for programs*
- Training providers (A&S): *ensuring providers understand self-direction*

## Appendix F: List of Abbreviations

AAIDD: American Association on Intellectual and Developmental Disabilities  
ADA: Americans with Disabilities Act  
ADHD: Attention Deficit and Hyperactivity Disorder  
ADL: Activities of Daily Living  
AWC: Agency with Choice  
CMS: Centers for Medicare and Medicaid Services  
CQL: Council on Quality and Leadership  
DD: Developmental Disabilities  
DDA: Developmental Disabilities Administration  
DDPA: Developmental Disabilities Program Administrator  
DSW: Direct Support Worker  
EOR: Employer of Record  
FMS: Fiscal Management Services  
HCBS: Home and Community Based Services  
IADL: Instrumental Activities of Daily Living  
ICF/ID: Intermediate Care Facility for Individuals with Intellectual Disabilities  
ICAP: Inventory for Client and Agency Planning  
IDD: Intellectual and Developmental Disabilities  
ISP: Individual Support Plan  
LTSS: Long-Term Support Services  
NASDDDS: National Association of State Directors of Developmental Disabilities Services  
NCI: National Core Indicators  
NRCPDS: National Resource Center for Participant Directed Services  
RWJ: Robert Wood Johnson  
SIS: Supports Intensity Scale  
SSI: Supplemental Security Income

UCEDD: University Centers for Excellence in Developmental Disabilities

## Appendix G: Olmstead-Related Decisions

State	Year	Decision	Description
Colorado	2000	<i>Mandy R et al v. Owens et al</i>	Plaintiffs challenged waiting lists and sought timely access to services in ICF/MR group homes or HCBS waivers. District Court ruled that any decision to dramatically expand HCBS or ICF/MR services would encroach upon separation of powers. Colorado argued that HCBS services could fulfill obligations to provide community care, rather than ICF/MR facilities. Circuit court ruled that Plaintiffs did not have an individually enforceable right and that while the state must pay for services, it need not provide them.
Delaware	2002	<i>Arc of Delaware et al v. Meconi et al</i>	Plaintiffs challenged waiting lists and lack of access to services in community-based settings. A settlement agreement was reached that opened new community-based residential placements and created a new Medicaid waiver program. The state also agreed to increased community funding and improvements in waiting list management.
Florida	1992	<i>Doe v. Chiles et al</i>	Plaintiffs challenged waiting list for ICF/MR services. Court ruled that waiting lists violated Medicaid law and the state had a legal obligation to provide ICF/MR services with reasonable promptness. The state significantly expanded access HCBS waiver services.
Hawaii	1998	<i>Makin et al v. State of Hawaii</i>	Plaintiffs challenged waiting list for HCBS waiver services. Court ruled that waiting lists are permissible once the waiver program reaches the mandated population limit. A subsequent settlement agreement revised application procedures for waiver services and instantiated person-centered planning.
Illinois	2000	<i>Bruggeman et al. v. Blagojevich et al</i>	Plaintiffs challenged lack of access to HCBS and ICF/MR services. The court ruled that the state is not required to arrange services close to a family or individual's home. The court also found that the state lacked a comprehensive plan to comply with <i>Olmstead</i> . A settlement agreement was reached that provides community-based services to plaintiffs and subsequently to individuals on the waiting list.
Maryland	1994	<i>Williams et al v.</i>	Plaintiffs challenged the lack of access to community supports. Court ruled that the state had fulfilled its

		<i>Wasserman et al</i>	obligation to reduce numbers in institutions and increased community services.
North Carolina	1990	<i>Thomas S. v. Flaherty</i>	Court ruled that institutionalized persons are entitled to services that are consistent with professional opinion, including community-based services.
North Carolina	2002	<i>McCree v. Odom</i>	Court held that states cannot claim sovereign immunity and complainants have individually enforceable rights under Medicaid law.
New Mexico	1999	<i>Lewis et al. v. NM Dept of Health et al.</i>	Plaintiffs included individuals in ICF/MR or institutions as well as those seeking waiver services. Court ruled the state must expand its program within available funds and slots within existing programs.
Oregon	2000	<i>Miranda B et al v. Kulongoski et al</i>	Plaintiffs challenged the lack of access to community placement for institutionalized persons. A settlement agreement was reached that created 75 community placements and an expansion of comprehensive and support services in order to reduce the waiting list.
Pennsylvania	2001	<i>Frederick L et al v. Dept of Public Welfare et al.</i>	Plaintiffs challenged lack of access to community placement. Settlement agreement was reached that provided a four year plan to place persons in one institutional setting into community-based placements.
Pennsylvania	2002	<i>Sabree et al v. Richman</i>	Plaintiffs challenged waiting lists for ICF/MR services. Court ruled that Medicaid law confers individually enforceable rights. A settlement agreement was reached that asserted the right to receive ICF/MR services with reasonable promptness
Utah	2002	<i>DC et al v. Williams et al</i>	Plaintiffs challenged waiting lists for HCBS waiver services. Court ruled that the state did not have a responsibility to expand waiver services, as the costs of doing so would be a fundamental alteration by shifting funding from other people with disabilities. Also, the plaintiffs did not meet the federal requirement for institutional placement, and therefore the waiting list did not need to be expanded.

Washington	2000	<i>Townsend v. Quasim</i>	Plaintiffs challenged income eligibility limits on HCBS waivers. Court found that medically needy persons should have access to support services without waiting lists.
Washington	2001	<i>Boyle v. Arnold-Williams</i>	Plaintiffs challenged inability to access full range of HCBS waiver services for current waiver participants. A settlement agreement was reached that instantiated a comprehensive assessment process, right to transfer between waivers,
West Virginia	1999	<i>Benjamin H et al v. Ohl</i>	Plaintiffs challenged failure to provide Medicaid long-term care with reasonable promptness. Court decided that states cannot solely rely upon lack of funds as a defense and must develop a plan to eliminate waiting lists and improve services. A settlement agreement was reached to expand access to HCBS services.

Adapted from: Kitchener, Wilmott, Wong & Harrington, 2008; Smith, 2007



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## Curriculum Vitae

### Research Interests:

- ❖ Consumer-Directed Medicaid programs for individuals with IDD and other disabilities
- ❖ Lived experience of social welfare consumers
- ❖ Harm reduction counseling and policy practice

### Teaching Interests:

- ❖ Human behavior and the social environment
- ❖ Direct practice with individuals, families, and systems
- ❖ Research methods
- ❖ Social welfare policy
- ❖ Social justice
- ❖ Substance abuse

### Education:

2012-present: PhD Candidate in Social Work, Virginia Commonwealth University, Richmond, VA

Expected graduation: May, 2016

*Dissertation— Implementation of Self-Directed Supports for Individuals with Intellectual and Developmental Disabilities: A Political Economy Analysis.*

Chair—Dr. Sarah Kye Price, Associate Professor, VCU School of Social Work

Dr. Matt Bogenschutz—Assistant Professor, VCU School of Social Work

Dr. David Fauri—Professor, VCU School of Social Work

Dr. Parthenia Dinora— Director of Research, Evaluation, and Program  
Development, Partnership for People with Disabilities

2008-2010: Masters in Social Work, George Mason University, Arlington, VA

Clinical Concentration—focus on dual-diagnosis

2003-2007: Bachelor of Arts in Psychology, College of William and Mary, Williamsburg, VA

**Teaching Experience:**

*BSW Program, Virginia Commonwealth University*

SLWK 230: Communication in the Helping Process—Spring 2014

SLWK 380: Foundations of Social Work Research I—Fall 2014, Fall 2015

SLWK 330: Person & Society II—Spring 2015, Fall 2015, Spring 2016

SLWK 442: Social Welfare Policy and Legislation Services—Spring 2016

*MSW Program, Virginia Commonwealth University*

SLWK 601: Human Behavior and the Social Environment I—Fall 2014, Fall 2015

SLWK 610: Human Behavior and the Social Environment II—Spring 2015, Spring 2016

SLWK 609: Foundations of Research in Social Work Practice—Summer 2015

*Distance Education Program, Virginia Commonwealth University*

SLWK 601: Human Behavior and the Social Environment I—Fall 2014 (TA Position)

SLWK 610: Human Behavior and the Social Environment II—Spring 2015 (TA Position)

**Research Experience:**

2014-present: *Co-investigator: Self-directed Supports for Individuals with Intellectual and Developmental Disabilities.* VCU School of Social Work

Assessed the expansion of self-direction in each state's developmental disabilities administration and the future of self-direction in state Medicaid programs.

Collaborated with multidisciplinary research team from the Research and Training Center (RTC) on Community Living at the University of Minnesota. Engaged directly with state-level department directors in recruitment and data gathering. Collected and analyzed original data set including documentary evidence. Facilitated state-to-state learning.

2014-present: *Implementation of Self-Directed Supports for Individuals with Intellectual and Developmental Disabilities: A Political Economy Analysis.* VCU School of Social Work

A sub-analysis of qualitative data from the larger project described above. Examines how interest groups, organizations, and political actors influence administrators and self-directed support programs. Expected completion by May 2016.

2013-2014: *Graduate Research Assistant:* VCU School of Social Work

Collaborated with Dr. Peter Nguyen on literature search and document drafting for a needs assessment for Asian Americans experiencing domestic violence in the Richmond



area. Developed skills with writing for academic publishing and working as part of collaborative team.

Collaborated with Dr. Jacqui Corcoran in data management and literature searching for a meta-synthesis on individuals with Major Depressive Disorder and other psychiatric diagnoses. Developed qualitative database management skills.

2012-2013: *Graduate Research Assistant: VCU School of Social Work*

Collaborated with Dr. Youngmi Kim on literature search, document drafting, and data analysis related to her research interests in asset building programs, food insecurity, educational expectations, education savings, and immigrant populations.

### **Practice Experience:**

2011-2012: *Community Support Specialist—Community Connections, Washington, DC*

Worked as part of a multidisciplinary treatment team focusing on individuals in long-term recovery from substance abuse and mental health issues. Implemented motivational interviewing and trauma-informed treatment practices as part of larger research initiatives. Built fluency with biopsychosocial assessments and collaborative treatment planning. Demonstrated group facilitation skills in relapse prevention, community residential, and medication support groups.

2010-2011: *Wellness Specialist—Pathways to Housing, Washington, DC*

Worked on multidisciplinary team as part of a harm-reduction, housing-first approach to client care. Provided intensive in-home counseling and case management services to clients diagnosed with chronic, severe mental illness and substance abuse issues. Coordinated launch of yoga program. Developed crisis intervention, de-escalation, advocacy, and motivational interviewing skills.

2009-2010: *Social Work Intern—St. Elizabeth's Hospital, Forensic Division, Washington, DC*

Completed 600 hour Concentration Year field placement with clinical supervision. Worked with clients who were found Not Guilty By Reason of Insanity or not competent to stand trial for criminal charges. Conducted biopsychosocial assessments. Facilitated group therapy sessions in legal competency and relapse prevention. Utilized dialectical-behavioral therapy and supportive counseling in individual sessions. Provided discharge planning and referral services.

2008-2009: *Social Work Intern—Samaritan Inns: Intensive Recovery Program, Washington, DC*

Completed 600 hour Foundation Year field placement with clinical supervision. Designed and facilitated group therapy sessions in relapse prevention and psychosocial support. Conducted biopsychosocial assessments.

2007-2008: *Residential Direct Care Staff*—Howard Center: Baird School Residential Program, Burlington, VT

Worked with children diagnosed with severe emotional disturbances a therapeutic residential home. Implemented Therapeutic Crisis Intervention. Supported children with a variety of emotional traumas, including physical and sexual abuse, as they worked towards family reunification.

2006-2007: *Direct Care Staff*—Wediko Children's Services, Windsor, NH

Lived and worked with a group of severely emotionally disordered adolescents in an intensive, 6-week residential milieu treatment facility. Trained in crisis intervention, de-escalation, therapeutic restraint, and cognitive-behavioral therapy techniques.

2005-2006: *Intern*—Community Care Behavioral Health, Piscataway, NJ

Facilitated life skills training groups. Performed case management services.

### **Scholarship:**

#### *Juried Presentations*

**DeCarlo, M.** & Bogenschutz, M. (2015, October). *Self-directed supports for individuals with intellectual and developmental disabilities*. Oral presentation at Annual Program Meeting of the Council on Social Work Education, Denver, CO.

Nguyen, P. & **DeCarlo, M.** (2015, October). *Physical intimate partner violence and the Asian-American community*. Oral presentation at Annual Program Meeting of the Council on Social Work Education, Denver, CO.

**DeCarlo, M.** (2015, January). *State of the states: Consumer-directed Medicaid services for people with developmental disabilities, results from a preliminary investigation*. Poster presentation at the Society for Social Work and Research conference, New Orleans, LA.

**DeCarlo, M.** (2014, November). *State of the states: Consumer-directed Medicaid services for people with developmental disabilities, results from a preliminary investigation*. Poster presentation at Association of University Centers on Disabilities conference, Washington, DC.

#### *Other Presentations*

**DeCarlo, M.** (2014, May). *State of the states: Consumer-directed Medicaid services for people with developmental disabilities, results from a preliminary investigation*. Poster presentation at VCU School of Social Work Research Symposium, Richmond, VA.

**DeCarlo, M.** (2013, April). *Is a universal living wage unjust? An advocacy presentation*. Poster presentation at VCU School of Social Work Research Symposium, Richmond, VA.

#### *Articles in Review*

Nguyen, P. V., Corona, R., Yaros, A., & **DeCarlo, M.** (2015). Physical intimate partner violence and Mental Health and the Asian-American community. Submitted 11/22/2015 to the Journal of Community Psychology.

#### *Articles in Preparation*

**DeCarlo, M.** (2015, October). Outcomes for individual and families in self-directed supports: A comprehensive review. Targeted at Journal of Disability Policy Studies.

**DeCarlo, M.** (2015, October). Self-determination and economic freedom of social welfare consumers. Targeted at Journal of Sociology and Social Welfare.

Nguyen, P. V., Corona, R., Le, A., & **DeCarlo, M.** (2015). Help-seeking in Asian-Americans: Results of a needs assessment. No journal targeted at this time.

#### **Financial Awards:**

2015-2016: *Humane Studies Fellowship*: Institute for Humane Studies  
\$5000 competitive grant secured to support dissertation research.

2015-2016: *Frederic Bastiat Fellowship*: Mercatus Center  
\$2500 competitive grant secured to support dissertation research.

2015-2016: *Graduate Research Assistantship*: Research and Training Center on Community Living  
\$3000 research support stipend for work on State of the States project.

2012-2014: *Graduate Research Assistantship*: Virginia Commonwealth University  
\$43000 annual tuition and stipend award.

#### **Service:**

2015-2016: *PhD Student Mentor*—VCU School of Social Work

2015-2016: *Harm Reduction Counselor*—Transformus Arts Festival, Asheville, NC

2012- 2016: *Volunteer*—Special Love for Children with Cancer

### **Memberships and Associations:**

Society for Social Work and Research  
Council on Social Work Education